

Care, Contagion and the Good Mother: Narratives of Motherhood, TB and Healing

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Abstract

South Africa is reported as one of the countries with a high burden of Tuberculosis (TB). In response to the epidemic, the South African National Department of Health attempted to improve access to health care and TB treatment with a variety of interventions - treatment and management programs. Although necessary for the macro project of producing a less TB infected South Africa, the focus of these interventions tends to neglect the particular stories and how TB affects particular lives. In pursuit of such stories, this paper considers how two women, Andiswa and sis Thembi, in Khayelitsha, Western Cape juggle motherhood and illness. Drawing on a body of literature that focuses on illness as a biographical disruption, good mothering and the impact of tuberculosis in poor families in South Africa, this paper explores how TB disrupts mothering. It looks at how these women manage their identities as mothers and their relationships when infected with the disrupting TB. I argue that despite the disruption, their lives show that TB produces moments of burdening and moments of unburdening.

Introduction

Factors such as housing, overcrowding in under-ventilated spaces, and lack of access to water and treatment have been shown to drive the spread and prevalence of Tuberculosis (hereafter TB) (Pronky et al., 2001: 624 – 625; Stein, 1950; Kriger and Higgins, 2002; Habib et al., 2009). The lack of sufficient government resources, funding, understaffing and lack of infrastructure are also some of the contributing factors to the enduring epidemic that leaves many people in socio-economic conditions that do not allow them to fight the disease (Bateman 2006, 2007; Naidoo and Mwaba, 2010). This is a phenomenon that Farmer (1996, 2005) speaks of in his work in Haiti around structural violence, issues of access to health care and how disease thrives in compromising economic conditions. The lens of structural violence helps us explain how political economy enables some people to have access to treatment and the necessary resources (such as nourishing food, transportation, income security, employment benefits such as paid sick leave etc.). These resources enable some people to have a successful treatment program whilst others are unable to meet treatment demands (Pronky et al., 2001:624 – 625).

Kleinman used the methodology of illness narrative which he describes as

“a story the patient tells, and significant others retell, to give coherence to the distinctive events and long-term course of suffering. The plot lines, core metaphors, and rhetorical devices that structure the illness narrative are drawn from cultural and personal models for arranging experiences in meaningful ways and for effectively communicating those meanings. . .” (Kleinman 1988:49).

This concept was very useful for me as my interest was to look at the everyday life particular stories and thus, how *the two women* were able to make meaning of their illness experiences for themselves and for their loved ones and how they told their own stories. This does not ignore the biological symptoms of TB but integrates them with the social consequences of having the disease and as such, the social experience of the illness. In a similar vein, Farmer’s

work is important as it gets us to think about the reality of pain and suffering which are part and parcel of illness. Farmer uses illness narratives to show the various forms of structural violence that exist in everyday life in ways that lead to poor treatment outcomes as well as some of the factors that make it impossible for some people to access treatment. However, his focus mainly lies in using these stories on a macro level to explain why peoples' treatment fails and, importantly, how structural violence as a concept helps us to move beyond individual blame of patients and to consider the structures and environments in which illness exists. While this centres the disease at the expense of a focus on people's lives outside of illness, I argue that illness narratives can help us do both. They help us show the impact of disease as well as help us focus on how life 'continues' in the midst of disease. It is in this reality of irreconcilable experiences of life that I wish to place my ethnography – in a place where more than one thing happens at once, filled with paradoxes and ironies. I acknowledge the role of structural violence and how it affects TB in South Africa but for this paper, I zoom specifically into how TB affects mothering. Narratives are important for their prioritisation of how people understand themselves / their lives and how they interpret their illness. They are also important as they help give shape and language to human experiences as suggested by Skultans (2000). Besides the vulnerability that is usually invoked in illness narratives, "Stories of illness evoke a 'me too' response. They speak to us because in recognising the vulnerability of others, we recognise our own: we too must face illness and death" (Skultans (2000:8). In those moments of vulnerability, illness narratives help us connect with people we read and write about at a level that is not just about the disease but about human experiences of health and illness.

In this article, I complement illness narratives with a focus on biographical disruption. Biographical disruption speaks to how people see themselves and the constant self-reconstruction that occurs as they make sense of their illness. With regards to TB, Mason, Degeling and Denholm (2015:1139,1140) argue that

“... the onset of TB can be conceptualised as a disruption to a person's biography – their conception of themselves and their future. Disruptions in biography alter assumptions about the healthy body, social relationships and the ability to mobilise material resources such that 'erstwhile taken-for-granted world of everyday life becomes a burden, of conscious and deliberate action'”.

Taking into account illness narratives and biographical disruption when thinking about TB helps us to directly acknowledge the contexts in which people get TB and for researchers and policy makers - to take seriously their own interpretations of their experience.(Bury 1982)

As evident in the recent special issue *Globalised Tuberculosis Control Local Worlds*, people have found ways to make sense of their experiences with TB and also found ways to resist its impact (Dixon and Macdonald, 2018). The special issue seeks to show how global as well as national policies affect people in local contexts. This paper shares that pursuit - the stories of Andiswa and *sis*¹ Thembi serve as a window to the realities that many women are faced with when they have TB and shed light on how a global problem like TB affects people on an individual-level. Motherhood is conceptualised in different ways and is constituted by social and biological factors. In her work on conceptualising motherhood in South Africa, Walker (1995) argues that there are three aspects to 'motherhood'. First is the practice of motherhood which focuses on the day to day 'mothering work' which involves childbirth, physical care and emotional care and involvement. Second is the discourse of motherhood which involves conceptions of the 'good mother'. Importantly for this paper, she argues that although white

¹ I use the prefix '*sis*' to show respect as *sis* Thembi is older than me.

and middle class women associate the idea of a good mother with the practice of motherhood, specifically the physical and emotional nurturing of the child, for black and working class women, ‘good mothering’ is mainly about their responsibility to discipline and financially support their children. Third is the social identity of mothers which is about how women construct their identities as mothers, informed by both the practice of motherhood and the discourse on motherhood.

Campbell (1990, 6) eloquently captures the pivotal role of black working class mothers in South African townships::

“It is mothers who often take the major responsibility for managing the scarce resources available to most working class families. It is mothers who take care of family members in times of crisis - such as sickness, unemployment, old age, detention and so on. They often take responsibility for their teenage daughters' babies. It is mothers that form the emotional nexus of the family. They advise, console, and comfort family members. They mediate ties of loyalty that exist between family members. It is mothers who coordinate family decision-making - and mediate between family members in the day-to-day business of living. They set up wider emotional and material support networks with other women in the community - neighbours, friends, relatives - and in times of crisis the survival of the family will often hinge on these networks.”

According to Campbell (1990), the role of mothers as financial providers is made more prominent by the absence of many fathers in South African townships. In post-apartheid South Africa, there are still many single mothers who are sole financial providers in their homes and this has been seen as a cause for concern that necessitates government involvement by other scholars (Sender, 2002); (Ntshongwana et al, 2015). In this context, where women feel the pressure to be (and to be seen as) ‘good mothers’ through their ability to be present in their children’s lives, and through their ability to provide for their children financially, I argue that a TB diagnosis disrupts that ideal of mothering. This paper explores the different ways in which TB disrupts mothering and how that burdens the mothers. I also look at how the mothers manage this disruption and the ways in which family and the temporary disability grant assist in managing the disruption caused by TB and therefore - offer moments of unburdening. The questions explored in this paper include: How does TB disrupt ‘good mothering’ ideas and practices for these black² mothers?’ and how do they make sense of and navigate this disruption?

Methods and Ethics

The ethnographic study this paper is based on participant observation, informal conversations, formal interviews and was supplemented by recorded interviews and Zimmerman and Weider (1977)’s Diary-Interview method. The latter involves myself and my research participants simultaneously writing in a personal diary, which then acts as a base for further research questions. The ethnographic fieldwork was conducted in 2012 in Khayelitsha, Cape Town, South Africa and follow up interviews were conducted again in 2018.

² I use the term “Black” because it is how my participants self-identify. Also in everyday language and in official documentations, South Africans still use the racial categories inherited from the apartheid-era.

The Key participants were Andiswa who is my high school friend and *sis* Thembi who is my cousin. Conversations with both women were in IsiXhosa as myself and the both of them are IsiXhosa speakers. My childhood family home is in Khayelitsha and at the time of fieldwork, I too lived in Khayelitsha. Therefore, I was not only familiar with my participants but I was also familiar with the 'field'. There is an enduring debate amongst anthropologists about doing anthropology at home. Many argue that doing anthropology at home might make one less objective and that one might struggle to distance themselves from their participants. Ohnuki-Tierney (1984: 14) argued that when anthropologists are outsiders, they encounter performance from their participants which results in 'outsiders' documenting and writing about a 'negotiated reality' Ohnuki-Tierney (1984:14). On the other hand, he argued that because 'native' anthropologists are insiders with prior knowledge of the context of their field site, they face issues of distancing themselves and objectivity but are likely to be presented with the true reality of participants. Furthermore, Van Ginkel (1998:251) notes that the difference when doing field work at home is the reflection on the implications of participant observation and the position of the researcher that is at home. The awareness and the reflection on the implications of my presence as not just a cousin or a friend but as a researcher became very important. The insider and outsider binary was not useful for me in reflecting on my methods and instead, I focused on the power relations between me and my participants and how they would affect the research process. *Sis* Thembi is older than me and she was aware that she could control our engagement and as the older person. Andiswa as a friend also knew that she could control the research process and both of them were aware that they did not have to get involved in ways that they did not wish. They were both positive about the research and felt that their stories could be useful and help others who are affected or infected by TB.

In 2018, Andiswa participated in the research again and shared news about having a newborn child. She was insistent on making time to talk to me despite the demands of a new child. I assumed it would be the same for *sis* Thembi. However, this was not the case. After struggling to get hold of *sis* Thembi for a while, she took my call. She was very upset with me for bringing up a part of her life that she had been working tirelessly to forget about. Although she was physically well and kept reassuring me of that, she was still struggling with what the Multi-Drug Resistant Tuberculosis (MDR TB)³ diagnosis meant for her life and for her children in 2011 and was receiving counselling to deal with this. This served as a reminder of how the conversation and reflection on ethics is an ongoing and one can never make assumptions about the relationship they have with their participants or assume that the relationship will remain unchanged. Although I had been able to go about the fieldwork with empathy and respect in 2012, this was a reminder for the need for constant reflexivity and continually asking for consent as participant's circumstances change and sometimes, they change their minds. As researchers, we always say people can withdraw from the research anytime but when it happens, we do not anticipate what it could mean - that a relationship might be broken and that you may have re-traumatised a participant. This is not a part I was prepared for when writing up ethics and consent forms at the beginning of the research. I should have thought more intentionally about what protection of participants meant in this context as it was beyond using pseudonyms. It included avoiding re-traumatising participants by not assuming that I will know how to protect them and also be aware of the possibility that remembering might hurt and people may wish to forget, an issue that Macdonald (2005) discusses in detail on her paper about ethics of the researcher, grief, memory and silences. I was however glad that *sis* Thembi

³MDR- TB- Multidrug-resistant tuberculosis or TB bacilli is a strain of TB that is resistant to at least the drugs isoniazid and rifampicin (WHO, 2010:1).

was undergoing counselling and I did not pursue further conversations about her illness experience again.

In 2012, my encounters with Andiswa consisted of walking to the braai meat stalls with Nwabi (Andiswa's daughter), chatting in the living room with a glass of cool drink, indulging in braai meat and making coffee in the kitchen. Sometimes, I sat with Andiswa's mother outside in the space where she cuts, cleans and cooks *oosmiley* (colloquial IsiXhosa term meaning 'sheep heads') and *amanqina* (IsiXhosa for sheep trotters). I spent hours listening to her tell me stories about when she was my age, the work that she does, and how and when she started her business. I conducted recorded interviews and used the diary method where Andiswa wrote in a personal diary, which I then used as a basis for further research questions as suggested by Zimmerman and Weider (1977). My interactions with *sis* Thembi consisted of casual conversations where she would tell me about her illness. I also heard and learned a lot about *sis* Thembi's illness at the lovely loud family conversation in her aunt's bedroom, sitting around the paraffin heater and some family members lying on her aunt's bed on the cold winter days. I attempted to have a formal interview with *sis* Thembi to clarify and confirm some of the things we had been casually discussing. However, this turned out to be a very emotional experience as it was hard for her to talk about her experience of the illness in what felt too formal and direct. It was for this reason that I did not give her a journal. I did not want her to relive her experience every time she felt she had to write on her journal and I remembered her words:

“ungaboni ndihleka xa sincokola sonke apha endlini, xa ndihleli ndedwa ndicingisisa ngokugula kwam, kubabuhlungu kakhulu, ndilile” (even though I laugh when we are chatting here at home, when I am by myself, and in deep thought about my illness, it becomes very painful, I cry).

I knew from this moment that it would be unethical of me to put her in a position where she had to sit, reflect and write in a journal after this experience or even continue with her as a research participant. However, after some time, *sis* Thembi approached me and said she was ready to talk one-on-one with me which was a fruitful insightful first conversation followed by many more. She explained that she felt it was important to share her story if it might help and motivate others affected and infected with TB and she was proud to play a role in raising awareness, something she believed my research report would do.

Introducing Andiswa and *sis* Thembi

Andiswa was diagnosed with TB in October 2011. At the time of diagnosis, her child was two years old. She stayed in Green Point, an informal settlement in Khayelitsha. She left high school when she was doing Grade 10 because she was involved in a car accident and later discovered that she was pregnant. Andiswa decided to stay home to recover from the accident, to take care of herself during the pregnancy and later, her daughter Nwabi. In a one bedroomed house, Andiswa stayed with her mother and Nwabi but she slept in her own *ihoki* (a small wendy house room outside the main house). At the time, she was unemployed and relied on the child support grant for Nwabi and the temporary disability grant while she recovered from TB⁴. Her mother also contributed to the household income when she sold enough of *oosmiley* and *amanqina*. Nwabi's father was in irregular employment but tried his best to contribute towards the child's clothes and nappies when he could.

4 As they are sometimes unable to continue with paid employment, TB and M/XDR- TB patients undergoing treatment qualify for a temporary disability grant, provided that they are not living in a state treatment facility and that they meet the means test. They receive the grant for a period of six to twelve months and it is re-evaluated after that period (Western Cape Government <http://www.westerncape.gov.za/eng/directories/services/11586/47485>).

Sis Thembi stayed in an informal settlement, in a two bedroomed house in BM section located in Site B, Khayelitsha. She stayed with her two sons aged 19 and 16 as well as her two brothers. She had a stall in the Mitchell's Plain bus terminus where she sold chips, drinks, sweets, cigarettes, etc. She was diagnosed with MDR TB in August 2011. Prior to her diagnosis, *sis Thembi* woke up in the early hours of the morning to set up her stall in time for the morning rush around 6am or 7am at the bus terminus. After a week of waking up early in the morning, a 30 minute walk to the train station and coming home when daylight faded, *sis Thembi* took weekends off work. She would use her day off to do laundry, visit friends, check in on her sons, prepare a home cooked meal and to run her errands. In order to ensure that income was consistent, *sis Thembi's* sons attended to the stall on weekends. When *sis Thembi's* illness began to weaken her body, her working arrangement changed. She could no longer attend to the stall and was too fragile to take care of herself. Due to this, she moved in with relatives (her aunt) in a different section within Site B. Similarly to Andiswa, soon after her diagnosis, *sis Thembi* received the temporary disability grant and often spoke of her brothers who stayed with her as useless when it came to contributing to the household income. They "would drink their money," *sis Thembi* lamented as she described how they misused their money on alcohol. Thus, her R1 200 (84,73 USD) disability grant became her main source of income as she could not financially rely on her brothers.

TB and economic disruption

In a country that is plagued by single motherhood, precarious employment and poverty, many black mothers are breadwinners in their families as indicated by the discussion on motherhood earlier in the paper. As sole providers, it causes mothers great distress when they are unable to fulfil this role of provider. There is a societal expectation that mothers will not only put food on the table but also affection and attention to their children in order to be 'good mothers'. The ability to work and earn an income is one of the most important features of good mothering as mothers enter into employment for the purpose of being able to provide for their children as suggested by Campbell (1990) and Christopher (2012). Similarly, Mutendi (2017) also argues that mothers work in order to provide a better future for their children. Therefore, we can see the importance of provision for black and working class mothers as a core role that they need to play in the lives of their children and as a way to maintain their identities as good mothers.

Andiswa and *sis Thembi* were under enormous economic pressure; *sis Thembi* even more so than Andiswa as she was the sole provider in her house. Andiswa relied on unstable income from her partner and mother's business, Nwabi's R280 (20,04 USD) grant and her own R1 200 (84 USD) disability grant. Under such economic pressures, illness added a financial burden in the lives of these two women due to the financial burden that accompanies illness. Magazi (2008) shows that a TB diagnosis is accompanied by new expenses that put further strain on a family's already limited funds. These new expenses tend to include transport, visits to private doctors before a TB diagnosis, healing rituals and 'special foods' and tended to put families under financial strain. This was evident in *sis Thembi's* case who often spoke about the need to spend on transport, healthy food and other necessities that aid the treatment process. For example, *sis Thembi* felt that she now needed yoghurt to take with her MDR-TB treatment to make it bearable. These new expenses made it more difficult for a household that had already lost regular income and at the risk of moving into deeper poverty. This was the case for *sis Thembi* – when she got sick, the household moved into a severe financial crisis.

The South African government frames being on TB treatment as worthy of a disability grant, thus a TB diagnosis alleviated some of the financial pressures of mothering and in severe precarity, quite substantially. The temporary grant is very important in lessening the socio-

economic impact of illness and assists in alleviating poverty in homes that are poverty stricken as suggested by Booyesen (2003:1-3). To illustrate this point, in the journal that I gave Andiswa she wrote:

“I found out from the clinic that people who have TB get a disability grant and I applied for it. Now I get money every month, it really helps me a lot. I can buy warm clothes since it is winter, for me and my daughter. We are from a poor family; it’s only me, my daughter and my mother in the house. The grant is very helpful when it comes to food and toiletries ...”.

Andiswa’s entry shows how helpful the grant was and how it relieved her financial burden.. *Sis Thembi* shared the same sentiments: she felt that she could sleep at night knowing that at least there was food for her children. When she started feeling well enough to walk long distances, she would go buy groceries and deliver them to her children. The social grant relieved both *sis Thembi* and Andiswa from financial pressures and therefore offered them a level of unburdening from existing financial pressures and those produced by the TB diagnosis. Without the grant, the financial burden would have worsened. In a context where the child support grant is spoken of negatively in popular media – as people burdening the state and tax payers for their own materialistic benefits, Andiswa and *sis Thembi*’s stories force us to take seriously the structural violence and enduring inequality that exist in society which puts some people in a position where the social grant is their only means of income and means of survival whereas other people are able to comfortably live with secure employment, health insurance and so forth. It also forces us to look at how conditions of poverty make it burdensome and very difficult for some to access health and well-being or be able to fight when a disease invades their lives. The social grant minimised the financial disruption and thus contained the mothers distress about their inability to provide for their children financially. It allowed them to hold on to a very important aspect of mothering – financial provision. However, there were other ways in which TB had disrupted their mothering and which endured even after they had access to the disability grant.

Disruption of the Practice of Mothering

Due to the gendering of care work and specifically of parenting, mothers are perceived to have a moral responsibility to be risk conscious and constantly manage any threats to the lives of their children (Knaak 2010). As Waltz (2013, 40) argues, there is indeed a dominant notion of sacrifice in the discourse about mothering — sacrifice is seen as a key defining component of “good” motherhood and, therefore, good mothers sacrifice energy, time and finances for their children (Waltz 2013, 40).

Andiswa and *sis Thembi* shared the sentiment that things changed when they got ill and that their mothering was altered by TB. In a sense, they felt as though their lives and particularly their mothering became disrupted and disorderly (Validoo et al, 2010:1463). Bury (1982) argues that when people experience a chronic illness, they tend to lose their confidence in their body and their ability to continue social interactions bringing about doubts of one’s self-identity. He terms this process 'biographical disruption'. Although TB is not a chronic illness, this concept is still useful in bringing into focus the meaning of illness for the individual, as well as the context in which the illness takes place. Additionally, Bury (1982) shows that people with illness deal with shifts in the rules of reciprocity between friends and family. This, I argue, is a key factor when mothering is disrupted by TB and its treatment. As a mother’s life is disrupted by illness, formations of care and the normative roles in care are shifted as well as the mothers ability to reciprocate and provide. Women experience significant guilt and distress, as they identify themselves as mothers first before their new identity as patient (Jackson, 2000).

This disruption to and of motherhood can happen in the physical presence of the mother because of her inability to care for her children in ways that she used to prior to her illness as she may be experiencing treatment side effects such as fatigue (Elmberger et al. 2008, Backman et al. 2007). Referring to the early stages of her illness, *sis* Thembi said: “*Izinto zazinzima, zibhidene, kufuneka bagade mna endaweni yoba mna ndigade bona*” (things were difficult, confused / roles reversed, they had to take care of me instead of me taking care of them). Here *sis* Thembi was talking about how she felt guilty when her children had to cook and take care of her. In this sense, TB disrupted the way in which *sis* Thembi ‘normally’ cared for her children and the way she understood her role and expected duties as a good mother. Here we also see how illness shifted formations of care and the normative roles in care completely. The sons took care of their mother and had to spend more time at the stall to ensure steady income and in that way, taking ‘care’ of the household. The responsibility of care had been disrupted, the children took over the role of caring which, although difficult for her as a mother, also unburdened her from having to care for others whilst ill. This disruption of care and the role as mothers was also evident in Andiswa’s life. Talking about this disruption, Andiswa said: “It was really hard on me that time so he (Nwabi’s father) took our daughter to live with him for three months”. Andiswa spoke about how the father of her child (with the help of his mother) took over the caring for Nwabi whilst Andiswa was too sick and could not take care of Nwabi. Andiswa’s mother could not take care of the child as she was very busy with her business. Here we see the acceptance of a situation that would have otherwise been frowned upon - where a partner who is not a husband was allowed and in fact asked to take his daughter from her mother to care for his daughter himself. In a context where children born out of wedlock and by teenagers are often cared for by the maternal grandmother or their birth mother, Andiswa would have been shamed by her community for ‘giving’ her child away in addition to having a child out of wed-lock. However, because of her illness, Andiswa says her community did not frown upon this arrangement and those who spoke badly of her decision to ‘give’ her child to her partner were reprimanded by others for not understanding Andiswa’s difficult position.

The issue of relying on others to care for one’s children is not a new phenomenon, nor exclusive to my research or just sick mothers, but also happens for other reasons, such as employment (Maqubela 2016). Collins (2005, 1152–1154) argues that the sharing of mothering responsibilities has been and continues to be one of the most important features of black motherhood and argues that the responsibility is shared with grandmothers, sisters, aunts and female cousins. However, when there is a contagious illness like TB, it becomes imperative that the child is not just taken care of by other people but is physically removed from the mother because of the risk of infection. This risk remains even when the mother is on treatment and is no longer infectious. The people who take on the duty of caring for children affected in this way empathise with the birth mothers and worry about the fact that they are too sick to take care of their own children or might in fact infect them. *Sis* Thembi sought care for herself and left her children to be taken care of by her brothers. She also reasoned that her children could take care of themselves as they were “old enough” and “there was no other way.” In this way, she escaped the “noise” made by her drunken brothers and her playful sons: “Yhu, ndiphumlile kwistress sakoo-BM” [I am resting from the stress of the BM section]. The “noise” that *sis* Thembi referred to was the racket made by drunken people shouting at each other, fighting, stumbling and falling on her doorstep or bumping into her house when they were unable to find their own homes. Apart from this obvious noise, she also managed to escape the metaphorical “noise” as discussed by Winterton (2010), the intense confusion and attempts at reconciling the seemingly irreconcilable expectations and realities brought about by a TB diagnosis. In *sis* Thembi’s life, this “noise” included the demands made by her sons and her brothers, such as asking for food and money. It also included the internal noise she felt when she could not

provide for her children as she was bed-ridden, fatigued and sick: “I can just imagine my son looking at me saying he is hungry and I would know that there is nothing I can do about it. At least now I am not there to see that.” Here we see that both Andiswa and sis Thembi were relieved of the physical, social and emotional — the “noisy” — duties of mothering, which included being there with the child, taking care of it, dealing with social expectations, as in Andiswa’s case, and various forms of noises, as in sis Thembi’s.

Relying on others to care for them and their children – allowed for Andiswa and sis Thembi to turn down the volume of the physical demands and noises. However, different kinds of noises came up. The physical and financial unburdening that Andiswa and sis Thembi experienced came at the expense of an emotional burden. Andiswa and sis Thembi shared feelings of guilt for not being able to take care of their children, not knowing what they ate at night or if they ate at all, worrying if they went to school and if they missed the mother. The mothers also dearly missed their children. Although it was helpful that relatives (and in the case of Andiswa, the fathers and his family) took care of the child, the mothers were concerned that they could not reciprocate these acts of kindness as it would take a while for them to get better if at all. Sometimes we would be having a conversation and sis Thembi would fall into deep thought and then say “*Yoh, ndiyabakhumbula abantwana bam*” (oh, I miss my children). Although sis Thembi felt relieved from the ‘BM stress’, sometimes I would hear her say: “*Ndikhumbula kooBM*” (I miss BM [section]). This did not mean that she missed the area as the translation might suggest, it meant that she missed her home and being with her children, she missed her house. In these conversations, she would laugh to herself at some thoughts, she shared some of the events that took place at her house in BM section displaying the constant noise that was happening. When sis Thembi started feeling well enough to walk long distances, she would go sleep over at her house during weekends so that she could spend some time with her children. Andiswa also spoke frequently about how she missed her daughter Nwabi and wanted her to come home. The narratives of both mothers were filled with worry related to their role as mothers and not being able to do it well. As a result, the idea that “I am going to get better for my child’s sake” was very persistent. Andiswa said that she decided to take her treatment properly, all the time and eat well so that she would get better and so that her child could come back home. Sis Thembi was worried about dying and about who would take care of her children if she died. Her fear of death and leaving her children alone and poor kept her going and made her want to get better. There was particularly a time when she was angry and stressed out because her brother had beaten her 19 year old son and she felt guilty for not being there to intervene. Bonani (sis Thembi’s brother) claimed that Yandisa (sis Thembi’s teenage son) had stolen his expensive shoes and that he was developing a habit of stealing. Even though sis Thembi was unwell at that time, she wanted to get up and go to her house to ‘fix the problems’. Her aunt did not allow sis Thembi to go as she felt she was too weak to walk there and that the stress was not good for her health. Instead, the aunt asked her eldest son (Sandile) to speak to Bonani, find out what had happened, let him know that sis Thembi was very upset at his behaviour and to not to hit sis Thembi’s children again. Situations like the one described here increased sis Thembi’s guilt: she felt that she as a mother was meant to protect her children, not “sit comfortably in someone else’s house” while her son needed her – she remarked. This burdened her. However, even though these situations increased sis Thembi’s layers of guilt, they simultaneously served as motivation to get better so that she could go ‘fix’ the problems in her house – once again showing the confusion and occurrence of different things at once during illness.

Wilson (2007, 3–4) argues that motherhood plays an intrinsic role in the everyday experiences of mothers with illness. In her research around HIV/AIDS, she found that the role and identity

as mothers made women feel an obligation to get better, and had an impact on their treatment adherence⁵ and their use of the health services. Their children served as a driving force that helped them adhere to treatment. This is very clear in the narratives of sis Thembi and Andiswa as they both spoke about how they wanted to get better for their children, so that they could be home with them and resume their mothering. Andiswa wanted to play with her child and hold her; sis Thembi wanted to check that her children did their homework and help with it if necessary; and both spoke about how much they wanted to cook for their children. This desire to be with their children motivated them to follow their treatment plans, eat well, dress warmly and “listen to the doctor,” as sis Thembi used to say.

In 2018, the impact of TB on mothering remained a key aspect of how Andiswa and sis Thembi remember their illness experience and a significant moment of disruption to their mothering. As a mother to her second child, Andiswa spoke at length about how she would never forget what TB meant for her mothering and alluded to the pain and emotional burden it caused.

“ITB ayonto endinothi ndingayilibala. Ndihlale ndihlale ndicinge ngayo, ingakumbi xa ndingazivaright. Ndiye ndicinge uba ndingaphinde ndibenayo ngoba kaloku ayipheli emzinjeni, ntonje iyanyangeka. Kwakunzima kakhulu kuba wayemncinci kakhulu umntwana wam. Wayengasoze aziqonde intlungu endandikuzo”(TB is not something I can say I could forget. I sometimes think about it, especial when I am not feeling well because it never leaves your body, it is just curable. It was very difficult because my child was very young. She could never understand the pain I was in).

Andiswa constantly thought about TB transmission and every time she felt unwell, she would fear that the “TB is back.” To deal with this fear of the past repeating itself, Andiswa was careful to dress warmly, avoided drinking from other people’s beer glasses or using their utensils at social events, and made sure she brought her own. She continued to do this to protect herself from being reinfected with TB, because of the fear of having to separate from her children. “Ndifuna nje ujonga abantwana bam” [I just want to look after my children], she repeatedly said. Andiswa’s attempts to protect others from infection reverberate with Abney’s (2011, 35, 40–42) description of a local TB “illness transmission model” where “dirt” is transferred through sharing utensils, cigarettes and drinks. Therefore, Andiswa’s attempts also serve as a window to her understanding of contagion.

Conclusion

This paper reminds us of the impact of the political economy on health and well-being. Inequality and poverty allow for some lives to be under a constant threat of illness and difficulties in healing, either due to how the illness changes their financial circumstances or how their social capital may or may not allow them to enlist the help of others. We also see the role of the child support grant and the temporary disability grant in alleviating some of the burdens brought about by illness and, in that way, producing a form of unburdening for those involved. This paper also shows us the process of disruption during illness. The financial disruption that TB produces complicates the mother’s ability to provide “as a good mother should,” and the grant provides a needed aid. However, there are other forms of disruption to the mothering practice. As shown in the cases of Andiswa and sis Thembi, mothers are left with a lot of emotional burden. They feel guilty for not being able to be there for their children and they fear death. However, these feelings and fears have a positive impact as they foster treatment adherence.

The biographical disruption and chaos in the personal narratives, which I call “burdening,” co-exist with moments of calm and relief — moments of unburdening. This is no surprise because,

as I mentioned earlier, the experience of illness can be filled with paradoxes and ironies. In this case, there is a continuum of disruption and chaos, moments of intense disruption taking turns with moments of mild disruption and relative calm. Brandt (2008) provides a very useful concept to cater for the moments where disruption and chaos are not applicable and introduces the term “disruptive experiences.” These are crucial moments of the experience, they are short lived but they do not define the entire experience as there are other parts of one’s life that take centre stage; illness just becomes part of life as opposed to everything being about TB. In this paper, then, we see both disruptive experiences, leading to moments of burdening, and less disruptive experiences that point to moments of unburdening. The mothers in my study move in between these moments as they at times occur simultaneously. The narratives of Andiswa and sis Thembi show that stories of people who are able to live with an illness go beyond devising coping or managing mechanisms but include hope and the ironies of the experience of illness, whilst also showing how burdens and emotions shift during an illness..

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