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*“Obubomi bulukhuni/It is a hard life, this” : Journeys in  
and Narratives of Childhood Cancer in a South African  
Public Healthcare Context.*



Dissertation presented in partial fulfillment of the Degree of  
MSOC SCI  
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DEPARTMENT OF SOCIAL ANTHROPOLOGY

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**PLAGIARISM DECLARATION**

This work has not been previously submitted in whole, or in part, for the award of any degree. It is my own work. Each significant contribution to, and quotation in, this dissertation from the work, or works, of other people has been attributed, and has been cited and referenced.

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

University of Cape Town

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## **ABSTRACT:**

*This research examines the ways in which a history of social segregation together with present actions by the state interact to inform the nature of healthcare narratives of mothers and children in the case of a childhood cancer diagnosis. I argue that families become internally displaced to seek life-saving treatment for the child diagnosed with cancer. By actively engaging with theories of 'home' and 'households' I aim to present greater insights into the ways in which people create meanings for these terms in the hospital setting. I argue that my participants come to share many of the characteristics of internally displaced people, due to the inequality that manifests in the healthcare system.*

*This thesis engages with discourses and theories of agency to examine the ways in which agency manifests in situations and spaces in which the agent has little choice. It is an investigation of the ways in which people 'make do' within a deficient healthcare system which is deficient and causes displacement.*

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**CHAPTER 1 : Out Of the Mouths of Babes: A Child's Profound  
Insights into the Experience of a Childhood Cancer Diagnosis.**

*The maximum dose of 'sleeping medicine' circulating through Aviwe's little body had done little to stop her writhing like an earthworm and mumbling non-stop. "She is no longer really conscious or feeling pain," the doctors were reassuring me (and possibly themselves). I sincerely hoped this was the case. Personally, I wouldn't want to be on the receiving end of the lumbar puncture or bone-marrow biopsy that awaited Aviwe.*

*The doctors' debated whether the batch of tranquiliser was 'faulty' as they had observed similar resistance when using it with other children. Aviwe wasn't displaying any signs of pain, but somewhere during the session she mumbled "obubomi bulukhuni" (It is a hard life, this).*

According to Fundiswa, Aviwe's mum, Aviwe was one year and ten months old when she uttered these words. The swollen glands in her neck were an ominous sign that treatment, in this case, may have come too late to save her young life. Fundiswa had taken her to the hospital at the end of the previous year, when her eye had started swelling after a fall. When the doctors told her that the only option was to remove Aviwe's eyes, Fundiswa refused. What happened then is slightly unclear. What is clear, however, is that Fundiswa was never told of treatment options such as radiotherapy and chemotherapy, both which could have been effective in the early stages of treatment, and that by the time Fundiswa and Nkosi were admitted to ward C5, the paediatric oncology ward at Frere Hospital, the prognosis was unfavourable. Aviwe's story captures many of the vantage points of a <sup>1</sup>Childhood Cancer (CHC) diagnosis.

On World Cancer Day 2011 (3 February), the African Organisation for Research and Training in Africa (AORTIC), declared their commitment to a multi-year initiative in partnership with organisations like the World Health Organisation (WHO) to improve the prevention, control and care of cancer in Africa (Sedibe, 2011).

Childhood cancer figures are difficult to come by<sup>2</sup>, but in 2008 it was estimated that 70% of the children diagnosed in the 'developing' world would die of CHC – a shocking figure when compared with the 20% of children in the 'developed' world (Naidu, 2003)<sup>3</sup>. Some of the factors Dr. Janet Poole, a South African Paediatric oncologist, claims to attribute to this high CHC mortality rate include poor health expenditure

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<sup>1</sup> Please see p.56 for a full list of abbreviations used in the thesis.

<sup>2</sup> These are rough estimates as it is very difficult to compile accurate figures. Some cases are never diagnosed. Even when diagnosis does occur the case may not be reported or there may not be a central cancer registry to receive the report. These statistics are from a presentation by Dr. Gita Naidu during the CHOC Annual Conference in 2008.

<sup>3</sup> In 2008, of the 650,000 Africans diagnosed with cancer, 500,000 died. This is more than double the number of people diagnosed in North America or Europe (Sedibe, 2011).

per capita and the limited treatment facilities, human resources, lack of diagnosis and drugs available to treat CHC (Poole, 2008).

This late or non-diagnosis is a consequence of, among other things, a general ignorance about CHC. As Professor Serigne Guey, the current AORTIC president remarked, “In Africa, there is a general lack of cancer awareness, which leads to late presentation of cancer. Most African healthcare systems are not in a good position to address the cancer problem” (Sedibe, 2011).

South Africa has seven functioning units, but some African countries do not have a single unit (Poole, 2008). This means that some families have to cross national boundaries in order to find medical treatment for CHC. Cape Town, with its three specialised paediatric oncology wards, is thus more the exception than the rule. Of the eight provinces in South Africa, the Eastern Cape is one of the most poorly resourced provinces. The Eastern Cape has with a population of 6,527,746, whereas the Western Cape has 5,278,585 (Statistics South Africa, 2007), but the Eastern Cape has only one paediatric oncology ward, located in Frere Hospital, East London.

The Eastern Cape has become an example of the ways in which the Public Health Care (PHC) system has failed the South African public. The recent maternal mortality report issued by Human Rights Watch South Africa did nothing to improve the poor perception of the province’s PHC system. With reference to the high number of maternal mortality cases, the report says that “poor quality and unresponsive care for mothers and health systems devoid of effective accountability to patients or the public are particularly important in shaping (and worsening) maternal-health outcomes” (Mepham, 2011).

The reason that I detour slightly here, discussing issues of maternal mortality in a thesis about CHC, is that the stories of the mothers interviewed for the HRW share similarities with some of my participants’ stories about their experience of a CHC diagnosis in the PHC system. Stories of discourteous health personnel and the poor quality of care at many of the PHC institutions were echoed in my participants’ narratives and those of the mothers in the HRW report.

To gain insight into what a CHC diagnosis meant for the mother as well as her child, I conducted my fieldwork in ward C5, a paediatric oncology ward in Frere Hospital, East London.

A non-governmental organisation, the Childhood Haematology and Oncology Clinics (CHOC), East London division, are entrenched in the functioning of the ward and acted as gatekeepers during my

fieldwork. In addition to putting me in touch with the relevant persons, they gave me board and lodging in their CHOC house, which enabled me to spend time with my research participants in the house where they slept, ate and played with more freedom than the limited space and ward routines allowed.

CHOC, in its early days, was the result of parents coming together to form a support group upon their children's cancer diagnosis. The organisation was formed in 1979 in Johannesburg and in 2000 parent groups from all over the country amalgamated to form one national organisation (CHOC, 2011). The organisation has grown to include Pretoria, Pietermaritzburg, Durban, Cape Town, Port Elizabeth, East London and Bloemfontein.

The NGO brings together children and families who are living with childhood cancer by facilitating treatment, community education and family support to "Keep more than hope alive"<sup>4</sup>. CHOC has some major corporate sponsors as well as national and local fundraising projects to maintain its funding.

CHOC's East London branch is not only a support group but deeply embedded in the work of the East London Child Oncology Ward. It runs active volunteer programmes and provides support for families and much-needed 'hardware' such as drip stands, which allow the ward to work<sup>5</sup>.

Some of the divisions have a 'CHOC house', which functions on the premise that any child declared medically stable and accompanied by an adult can spend the evening at a house, where they can sleep in a soft bed and receive a home-cooked meal before returning to the hospital the next morning. A CHOC house is bought with funds from the organisation's national treasury, but its maintenance is the local division's responsibility. (See Addendum B for photographs of the CHOC house.)

As Rosemary Blake argues in her honours thesis, *Please Keep These Doors Closed*, health narratives have less to do with the disease as a biological entity than with the experiences of success or failure in the healthcare system (Blake, 2007). Blake suggests that "...perhaps the children were seeing 'cancer' not so much as something that they have but rather as something (or a series of somethings) which has happened and continues to happen to them, something contrary to their desires and, significantly, something which is experienced holistically rather than on 'separate' levels" (Blake, 2007 :11).

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<sup>4</sup> For a more detailed version of the services CHOC provides please see Addendum B.

<sup>5</sup> According to one of the doctors C5 was reasonably 'well-off' when compared to the other wards at Frere, which has had its fair share of scandal.

Ross argues that social science has focused mainly on the prognostic and diagnostic aspects of illness, but that very little attention has been paid to the ways in which people “make sense of daily life in the face of illness, or about its impact on accustomed modes of sociality and ordinary ways of relating” (Ross, 2010:169). In my conversations with my participants very little time was spent on the biological nature of the tumour, rather the conversations were treatment narratives and expositions of the ways in which the CHC diagnosis had displaced the children from their daily lives. Spending my time between the hospital and the CHOC house, I had the opportunity to share in my participants’ daily lives in the hospital context, a displacement from their ‘normal milieu’ to a cold ward where schedules were dictated by ward rounds and medical procedures.

I will investigate how the various historical, political, social and economic factors combine to bring about the displacement from home my participants experienced due, among other things, to the inequitable distribution of PHC services.

Incidence of childhood cancer is distributed fairly equally among different demographics, but the experience of the diagnosis will be largely determined by the availability or lack of diagnosis, treatments and aftercare.

Michael Taussig, in Fiona Ross’s book *Raw Life, New Hope*, notes: “...the incidence of both [health and disease] are heavily determined by the specificities of social organisation” (Ross, 2010: 167). Due to various political and historical elements, my participants were positioned to become users of the Public Health Care System. As Ross notes, “...the political economy of hardship set in place by colonialism and sedimented under apartheid perpetuates inequities and will take generations to redress” (Ross, 2010: 180). Health is thus a matter of context: “in short, all of the forces that bring a patient to a doctor (or keep a patient from a doctor), all of the processes leading to sickness and then to diagnosis and treatment, are related to a series of large-scale social factors” (Farmer, 1999: 10-11).

Chapter 3 thus aims to grapple with these questions: *What processes and actions influence the PHC system in South Africa? How do these processes impact on the treatment narratives of PHC users?*

Henderson uses the term ‘fragility’ to explain the ways in which the lives of children can ‘shatter’. According to Henderson, ‘fluidity’ is the characteristic discontinuity and flux of a social context in which children’s senses of self emerge as multiple and variable. Attempts to reconstitute social worlds, sometimes through ritual processes, seldom reach a point of finality. Healing and repairing of the social

fabric is thus an ongoing process. Fragility refers to “the shadow, or the traces, of apartheid state policies in the everyday lives of children” (1999: 25). ‘Fragility’, in my research, however, was a concept which was entrenched in the experiences of not only the children. The CHC diagnosis had ‘shattered’ the worlds of the mothers, who had left their studies, work and/or support networks to accompany their child on the treatment experience.

Henderson asserts that contexts described as ‘fragile’ “demand of children that they be dexterous, resourceful, and adaptable, that they take responsibility. Such dexterity can however lead to a lack of focus, a mercurial adaptation to circumstance and a lack of future orientation. It can also lead to periods of dissociation where children demonstrate an embodied disaffection with, or challenge to the world” (Henderson, 1999: 158). The ‘motherless’ children in the hospital would align themselves with some of the mothers to help fulfil mothering tasks when necessary. Yet this ‘dexterity’ in relationships was also evident among the mothers who had in many cases been cut off from local support networks and had to re-establish networks in hospital to deal with the situations.

Henrietta Moore (in Henderson, 1999: 14; 1994b: 133) notes that “local conceptions of self may vary in the way in which agency and motivation are conceptualised as arising internally or externally to the self; in terms of whether a distinction is made between body and mind, or whether other sorts of beings are integral to the conception of the self; and even whether the body is the prime locality of the self.” Agency is thus a matter of context, not a synonym for free will or resistance, but rather, in my participants’ context, analysed in the ways in which they navigated and uncovered the various resources available to them, no matter how scarce.

They were ‘making do’ in the hospital, while the concept of ‘home’ symbolised a life no longer dictated by hospital routines and rules.

In Chapter 3, together with the aforementioned questions, I will tackle these questions: *Does the PHC system allow my participants the agency to use creative ways to be “dexterous, resourceful, adaptable and take responsibility”?* *How do they use this agency if it is available to them?*

The effects of the cancer diagnosis extended beyond the children’s bodies and the hospital space, manifesting in the lives of their mothers<sup>6</sup> at home. Children and mothers were displaced. On careful

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<sup>6</sup> In the case of my main participants the coupling of parent/child happened to be biological mother and child. Yet it quite frequently turned out to be other family members who fulfilled a ‘mothering’ role when the biological mother was unable to come to the hospital to stay with the child. In this thesis I will refer to the child’s primary

analysis, they share some of the experiences of peoples displaced within their own country's border through persecution or development. Chapter 5 examines the ways in which the narratives of my participants' journeys with CHC echo the experiences of IDPs in terms of their displacement from home, work, school and their struggle to find a space within a host community. This comparison of experience forms the backbone of Chapter 5, which seeks to answer these questions: *Do my participants share any of the qualities attributed to IDPs. What are these experiences? Can my participants be described as IDP?*

In conclusion, this thesis examines how various historical, political, economic and social factors interact to shape the experience of individuals' healthcare journeys. Even though the focus is on individual stories, there are various threads that connect the variety in the stories as to provide insight into the ways in which a CHC diagnosis can bring about a displacement in the space, hopes and dreams of daily life, not only for the diagnosed child, but also their families.

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care taker as 'mother', yet it needs to be recognized that this is a fluid term that does not necessarily indicate the biological mother or even a blood relative. As Henderson illustrated in her PhD thesis on childhood in crossroads, the 'mothering' duties may be shared among adults and was not merely the precinct of the biological mother (Henderson, 1999).

## **CHAPTER 2: Methods and Ethics**

## **Introduction**

*As I sat on one of the hard wooden benches looking at the booming TV showing yet another repeat of the public broadcaster's ever-diminishing repertoire, my mind was running methodological circles. At the best of times I cannot sit still and watch TV for hours and yet here I am, supposedly doing fieldwork, but sitting in front of the ward TV every day. All my creative methodological ideas, which I was going to apply in the field, had been dumped at the ward door a long time ago. What should I be doing? How can I instigate something?*

And then it dawned on me. This was exactly the frustration some of my participants were experiencing. Some of them had suspended their daily tasks and roles to come and live in the 'boring' hospital, in which days dragged by. I was feeling extremely inept as an anthropologist, but the sudden dawning of insight resulted in a paradigm shift. By obsessing about the clever methodologies I should be using in the field, I was potentially missing some of the most important aspects of the experience within the PHC. From that moment onward, I engaged with my participants through their pre-existing activities and discovered a research experience rich in ethnographic data.

Method is not an exact science. To obtain relevant data it has to acquire an amoebic nature, moulding itself into the research field, filling out all the nooks and crannies that we, as researchers, need to enter to construct a representation of our participants' life worlds that contains at least some semblance of their reality.

This chapter provides a detailed account of my research field. It reveals the challenges my planned methods presented and how I had to diverge from my planned route to create the space for my participants to dictate their journeys in their own ways. It provides insight into the ethical framework that guided my research, which, due to the nature of my participants' age and medical conditions, presented me with complex analyses of the ethics of researching with children.

## **Recurring Themes of Cancer**

In 2003 I started my academic career as an Occupational Therapy student. My heart plummeted as my eyes focused on the 'Paediatric Ward' placement at Tygerberg Hospital during my third year of Occupational Therapy studies. I had never been particularly driven to work with children, but this paediatric block would turn out to have the most significant impact on my future study and career choices.

This lasting impact was all due to one of my first patients, a young boy diagnosed with a medullablastoma<sup>7</sup>. It would be my first contact with such a young child with cancer, and it would also be during this time that I first became aware of CHOC's active role in the ward.

At that time my particular fascination with CHC was that the physical effect of the cancer on the child's body brought into question his place and role in society. This also led me to question the ways in which it came to redefine 'normal' life for, not only for my participant but also for his family. This interest in childhood cancer was reignited when, in 2008, during my community service year in Kwazulu-Natal I made contact with CHOC's Pietermaritzburg division, which distributed educational CHC materials to local clinics and doing in-service training on childhood cancer with doctors and nursing personnel<sup>8</sup>.

The health education work I did on CHC and other illnesses during my community service year inspired me to study social anthropology. I wanted to gain the skills and knowledge to develop relevant health education which was informed by the context in which it was being implemented. This dissertation is the next step in the evolution of a subject that has morphed from an interest into a passion. My research gave me the opportunity to work intimately with children with cancer and with their families and healthcare providers to understand what a CHC cancer diagnosis meant for them.

I conducted fieldwork in East London the last metropolitan area (when travelling from Cape Town) before entering the former homeland of the Transkei<sup>9</sup>. My stay was graciously facilitated by the CHOC foundation, which not only provided my board and lodging but also acted as gatekeepers into the hospital and as general 'go-between' contacts.

The choice of East London was not a serendipitous one. Had I wanted to study childhood cancer I could easily have stayed at home and visited institutions such as Groote Schuur and Red Cross Hospital – both leading institutions in the field of paediatric oncology. I chose, however, to base my research in the Eastern Cape Province. The province is no stranger to bad publicity in the healthcare sector and has the poorest health indicators in the country (Mepham, 2011). As I loaded my car and trekked the thousand

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<sup>7</sup> A malignant form of cancer located in the medulla of the brain. Please see pg.56 for a full glossary of medically related terms.

<sup>8</sup> CHOC distributes educational materials to various centres to educate communities on CHC warning. They use the acronym SILUAN to relate to the most common signs of childhood cancer.

<sup>9</sup> Tellingly, a lot of the participants who hail from the former Transkei still refer to the area as Transkei. This name is still real for some of the people who live in this former homeland, whose memories of this name make history present.

kilometers to East London, I wasn't aware of how simple and straightforward my journey would seem when compared to the journeys my participants would tell me. My initial field site (ward C at Frere Hospital and the CHOC house) would grow to traverse provincial borders as I maintained contact with some of the participants and continued to share in their health experiences long after my six-week fieldwork block ended.

### **Lost in Translation: Methodological Concerns in the Field.**

In my proposal I had envisioned using methods such as diaries with the children, which would, hypothetically, provide me with profound insights into the CHC experience from a child's perspective. The reality, though, was the majority of the children couldn't write. Most of them enjoyed drawing, but it was a sporadic occurrence and they did not enjoy drawing on request. My idea of using cameras to document ward life also proved a pipe dream: cameras had been banned from the hospital following the its poor media coverage after journalists managed to take secret photos of the state of the wards<sup>10</sup>.

In the first week or two of my research I felt despondent as my hopes for 'child-centred research' were disintegrated – until I realised that there was a wealth of data contained in the daily routines and actions of the children, but also their mothers and health staff.

I adopted a research process which constantly revised the pre-planned 'principles' (Fox, 1999) of my research proposal as it became apparent that they didn't fit the context of my research. As Mayall argues (in Balan et.al, 2003), research that is child-centred acknowledges children's ability to present and reflect on their own experiences. The children's representations of themselves became apparent through their daily actions, routines and snippets of conversations I caught through the odd, spontaneous translation.

James and Prout argue that ethnography gives children the opportunity to present their stories and meanings in their own voice (James & Prout 1990: 2005). As this is an ethnographic study, my main research method was participant-observation or, as Ross chooses to refer to it, "one among many ways of being attentive" (Ross, 2010: 10). This requires inquisitive anthropologists to exile their notions of the ways things 'should' be (Ross, 2010: 10) and focus instead on the way things are (Ross 2010). Carnevale

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<sup>10</sup> Members of CHOC are however allowed to take photos as it is seemed as they are seen as part of the ward family (see Chapter 4). Through my association with the organization I was able to take numerous photos, but have decided to keep them a personal mementos due to the various ethical considerations in exposing individuals with medical conditions.

et al. argue that participant-observation is a useful strategy to employ because it works to balance the power dynamic between the researcher and participant. This results from the method's flexibility, its emphasis on relationship formation, and the use of multiple data sources which are sensitive to the context of the research field (Carnevale, 2008).

I agree with Carnevale et al. that a researcher who becomes entrenched within their participants' context can provide a more nuanced version of their life-worlds than one who, say, sweeps in and conducts a survey. I think that no matter how entrenched we become in these contexts though, anthropologists need to be reflexive of the ways in which factors such as education, social class and belief systems, may influence the representation of our participants life-worlds. These differences may result in an interpretation and presentation of participants which has little in common their version of their life. Reflecting on the processes and contexts which shape our observations becomes crucial if we wish to represent our participants' experiences in such a way that they would still recognise it and name it true.

In constructing this thesis I am not trying to create an illusion of objectivity. By suspending a fixation with objectivity the researcher becomes more open to be surprised by a world which is "richer and more complex than it is assumed to be" (Thomas, Hylland & Eriksen in Ross, 2010: 14).

Participant-observation, however, is not just sitting around idly and writing haphazard notes. As Savage notes (in Carnevale et al.) participant-observation is "both technical: a body of practices, procedures and rules (i.e. combination of research strategies) [and a] theoretically-informed approach to the production of data" (Carnevale et al., 2008:21). What we witness must be interpreted within its context using relevant theoretical frameworks.

I find Nick Fox's notion of the 'nomad' (adopted from Deleuze in Guattari (1998: 380)) a useful analogy for a researcher who does "not seek to control; she takes what is on offer, assimilates it, and moves on" (Fox, 1999:7). Using this approach, we allow our participants to become just that as we are guided and fall into their rhythms, giving us raw data which we can interpret with relevant theories.

In *Please Keep These Doors Closed*, Rosemary Blake relates her difficulty in extracting 'illness narratives' from her participants. The narratives she encountered were based on treatment and how the experience of illness was entrenched in the negotiation of the health system (Sered & Tabory in Blake, 2007). The conversations I had with my participants echo this observation. The 'illness narratives' were contained in the other phenomenological encounters I had in the ward, experiences which words could not convey. Phenomenology as a methodological process allows for a multi-modal account of the illness

narrative that is not limited by words. By focusing more on what was being done than what was being said I unknowingly took a phenomenological approach to research.

Phenomenology was born from the frustration with the linguistic and cognitive models used to interpret the embodied experience (Lock, M. 1993; See also Csordas, 1990; DeVish, 1985; Frank, 1986; Gordon, 1990; Jackson, 1983a, 1989; Young, 1993). Jenks is of the opinion that “a phenomenological perspective could enable us to gain insight into an existential and generative sense of sociality that emerges from within the consciousness of the child.” Thus a phenomenological approach is useful when participating with children. I also believe that this approach is valuable with adults, especially in a context where speaking can elicit pain and become an act of violence (see Das, 2007).

By trying to capture experience in its full, multi-sensory form, we are able to transcend some of the limits of language to express the experience. Manen is of the opinion (in Bjork, Nordstom, Wiebe & Hallstrom, 2010) that phenomenological accounts can never be generalised while Dahlberg (ibid.) argues for generalisations among groups who share a similar context. My opinion is that phenomenological accounts cannot be generalised as the individual’s experience is unique to the space and time in which it occurs. The aim of my research is not to try and generalise individual experiences. Instead it is to give a human face to statistics by presenting the ways in which childhood cancer is embodied – not only within the individual, but also by and within the social body. I use individual narratives and experiences to trace out networks which reflect the historical, political and social factors that inscribe and are inscribed by these bodies, while taking into account the ways in which these inscriptions are resisted (See Desjarlias, 2003). As Fiona Ross in *Raw Life, New Hope* points out “focusing on a small site allows us to see these tensions play out in people’s lives” (Ross 2010:3). This reflects Geertz’s notion that “Small facts speak to large issues” (in Ross 2010:8).

Benjamin Paul was quoted (in Good, 1994: 26) as saying: “if you wish to help a community improve its health, you must learn to think like the people of that community”. This appears convincing but, as Paul Farmer states, “anthropologist and informant are not separate and equal; both are caught up in a global web of unequal relations” (Farmer, P, 1999: 6).

I am a white, agnostic university student with a relatively stable source of income who grew up in a ‘nuclear’ urban family. Most of my participants were black religious parents with high-school educations. Many were unemployed or employed in the unskilled labour sector and had varying complex family systems or very little family support. My aim was to become “the tool through which knowledge is

gained: [an] approach [which] is both subjective and objective” (Ross, 2010: 10), but to do so I had to employ such reflexivity<sup>11</sup> to reflect the ways in which these various positionalities influenced my interpretations.

I thus engaged in what Fox would term ‘action research’, which is based on a commitment to “reflexivity, collaboration and difference” (Fox, 1999: 187). ‘Difference’ points to the fact that research doesn’t shy away from differences, but instead of framing them as problems it chooses to celebrate the diversity contained in differences. While I agree that ‘difference’ should not be avoided, I also believe we should not enter the field with a presumption of difference at the risk of conducting anthropology based in alterity. Key to conducting ethnographic research is the ability to be surprised and reengage with presumed theories to gather a sense of how things are, and not the way we suppose them to be theoretically (see Fox, 1991; Moore, 1999; Gupta & Ferguson, 1992).

In the field, I encountered difference which was born from the varying contexts I explained earlier. In these cases, I subscribed to Fox’s enthusiasm for difference. I approached it as an opportunity to learn from my participants. One of the mothers became my isiXhosa teacher, with several of the mothers and nurses contributing the odd comment. In return, I was able to use my knowledge of pathology to explain medical concerns in detail. Our different knowledge and experiences thus became a way of establishing mutually beneficial relationships.

Clifford argues that ethnography is constructed from ‘partial truths’ (Clifford in Heap, 2003: 43). As such ethnographic accounts cannot be examined in a vacuum but rather threaded together by analysing the various vantage points and contexts which give shape to these accounts and exposing the networks which give rise to these experiences (Handrel and Segal in Heap, 2003). I was fortunate to be able to perform various roles, allowing me the diverse vantage points of the various participants involved in the experience of CHC.

I was invited to all CHOC meetings and was drawn into the daily functioning of the organisation. I was accepted on doctors’ ward rounds, attended medical procedures and was even asked for my opinion on occasion. I assumed the role of ‘carer’ on a few occasions, when I would try to comfort a child or volunteer my services as ‘adult’ to allow a child to spend an evening at the CHOC house.

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<sup>11</sup> Reflexivity is ‘an awareness of the ways in which present and past forms of power and history shape our expectations, positions and actions...’ (Ross, 2010: 14).

I was thus able to navigate different spaces and experience different relationships, giving me the opportunity to observe and describe the various influences that shape and are shaped by a CHC diagnosis.

## **Ethics**

My decision to work with children (and children with a medical condition) necessitated an extensive ethical section in my research proposal to attain the prerequisite ethical clearance for fieldwork. Section 10 of the South African Children's Act encourages child participation in "any matter concerning that child" as long as the child is at an "age, maturity and stage of development... to [be able] to participate in [an] appropriate way [with the] views expressed by the child given due consideration" (2005: 30).

As numerous authors have argued, childhood is a social construct that is contextually defined. The child as research participant should not be assumed to be inherently different or vulnerable (see Hart & Tyrer, 2006). Following this argument's trajectory, various authors have argued for ethics that are context-based and not subsumed in the constructed concept of 'childhood'. Context-based ethics thus do not differ from the ethics employed with adult participants (see Bray & Goosen, 2005).

Mayal argues that complications in child-centered research do not arise from children's inherent inabilities, but from the social position ascribed to the child. The major issues of the researcher-researched relationships in child-centred research thus echo the premise on which ethical adult-centered research is based (in Dixon-Wood, Young & Ross, 2006).

Christensen and Prout present a notion of 'ethical symmetry' (Christensen & Prout, 2002: 431) which is based on the concept that the starting point for the researcher-child relationship rests on the same premise as that between adult and researcher: the differences encountered are the products of the context in which the participant is located, not products of the label of 'child'. I aimed to attain 'ethical symmetry' by having the children guide my actions as much as possible. If they didn't want to participate in a certain activity I did not force them. We engaged in activities which they would usually be doing by themselves in any case, such as drawing or doing schoolwork. The only activity that I actively constructed was yoga, but the children could decline to participate and actively executed this right.

My participants were verbally reminded of my research on a nearly daily basis. I felt that this was important, especially as we became more friendly, as I was aware they may disclose information they would to a friend and not necessarily to a researcher. The fact that I was conducting research never

presented a problem, but I have refrained from revealing information that could potentially endanger or embarrass my participants (see Nyamnjoh, 2010).

I explained my position as researcher in straightforward terms to the children, and I gave them the opportunity to sign an isiXhosa consent form which indicated the information which had been shared verbally. In basic terms I explained that I was doing a project for university on what it means to have CHC. They would still be able to take part in any activities I would do with the children in the ward, even if they decided that they did not want to participate in the project.

I believe that it is important to obtain context-specific informed consent to protect both the adults and children from research that is 'covert, invasive, exploitative or abusive' (Alderson in Dixon-Woods et al., 2006: 166). According to Montgomery in Balen et al. (2006), ethical 'assent' is not informed consent, as understood by law, but an agreement by a person that something may be done to or by her or him, even where she or he does not understand the purpose of the act. In my case I argue for a concept of ethical assent to be attributed to both the children and adults as I cannot describe with certainty the degree to which the participants understood the meaning of my research. I did, however, try to revisit this assent as much as possible to ensure that my participants were always aware of what I was doing and the motives behind my study.

In line with Section 13 of the Children's Act and American Anthropological (AAA) guidelines, I attempt to protect the confidentiality of my participants by using pseudonyms and refraining from using any identifying information (Children's Act, 2005; AAA, 1986). I have decided to use the name of the hospital, as it is the only hospital in the Eastern Cape which houses a paediatric oncology ward and as such would be virtually impossible not to declare.

I did not give my participants monetary compensation but attempted to repay their participation in other ways. I found that many of the mothers prized photographs of themselves and their children, so I printed numerous photos as gifts.

Knowledge is also a well-received gift. If I had advice to give based on my occupational therapy background, I gladly gave it. In many cases I would explain to the mothers some of the more medical aspects of the child's cancer diagnosis. I also tried to assist in any way I could, whether it was helping type CVs or co-ordinating birthday parties for the children through CHOC.

As a parting gift, I gave all of the participant children spoons engraved with their names. This may seem a strange gift, but the hospital rarely had cutlery available and the mothers and the children had to make do with the spoons they had between them. I later received feedback from CHOC: apparently the children were very happy with their gifts, especially as the names engraved on the spoons meant that no-one could steal their spoon.

### **Conclusion:**

*Social life always overflows the categories that we create for thinking about it, and sometimes a willingness to be surprised can generate novel and useful insights into social arrangements and relationships which themselves are always in a state of flux.*

Ross, 2010: 14 (Also see Fox, 1999).

This quote describes my thought processes in first writing a proposal, then doing fieldwork and finally deciding how to present my data. I hope that, by ‘putting a face’ to statistics, my dissertation presents a new way of looking at the ways in which people navigate an inefficient health system.

As Ross points out, it is difficult to write about what she terms the ‘ugliness’<sup>12</sup> of social life as there is a risk of ‘pathologising’, of generating fixed positions and of blaming victims (Ross, 2010:5). Greenhouse, Mertz and Warren are of the opinion that anthropologists working in ‘unstable places’ “would attempt to represent the lives and experiences of individuals, families, and communities with whom they work as richly and sympathetically as possible” (in Delvecchio Good, Hyde, Pinto & Good: 2008:9). My thesis, like that of Ross, attempts to tease out the ways in which marginalised people make meaning and navigate a system: the “ways they make do and get by” (Ross, 2010:7).

These narratives are not meant as generalised versions of national or international situations – the ‘poster children’ of the lacks of our health systems. I merely wish to cast light on the ways that various historical, social and political forces interact and shape the healthcare experiences of individuals and their families and the ways in which they navigate the ‘ugliness’ of daily life.

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<sup>12</sup> Ross uses Milan Kundera’s definition of ugly which he describes as “irreplaceable: the omnipresent ugliness of the modern world is mercifully veiled by routine, but it breaks through harshly the moment we run into slightest trouble.” (in Ross 2010:5).

**Chapter 3: The Ghost of a Health Regime Past: A Political and  
Historical Reflection on the Public Healthcare System in South  
Africa**

## Introduction

*Diana, I and some of the other mothers are chatting while we watch the children clambering on the frail jungle gym during one of their rare escapes from the ward. We catch some of the rays of sun filtering through the tree tops. They thaw some of the cold which has seeped into our bones while we sat in the frigid ward. Diana is about to make a 'quick' return home to fetch some necessities. Her initial estimate of a two-week hospital stay left both her and Nocwaka ill-prepared for the months they would be spending in the ward.*

*Diana provides an itinerary of her journey home.*

*"I will have to stay the night at Nelson Mandela Hospital [in Mthatha]. I will not make it in time to take the hospital transport back home."*

*I inquire whether she will have a place to sleep in the hospital.*

*"Oh no!" Another mother confirms this. "We sleep on the plastic hospital chairs. If you have a sick child it's even worse. They have no sympathy. It's a hard life, this."*

Diana echoes the words of 22-month old Aviwe, whose mumblings of "it's a hard life, this" featured in Chapter 1. Diana, Aviwe and my other participants' stories would illustrate the degree to which the experience of a CHC diagnosis was much more than a diagnosis of overactive cell division. The experience of childhood cancer spread beyond the child's physical body to include a network of social connections that included the child's family and friends, mapping out a variety of health journeys.

Rosemary Blake's thesis, *Please Keep these Doors Closed* (2007), illustrated how the health narratives of CHC are less about the biological nature of the disease and more about the ways in which the diagnosis intrudes on the children's life worlds. According to Sered & Tabory (in Blake, 2007:25) discourses on health and illness present as 'treatment narratives' the "tales of failure or success in negotiating the medical system". This negotiation transcends the individual body to include historical, social and political processes which determine not only health but also the services available to maintain and promote health.

This claim resonates with Fiona Ross's participants' claims that *Ons kry swaar* (Our life is hard) (Ross, 2010: 123). In her study of life among the impoverished inhabitants of *The Park* she discovered that "people struggle with the heaviness of everyday life" and that this is an ongoing struggle to "achieve forms of decency that have cultural and social values" (Ross, 2010: 123). In my research, this resonated with the ways in which my participants try to 'make do' and replicate some aspects of 'normal' life in the setting of the hospital. In this chapter, I will analyse the body politic and its inscriptions on the body and observe how these inscriptions manifest in my participants' treatment narratives.

Nancy Scheper-Hughes and Margaret Lock argued for a notion of the body which transcended the physical boundaries of the body. The *individual body* presents the individual's sense of an "embodied" self which consist of parts such as the mind, psyche, soul, matter, etc. (Scheper-Hughes & Lock, 1987:7). The *social body* acts as a text or a representation of society by the ways in which the individual body is inscribed and inscribes society. The *body politic*, which forms the main focus of this chapter, refers to the ways in which bodies are regulated, surveyed and controlled by structures of power in the society (Scheper-Hughes & Lock, 1987:7). This draws on the theories of Michel Foucault which argue that bodies can be seen as texts of social change and are imprinted by the ideology of the society in which they are located. In other words, the body can be read as a text or a microcosm of the social space in which it is located (see Farquhar & Lock, 2007a; Farquhar & Lock, 2007b).

I cannot, however, regard my participants merely as victims of a deficient system – this would do a great disservice to the ways they navigate a system which sometimes renders its patients more ill than healthy, and take some measure of control over their own health. I am not proposing a definition of agency synonymous with 'free-will', but rather one which takes account of the ways my participants 'make-do' within their contexts. This 'making do' relates to Henderson's 'dexterity' in her analysis of the ways children navigate the 'fragile' milieus of Crossroads, the results of a history of migrancy and second-class citizenship within the political and social sphere of South Africa (Henderson, 1999). This dexterity was also illustrated in Ross's analyses of the ways in which her participants in the The Village/The Park 'made do' (Ross, 2010). Kinship networks were revisited and friendship networks used to procure the necessary resources in an impoverished setting (Ross, 2010). I find Ross's use of 'opportunists' to be a useful way of describing how making-do manifested in the hospital, in the ways my participants were 'alert to possibilities, however slim, to make ends meet and get by' (Ross, 2010:124).

### **In the Presence of the Past**

On my way to the field site, the green hills dotted with huts almost seemed foreign to my Cape Town eye. This, I thought, must be the kind of scenery international tourists have in mind when they think of the 'real Africa'. Yet this was a far cry from my daily reality of Africa, living in a cosmopolitan area, where I had at least seven public and private hospitals within a 15-minute drive of my home. I might just as well have been in a different country.

Michael Taussig in Ross (2010:168) notes: "Health is part of the human condition, as is disease and the incidence and manifestations of both are heavily determined by the specificity of social organisation,"

with social class acting as a general classification of health (Ross 2010). The meaning of this quote is thus twofold: not only is our general health determined by the construction of our living spaces, but, more relevant to this dissertation, also by the state of the PHC system<sup>13</sup> one enters when ill. The PHC system often fails to provide the health services it is set up to provide. This notion of inequality is poignantly captured by the following quote from former South African President Thabo Mbeki (quoted in Antjie Krog's acclaimed *Country of my Skull*):

*In South Africa, inequality is part of the landscape of our country. In his 'two nations' address, then Deputy-President Mbeki alluded to what he saw as a South Africa which was comprised of 'a rich white nation and a poor black nation' (Krog, in Heap, 2003: 6).*

The Charter of the Public and Private Health Sector of the Republic of South Africa states that all South Africans have access to equitable health services. Access is defined as “[the] capacity and means to obtain and use an affordable package of healthcare services in South Africa in a manner that is equitable” with “equity” referring to “the fair and rational distribution of an affordable package of quality healthcare services to the entire population of South Africa” (Picone, 2008:48). Yet the hours-long journeys my participants undertook to Frere, the only hospital with a paediatric oncology ward in the Eastern Cape are just one of the manifestations of the inequality contained in the PHC system. (Cape Town alone has three public institutions providing specialised paediatric oncology treatments,)

The PHC system acts as a microcosm of the forces at play in both local and global networks. An understanding of the PHC structures requires analyses of the various political, economic and historic factors that have formed it.

Today's segregation of healthcare predates the state-engineered segregations of the apartheid regime (see Acosta & Karlsson, 2008). The 'preservation' of health would function as the motivation behind the first

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<sup>13</sup> The health care system in this dissertation (unless otherwise specified) refers to the services rendered in PHC system within South Africa. This is not, however, to assume that this is the only healthcare system people use in South Africa. Traditional healing practices are an important service to many health-seeking people in the country. As Feierman and Janzeh point out, state-sanctioned health care may be effectively available only to a certain portion of the population (Feierman & Janzeh, 1992) and health care practices can be plural in nature. I chose not to relate to this area of health care in isolation because it was not an area of health care that many of my participants disclosed to me. Many of them told me that although they knew people who made of traditional healers, “Me and my family do not believe in it.”

legislative acts to segregate along racial lines, a common phenomenon in African countries (Fassin, 2007)

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Cedric de Beer (in Fassin, 2007) suggests that segregation propagates inequality through a dual process. First there is a disparity in living conditions, with some conditions more diseased than others. Secondly, resources are unequally distributed (also see Marks and Anderson, 1992). This corresponds with Ross's assertion that people's life duration is less about "life extension and enhancement technologies [and more about] healthy lifestyles, freedom from violence and basic access to healthcare and medication" (Ross, 2010: 171). Fiona Ross remarks of her extensive fieldwork in The Park/The Village "how terribly ill many of its residents were" (Ross, 2010: 169). Rudolf Virchow's studies of health between various classes and locations came to the conclusion that 'material conditions of life created a substratum in which either health or illness flourished" (in Yach & Tollman, 1993:1046).

Ross's reflection on the health among the residents of The Park/The Village was that they always seemed ill. They were hosts to a range of diseases and babies were welcomed into the world with remedies to keep them safe and healthy. Both the physical environment and the nature of the social body would come to regulate the health structures of the inhabitants (Ross, 2010). Vena Das, however, makes a valid point when she warns us against falling into a rhetoric of social causes of illness at the risk of glossing over the biological causes (Das, 2006). There is a great deal of uncertainty of what causes CHC and it is fairly equally distributed among all different social groups. The experience of CHC and the ways it impacts on daily routines and ways of being, however, are influenced by the body's position in the political-economy.

The person cannot be considered apart from their body, which acts as the vehicle through which we and the world engage with one another and is crucial in constructing concepts of personhood (Burkitt, 1999; Grosz, 1994). In South Africa the meanings of the body have been inscribed by a history of colonialism, segregation and apartheid. Bodily meanings were determined almost exclusively by race. As Das (cited by Ross, 2010:169) remarks, "culture works to distribute pain unequally in populations." Paul Farmer has also written extensively on the ways in which infections unequally distributed among populations (Farmer, 1999), a phenomenon illustrated in South Africa.

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<sup>14</sup> In 1901 a plague hit the Cape and the Cape Government decided to employ what Swanson terms as 'sanitation syndrome' the justification for hypothetical reasons of public health (Swanson, in Fassin, 2007: 129). In this instance it presented as the relocation of 'African' populations from the overcrowded inner city to the newly established 'native locations' located on the outskirts of the city. The conditions of the 'slums' they were presented as the rationale behind move, but the statistics of the epidemic, do not seem to confirm this.

The pain created through segregation and apartheid is still mostly colour-coded along old lines and spaces of segregation. Debbie, head of division of CHOC East London remarked that some of the other CHOC division heads were reduced to tears when they saw the Frere ward, comparing it to the wards they worked in the rest of the country. Where other hospitals had cheery rooms for a variety of functions, C5's cramped dining room also 'moonlighted' as a school, play room, relaxation area and even a yoga studio while I was there. If the dining room was too constricting, the soccer games and races would move to the corridors of the ward. The only outdoor activity, which could only occur in the presence of an adult, was playing on a jungle gym which swayed dangerously from side to side as the children channelled their stored energy into its shaky legs. CHOC had sponsored much of the materials and equipment in the ward, among other crucial items such as drip stands. How well the ward would function without this NGO's presence is an open question. My participants' position in Frere thus became a reflection of the ways in which the inequality contained within the PHC system was not only related to who you are, but also where you are.

### **On Flogging a Dead Horse: Moving Beyond the Sins of the "Previous Regime"**

We can see that the history makes its presence known in the here and now. However, by constantly reverting to past 'sins' we are at risk of excusing the current actions and inactions that shape the treatment narratives of PHC users in South Africa. The government says that healthcare should be the right of all South Africans. Section 27 of the South African Bill of Rights on Health Care, Food, Water and Social Security (South African Government Information, 2009) declares the following:

1. *Everyone has the right to have access to*
  - a. *health care services, including reproductive health care;*
  - b. *sufficient food and water; and*
  - c. *social security, including, if they are unable to support themselves and their dependants, appropriate social assistance.*
2. *The state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of each of these rights.*
3. *No one may be refused emergency medical treatment.*

Yet these rights are not always provided for by the state. During my tenure at Frere, cameras had been banished from the ward following a scandal that erupted after journalists had secretly taken photos of the state of the wards, exposing the state of the hospital and uncovering the reasons behind the sudden

upsurge in infant mortality there<sup>15</sup> (Daily Dispatch, 2007; Also see Mail & Guardian, 2007). The state was certainly not providing the healthcare declared in the Bill of Rights –on the contrary, the ‘care’ it was providing sent its youngest healthcare users straight to the grave. The state’s provision of ‘social assistance’ was also questionable in my field site. Despite the major social implications of a childhood cancer diagnosis, there was no social worker for the families to ask for help<sup>16</sup>, not only to deal with social and emotional issues but also for practical measures such as applying for social grants.

Healthcare resources are scarce and unfortunately the, the health sector is just as prone to corruption as other public sectors(See Mail & Guardian, 2008, 2010) and the effects are felt most noticeably by the people the sector exists to serve. Mismanaged budgets, irregular tenders and money that just ‘disappears’ have crippling effects on the medical services the PHC sector is supposed to render. In Frere, this manifested in various ways. Days passed without any toilet paper being delivered to the ward and the food served at dinner time became less and less distinguishable. At one stage, the only bottle of soap in the ward had to be locked away the doctors’ rooms to they could wash their hands before performing procedures.

Factors such as these contribute to South Africa’s hemorrhaging of medical staff. In 1989 Ennew and Milnew reported a 1:330 ratio of doctors to white patients compared to the 1:12000 ratio among the “black” population, with the ratio becoming steeper the more rural the community (Ennew & Milne, 1989:132). Current figures suggest an average of 57 medical practitioners per 100,000 people (lower than Brazil’s 185 and Mexico’s 190) (WHO and CMSA in The Bulletin, 2011). According to Dr. Beale, chairperson of the SA Paediatrics association, there are only 29 active registered paediatric surgeons in the country, a ratio of one per 1.75 million people.<sup>17</sup>

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<sup>15</sup> The Daily Dispatch did an expose termed “Dead on Arrival” in which they reported that 37 babies had died in Frere hospital within 48 days within the first few months 2012 due to what they report as negligence and poor management.

<sup>16</sup> CHOC East London were interviewing for a social worker for the Frere ward while I was doing my fieldwork and the new social worker started working in the ward soon after I left. Based on the feedback from Debbie, the social has become an invaluable part of the team in C5. Not only does she provide support to the families, but she relieved a huge burden from the two doctors in the ward who had to deal with the social matters on top of their clinical responsibilities as well.

<sup>17</sup> According to the Health Professionals Council of South Africa, 29.9% of public sector posts are vacant (2006 Health Review) and 25% of clinical posts have been sacrificed to allow a 30% increase in administrative posts (The Bulletin, 2011). According to Hudson, “the shortage in medical skills is now so severe that many essential services in the public sector can no longer be rendered without increased risk to the patient” (Hudson, 2011:21).

Black people still constitute the majority of poor people in South Africa and thus the majority of PHC users.<sup>18</sup> All the participants in this study, except for Tanya and Bradley who were coloured, were black.

Reasons cited for this ‘brain drain’ included poor working conditions, poor payment, lack of funded PHC posts, unfunded registered posts (meaning that specialists are unable to train) and a desire to avoid community service (also see Hesselning, 2001). The recent murder of a doctor also brought to the fore the difficult and dangerous working conditions health professionals need to navigate, putting their own health at risk to bring health to their patients (see Mail & Guardian, 2010, 2011).

Discontent over poor working conditions and inadequate remuneration has led to strike action in the health sector in recent years. Unfortunately, once again it is the users of PHC, who have limited options of treatment centres, who suffer the chaos that ensues with a health strike.

Tanja told me how a strike in 2010 left the hospital almost devoid of nursing staff. The doctor spent most of his time in the ward, even sleeping there. He took the time to show her and Gcobisa how to do basic nursing tasks and write discharge reports to assist in the ward. An emergency meant running to an adjacent ward in search of a nurse or another doctor on duty to sort out the problem. The space, which was supposed to provide safety in the face of illness, was becoming a potentially hazardous environment, which could take the very health the children had been given.

This emigration of well-qualified health professionals (see Webb in Karlsson, 2008) may contribute to what Das has observed as one of the biggest issues pertaining to the healthcare of the poor: delayed diagnosis (Das, 2006). This has been one of the major reasons cited for the skewed mortality figures on childhood cancer in the ‘developing world’, which show how children are severely under-diagnosed and sometimes go undiagnosed due to a lack of awareness<sup>19</sup>. Every one of the mothers I spoke to noticed that something was wrong and took the child to the clinic, but cancer never featured in the diagnosis. Nokukhanya shared how Anathi’s retinoblastoma, presented with an eye that was red, which was treated with drops. She continued to tell the clinic nurses that something was wrong but was only referred to a

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<sup>18</sup> About 18 million people live in the poorest 40% of households and are thus classified as poor, and 10 million people live in the poorest 20% of households and are thus classified as ultra poor. Most of the poor live in rural areas: 45% of the population is rural, but the rural areas contain 72% of those members of the total population who are poor. The poverty rate for rural areas is 71%, Poverty is more concentrated among black citizens (May, 1998).

<sup>19</sup> According to SIOP, only 20% of children diagnosed with cancer live in the ‘developing’ world, yet 70% of them will die due to a delayed diagnosis. This compared to the 80% of diagnosed children in the ‘developed’ world of which 20% die. It must be noticed though that figures are very difficult to estimate as there is severe underdiagnosis of childhood cancer and many countries do not have cancer registries to report cases.

hospital after numerous returns to the clinic, by which time the cancer was so advanced that an enucleation (removal) of the eye had to be performed. The doctor and the ward sister at Frere confirmed that poor education on the subject of childhood cancer leads to many of the advanced-stage cancers they saw.

In an attempt to provide equitable health services the Minister of Health, Aaron Motsoaledi is pushing for the implementation of a National Health Insurance (NHI), which would theoretically provide more equal health treatment regardless of income, enabling a greater proportion of the population to afford and access services currently classified as private. Debate raged around the subject, with members of the South African Institute of Race Relations arguing that that the NHI would not be financially viable and that revisiting management and structural issues within public health institutions would do more for health in SA than any NHI (Mail & Guardian, 2010c).

Currently, a minority of the country's population still has access to the majority of health finances<sup>20</sup>. There are many historical actions which have contributed to this blatant inequality, but 16 years after the birth of democracy we need to widen the scope of explanation to include more current actions if we are ever to address the chasm in the healthcare system. Democracy is a system that can exploit and the PHC functions as a microcosm of the exploitation within the larger society. Mafeje claims a democracy that claims equality before the law does not necessarily translate to social equity (Mafeje, 2002; Munck, 1994). According to Mafeje, the presumed ability to choose who rules the country hinges on the premise of free choice, which disregards the historical political, historical and economic structures which have enabled or limited these choices. Wolpe asserted that democracy is a process that takes years to consolidate and that one or two elections is no guarantee of democracy (Wolpe in Munck, 1994). It can thus be argued that South Africa's PHC acts as a reflection of this democratic process, in which not all choices are equal and which capitalist gains have left a large sector of the population impoverished.

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<sup>20</sup> By 1999, 73 % of all general doctors and 75 % of the medical specialties worked within the private sector, and a minority elite of less than 20 % of the population had access to 60 % of the financial resources of the healthcare system. The historically underprivileged majority had less than 40 % of the financial resources to their healthcare, the public sector where only 25 % of all doctors worked. This led to a greater gap in the society. The government spending trends combined with heavier burden on public healthcare, result in that the HIV/aids epidemic is negatively influencing the availability and quality of the public sector services ( Harris & Seid in Acosta & Karlssoon, 2008, ; see also McIntyre, Doherty, Gilson, 2007)

### **Cake From Crumbs: Making Do in a Hard Life.**

The above description of the PHC system could leave one feeling morbid and depressed at fighting what sometimes appears a losing battle. Yet looking back at my field notes I am struck by the joy, laughter and warmth I encountered in the dreary, freezing corridors of C5. Despite the historical processes that had bracketed my participants as poor and the current challenges the PHC system presented, my participants were eking out an existence despite all these inscriptions on their bodies. The processes which influenced their health journeys were undeniable, yet they did not become mere bodies which functioned as receptacles of political and historical inscription. They were not mere 'victims' of an inefficient system. As Henderson (quoted in Naomi Marsak's Thesis, *It's a Whole Letter you Could Write* (2010),) states the overstating of vulnerability may lead to the 'strength and dexterity' to overcome difficulties being ignored (Henderson, 1999, see Marsak, 2010).

Deleuze and Guattari's concept of the Body without Organs (BwO), dealt with at length by Nick Fox, acknowledges a "body [which] is a psychic or philosophical surface which is imprinted by the forces of the social" (Deleuze and Guattari, 1984: 9 in Fox, 1999: 8), but in their model the body has the opportunity to "break free from striation (through the affirmation of its potential to be other and with the assistance of others) and move into a smooth space" (Fox, 1999: 8). I do not wish to overestimate the agency available to my participants, which can be tantamount to "blaming the victim" (Farmer, 1999: 9), but rather enter into a discourse about a BwO which recognises that body's potential to "[break] free from discourse, [by] refusing a single chain of meaning" (in Fox 1999: 15) enabling my participants to dictate some of the narrative on their health journey.

Cebisa offers a prime example of the ways in which individuals can and do take matters into their own hands despite the entanglements of protocol. A previous admission to her district hospital had left Nkosazana with an oozing wound post-surgery. Cebisa resorted to treating and cleaning the infected wound herself, but she did not leave the matter at that. She took photos of the wounds using her cellphone and would bring out the photos whenever there was mention of her returning to that hospital (which was closer to their home), refusing point-blank to return to the hospital which had quite possibly been detrimental to Nkosazana's health. Cebisa would track down surgeons she knew from previous interactions and insist that they operate on her, possibly affording Nkosazan the personal, client-centred treatment that can easily fall by the wayside in an overburdened PHC system.

“Breaking free” could also transcend the individual to include group action. In Frere the food quality served as an indicator of the budget’s ‘health state’. Food providers stopped delivering stock after accounts remained unpaid for months and as a result meals consisted of any bits and pieces still remaining in the store cupboard. I was told how patients were at the point of rioting the previous year when food quality dropped so much that the patients refused to eat it, sending plates of food back to the hospital kitchens.

This action was not isolated to the hospital food only. In general my participants would only eat food they knew. The housemother at CHOC had long ago learnt that keeping to ‘traditional’ food like *umpokoqo* (porridge), *umaas* (sour milk), *samp* (cracked mielies) and meat was a better option to trying to serve lasagne or other unfamiliar meals which would return to the kitchen untouched. In fact, dinner times were one of the few times I felt like an ‘outsider’: my unfamiliar vegetarian fare was analysed suspiciously and provided the children with ward gossip.

Through the involvement of CHOC and Reach for a Dream, the ward had a fairly well-established ward programme. Barely a day went by without at least one volunteer session occurring. Yet the children were very firm in their ideas of what and what they would not do. They were quite adamant about which activities they enjoyed and would refuse to participate if something did not meet their fancy. The children would participate in the ward on their own terms and not according to the rules set by well-intentioned volunteers.

My participants may have had little agency within the treatment context in which a childhood cancer diagnosis had enveloped them (they had to visit the health institutions) but I never perceived them as “victims”. They created and found spaces within the processes which were scribing their health journeys in which to assert their agency, making the PHC system not merely a shaper of their lives but to a certain extent something shaped by them in return. In some ways, the adversities encountered in the system were actively turned into positives. Gcobisa and Tanja interpreted the nursing they had to do during the strike as skills they could possibly use later in life. This became a way for both of them to redefine the spaces which had come to chart their initial journey.

## Conclusion

Our physical bodies have certain values attributed to them. In South Africa that currency was based mainly on skin colour due, in part, to health legislature which aimed to segregate communities based on arbitrary racial classifications. History make its presence felt in the past inequalities which perpetuate into the present and this is only further compounded by the more recent histories of mismanagement and corruption which have wracked the health sector. The inequalities established by previous regimes are compounded by various actions which have contributed to an ill-functioning health system – one which, in some cases, has had a greater effect on people’s daily lives than their biological diagnosis.

Since the inception of democracy in 1994 there have been advances in the health sector, with a range of clinics and hospitals being built (Mediaclub, 2011), but this does not equate to service. Due to the great lack in health personnel, posts are empty and there is no guarantee of quality healthcare. Brand-new hospitals become white elephants. At times my participants travelled many hours to Frere, passing brand-new hospitals to access quality healthcare. As Cebisa related, she would rather be further away from home than return to a hospital that provided sub-standard care. Diana was quite adamant that Nelson Mandela Academic Hospital (NMAH) in Mthatha (a relatively new and well equipped hospital) was a ‘bad hospital’ as the nurses were unfriendly. It was a statement I heard more than once: a stopover at NMAH was dreaded.

I do not wish to suggest creating a paediatric oncology ward in every district hospital, which is an unrealistic pipe dream. More hospitals will not necessarily provide proper care and a health institution can deprive health users of the health they have.

But my participants were not victims of a dilapidated system. Although their health journeys’ courses were inevitably directed by historical, social and political influences, they managed to do their own navigation in various ingenious ways. They took ownership as both individuals and groups and on some levels made the system work for them as it would in an ideal world. There is a very fine balance between overemphasising agency and victimising participants, hence the continuing argument between agency and structure. The agency I elude to focuses on the extent to which we can move freely and construct our own realities in systems and structures of constraint.

By focusing on individuals’ trials and tribulations, I wish to reflect that agency is not a smooth process but a constant negotiation of the hurdles on the journey. I explore the spaces my participants found to break free and put an individual stamp on a journey with CHC. Their stories may share commonalities, but the experience was still deeply personal and individual.

**Chapter 4: Home and Away: The Displacement Inherent in a  
Childhood Cancer Diagnosis**

## Introduction

*The doctor asks everyone except the relevant personnel to leave the room and sits down across from Diana. “Mommy, you have some important decisions to make. Nocwaka has cancer that is going to require treatment for six months to a year and she will need to stay in hospital for that time. Do you have any family members who can come and stay with her in the hospital? We can transfer her treatment to the city where you have a job, but you’ll need to go to the hospital every week for treatment and may have to stay for more than one day depending on how Nocwaka does on treatment. The other option is to leave Nocwaka at the hospital until her treatment is finished. We will take good care of her, we are a family here.”*

The doctor was giving Diana the opportunity to make an informed decision, but there was very little freedom in her choice. Diana’s mother was elderly, in need of care herself, and none of Diana’s other family members could give up their breadwinning jobs to come and care for Nocwaka. Diana’s relationship with Nocwaka’s father was drama-filled and her most recent interaction with him had not ended well. Although Nocwaka’s treatment could be transferred to a hospital closer to Diana’s work, there was no guarantee that her employer would be willing or able to accommodate the lengthy hours and days she would have to spend at the hospital. Even though some children stayed at the hospital without any family, this was not a viable option for Nocwaka: she simply stopped eating when her mother left for a short trip home and was so malnourished on her mother’s return that she required nose-tube (NG) feeding. For Diana there was little choice but to give up her recent promotion and her flat in Durban and relocate her life to a shared, glass-encased cubicle, with a battered steel cabinet for a cupboard and a mattress as a bed, for the months Nocwaka’s treatment would take.

The more I reflected on my participants’ journeys with childhood cancer, the more their displacement of the spaces that constituted their daily lives became evident. I am alluding to a displacement similar to that of internally displaced refugees in Somalia, who fled drought and possible persecution within their own borders (Mail & Guardian, 2009), but in this case a displacement due to a public sector which is failing the society it is set up to protect. I focus on the PHC and the way in which inequalities in the PHC manifest in the health journeys of individuals. As Das (cited in Herzfeld and Henderson 2004:43) asserts, “anthropologists are challenged with the task of rendering suffering meaningful in a context where bureaucratic systems often justify exclusion of certain categories of people and therefore cannot recognise their suffering.” Statistics are hard to come by, but they are also unable to “tell us about how people experience the world or attempt to make sense of the events and processes that shape a life” (Ross, 2010:

9). Thus, I present the health journeys of my participants by reflecting on the similarities they share with internally displaced people (IDPs), to bring to light a dysfunctional health system that is contributing to a displacement of participants from their life-worlds.

### **Internally Displaced Persons : Seeking Refuge within Borders**

To understand the similarities between my participants and people defined as IDPs we need to take a slight detour to reflect on what is understood by IDP. IDPs are defined by the UN Office for the Coordination of Humanitarian Affairs (OCHA) as

*“...persons or groups of persons who have been forced or obliged to flee or to leave their homes or places of habitual residence in particular as a result of or in order to avoid the effects of armed conflict, situations of generalised violence, violations of human rights or natural disasters, and who have not crossed an internationally recognised State Border”* (in Turton, 2003:15).

The meaning of the term is constantly being contested and redefined in an attempt to create a uniform definition which can guide policymakers (Turton, 2003). As definitions go, IDP, in itself an offshoot of the term ‘refugee’ has sprouted additional subsections. One of these relates to forced resettlement as a result of development, so-called ‘development-induced displacement and resettlement’ (Turton, 2003: 15, see also Mooney, 2005) in which members are relocated by the state in order to ‘develop’ the area which they identify as home. The majority of these IDPs are forcibly resettled by their governments and constitute the “poorest and politically most marginal members of a society but they are also likely to become even more impoverished as a result of the move” (Turton, 2003: 9). IDPs become what Martins refers to as “forced migrants” who flee their “homes or places of habitual residence because of events threatening their lives or safety” (Martin, in Turton: 6). As I will come to show, this very statement is echoed in the health journeys taken by health participants, who are internally displaced by their or their child’s cancer diagnosis due, amongst other reasons, to the unequal distribution of the healthcare system in the country as described in Chapter 3. They need to leave their homes when local healthcare institutions are unable to provide the necessary treatment for a childhood cancer diagnosis due to numerous factors ranging from a lack of knowledge to a lack of personnel and materials.

According to Brun (2003:378), “social rights are related to welfare, and should provide economic security for all and enable each individual to participate fully in social life, according to the standards prevailing in the society” (Brun, 2003:378; see also Baubock 1994; Held 1989). As social rights are not equally

distributed among all South Africans, some members of society become lesser citizens by their inability to access their constitutional rights. South Africans may not be fleeing their homes *en masse* in search of sufficient healthcare but, as Mooney states, the use of a rigorous criterion such as ‘forced to flee’ and people ‘fleeing in large numbers’ as a criterion for IDP disregards those who are ‘obliged to leave’ their homes in small groups or individual basis (Mooney, 2005 :11). The political and historical factors which have shaped the South African PHC ‘obliged’ my participants to leave their homes to access what would save their lives.

I realize that I risk overextending the definition of IDP here. Robert Goldman, a member of the team that drafted the Guiding Principles for dealing with IDPs, had a specific focus of providing aid to communities in need of aid and assistance. As it stands, IDP is not a legal definition but a concept that organisations can adapt to suit their particular protocols (Mooney, 2005). I am thus not trying to argue whether or not my participants are IDPs – rather, I wish to investigate the ways in which their health journeys share similarities with IDPs to grapple with the ways in which the inequality of health rights in South Africa has marginalised its citizens and unsettled them from their own homes and livelihoods. Displacement occurs through the disregard of rights, but through the act of displacement other rights such as personal security, subsistence, family and community values, self reliance, prospects for return and alternative settlement are transgressed in turn (Stavropoulou, 1998).

In the following pages I will explore the ways in which the journey of CHC becomes one of displacement and reflect on the ways in which my participants navigated this journey.

### **The Land of the Silver Bird**

One day while chatting, Debbie tells me how she once had to use all her persuasive skills to get a grandmother and child onto an aeroplane to Cape Town to receive specialised treatment at one of the hospitals. The grandmother had apparently never seen an aeroplane and had initially refused to get into the “belly of the silver bird.”

This is quite an extreme example but it provides a snapshot of the profound ways in which my participants, on receiving a CHC diagnosis, could be displaced from home. For the involved participants, a journey with childhood cancer meant leaving what they called home with a little more than a suitcase, leaving family, friends and work in order to find the life-saving treatment. They were displaced from all

that was familiar to them and forced to relocate to a paediatric ward in order to acquire life saving treatment.

A recurrent theme here is that of 'home'. The location of the ward may have shared a province with my participants' home spaces, but to call it a 'foreign' environment is not to overstate how alien some of its aspects were. My participants' displacement was more than just a matter of kilometres; it was a displacement from that which was known.

The notion of home has been one of anthropology's prime interests since its beginnings. It has become particularly relevant with a rise in national and transnational movements in which the concept of home is constantly revisited, redefined and renegotiated (Golob,1999; Appadurai,1996).

'Home' becomes central to discourses on personhood through the "powerful influence it exerts in shaping people's lives" (Allan and Crow in Yantzi & Rosenberg, 2008: 1) through the social body's inscription of our bodies (Scheper-Hughes & Lock, 1989). According to Blunt and Dowling, 'home' is the intersection of three concepts (in Yantzi & Rosenberg 2008):

*First, the home is both a material and imaginative space, "a spatial imaginary: a set of intersecting and variable ideas and feelings, which are related to context, and which construct places, extend across spaces and scales, and construct places" (Blunt and Dowling 2006, 2). Second, meanings, experiences and people's identities surrounding home are inextricably bound to wider social and power relations. This leads to 'a dominant ideology of home' that legitimates and privileges some meanings, experiences and social relations that centre on home, while marginalizing and excluding Others (Blunt and Dowling 2006, 26). And finally the home is not an isolated place; changes in the political, social, economic and cultural processes of society affect the physical, material, and emotional conditions of home (in Yantzi & Rosenberg : 303).*

Anthropology has come to focus on the construction of 'home' through the "lived experience, where emotions play an important role in the discursive construction of the meaning of home" (Mallet in Golob 1999:121), with spaces which illicit fear and unfamiliarity (Al-Ali and Koser 2002:7 in Golob, :122) being undeniably 'non-home'. According to Jaka Repic, 'home' is not bound to a physical location .It can be an imagining based on a symbolic geography to which meaning is attached and is experienced as the actual territory. Despite being a construction of the mind these places which are experienced only through social memories, can be as real as actual, experienced places (Repic In Golob 1999:122; see also Mercer, Page & Evans, 2008).

Accordingly, a concept of home should consider “various modalities, as for instance memory and longing; the conventional and the creative; the ideational, the affective and the physical; the spatial and the temporal; the local and the global; both positive evaluations and negative” (Rapport and Overing in Golob: 122) – in short, all the ‘imaginings’ of home.

Ngwane illustrates how those who are trying to create a social unit may not share the same modus operandi or ideals, which may result in conflict. The attainment of the goal may only be ‘momentarily complete’ and as such the idea of the household is based more on an ideal than on a reality (in Ross, 2010: 90-91). Yet Ross argues that these ideals as concepts may have reality and that ‘household’ may focus the attention on attaining these goals. The ‘household’ thus functions as an ‘analytical’ category which is based in social relations that can shift at any time. The construction of a household is seldom the aim but rather the formation of relationships which are ‘material and affective’ (Ross, 2010). Relationships in C5 shared these characteristics of household. Relationships worked to provide support and companionship in a situation where the ties with home had been disrupted. Material sharing occurred as well, such as in the sharing of food.

Although I spent a long time in the hospital I never heard it referred to in terms of ‘home’. Yet the time my participants spent there necessitated that they claim spaces, establish routines and recreate networks while still identifying ‘home’ as that place they would return to upon discharge. ‘Home’ as imagined by my participants may have been based on an illusion of a stable, unchanging environment, a concept found in literature of diaspora, but this illusion gave a sense of stability in a space of change and mobility (see Mercer et al., 2008).

The ward did not resemble my participants’ descriptions of ‘home’. It was never designed to be a living space for families. The glass-encased rooms were probably designed to afford the nurses a round-the-clock view of their underage charges, but this left little space for privacy<sup>21</sup> – rather, it became a

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<sup>21</sup> Sometimes the glass did allow isolation. At times children got infections or became susceptible to illness and had to be isolated in a room with only their carer and nursing personnel allowed to move in and out. At such times, even the friends who came to wave through the glass were not sufficient to ease the isolation from taking part in communal ward activities. Malusi, a young boy with a blood disorder, was one such case. He was one of the older boys in the ward and became quite depressed, especially when his grandmother wasn’t around. A volunteer and I would smuggle in books and games but these did little to stop the tears that sometimes became the only way to express the isolation. Despite the translucent characteristic of the glass, it still functioned to isolate Malusi from his friends and the activities taking place in the ward.

panopticon<sup>22</sup>. People could look in on procedures being done and conversations were never truly private. Participants were frequently in each other's rooms and could constantly view each other's actions through the glass which surrounded each room. Each child had a bed with a battered steel cupboard which functioned as their cupboard (and their carer's, if they had a carer). Anything that couldn't fit into the cupboard was kept in a suitcase or plastic bag.

Spaces in the hospital were usually stationary, but occasional moves did occur when children were discharged. On one occasion, after spending quite some time in a room which only housed boys, Nolitha had to move into another ward so she could be with all the girls. She quite happily tugged two plastic bags filled with teddies and clothes, her badge of spending months in a hospital frequented by volunteers and their donations, to her new spot right in front of the big-screen TV. Both her room and the room she had shared with the boys had televisions and these, the dining room excepted, were the most communal spaces where everyone would gather to watch television. WWE (wrestling) and soap operas proved firm favourites in C5 and around two o'clock in the afternoon every eye would be fixed on the wrestling blaring from the screens.

Some participants embraced this communal space while other participants tried to keep to themselves as much as possible. Gcobisa was one who engaged cautiously with the other participants. She felt they were gossiping about her and would keep mostly to herself. But in the end even the most 'private' members got pulled into the ward and started participating in ward activities, chatting jovially over meals or having their hair done. I jokingly referred to Diana's room as the hair salon as she was almost always in the process of doing someone's hair.

CHOC house's aim is to provide a "home away from home". The house had a wide range of toys and the adults and children usually stayed up quite late watching television or movies. The bed and warm cooked meal ("traditional meal") was in many cases a welcome reprieve from sleeping on the floor and eating rice for the umpteenth time. The children would usually come looking for me excitedly around 16:00 in the afternoon, chiming "CHOC! CHOC!" and some of the children would be truly upset when they couldn't go.

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<sup>22</sup> This term, first used in 1791 by Jeremy Bentham, became famous when Michael Foucault used it in *Discipline and Punish* (1975) in which the panopticon became a vestige of power through the act of constant visual observation. By knowing they were watched, participants, or in Foucault's study patients at a mental institution would regulate their own behavior (ODS, 2009). The glass that surrounded my participants' rooms thus facilitated a type of panopticon as their actions could always be watched and judged by others, which may have changed the way they behaved.

I recall in particular Buyiswa, a young girl who had to undergo a regime of treatment that required her to remain in hospital under observation for two weeks. Days passed without a single smile crossing her lips. She was upset that she could not join her friends in the CHOC house.

The space that would house me for six weeks became a home the moment I walked in. I felt wanted, had a comfortable bed and access to warm water. I could shower or bath, have a warm meal and do more or less what I wanted to do, while always feeling welcome thanks to the housemother's warm personality. If this house presented me with such a sanctuary, I can only begin to imagine the reprieve it could be from the boredom of ward life for the children and carers and it is no wonder that they were quite avid to go.

The displacement was not only a matter of the change of a physical locale though. It involved a displacement from daily roles and activities. The carer who came to look after the child in hospital at times left behind work or education to support their child, as illustrated by the following vignette.

*Cebisa leaned leisurely in 'her' lazy-boy while giving me a 'travel log' of her and Freedom's journeys with childhood cancer. She had worked as a cleaner and waitress at a hotel in Gauteng while Nkosazana and her older brother lived with their grandmother. She had enjoyed her job, it wasn't too 'high stress' and she had enough money for treats like doing her nails, something she was meticulous about even in hospital. She had had to give up her job to come and live in the hospital when Cebisa was diagnosed with cancer, and now she was dependent on the social grants she received from the state. Money was tight and days would pass without her being to buy airtime for her phone to stay in contact with her family.*

'Home' as a concept describes much more than a physical space – it also implies the actions and routines we follow in the physical 'home space' (see Golob, 1999; Kidd & Evans, 2010; Yantzi & Rosenburg, 2008). For IDPs, the displacement includes displacement from a livelihood, which was contained in the concept of 'home' – an aspect of displacement shared by my participants. Displacement is thus a multi-layered process. It is not merely to be moved from a specific location but also to be displaced from the daily rhythms of a life.

Cebisa had spent the better part of the previous year in hospital, while Nkosazana was receiving treatment for cancer. She was looking forward to her life in a village that was relatively nearby (although not close enough to travel to and from hospital), where she had a hut she shared with a cousin. When I asked her about returning to work, she said she would like to do something similar, "but something closer to home," as she would like to be closer to her children. Like Diana, she had left a job that allowed her to provide

for her family in order to come and stay in hospital with her child. Both her and Diana's jobs were unskilled positions which could be filled relatively easily and, unfortunately, it was likely that their jobs would no longer be available on their return home. Their displacement would likely continue when they returned to 'home'.

Many families report that, following a CHC diagnosis, life no longer resembles a life which they imagined as 'normal'. In my participants' cases many of the threads that created their life-worlds were ripped out with a CHC diagnosis. They were forced to create new life-worlds that might bear little resemblance to 'normal' life.

The journey with CHC was also the suspension of a aspiration to work. Within my first few days in the ward Gcobisa approached me to help her with her Curriculum Vitae. She and her friend spent their weekends job hunting and regarded a well-typed curriculum vitae as crucial in finding a job<sup>23</sup>. Presently, Gcobisa was dependent on the grant money and it usually did not last the month, especially on the few occasions when they were discharged home. She did not have a good relationship with her family and usually had to try and make do alone. Tanja told me how she had tried to send Gcobisa food with her cousin, on occasions when food ran out.

These narratives illustrate the ways my participants had to sever ties with their communities and suspend activities that provided some sort of independent income, becoming dependent on either grants or the help of others. They share this situation with IDPs, who are denied the right to occupy the space that contains their lives and livelihoods (Brun, 2003: 379-380).

According to Ross, "household" is a porous concept which changes its composition under varying political and economic circumstances (Ross, 2010). Due to the displacement my participants had undergone, they had to form new 'household' relationships which were based on feelings of "reliance, affection, trust and social and economic debts" which can transcend a physical space (Ross, 2010:93). The relationships forged by the participants would extend beyond the hospital ward. They kept in contact via SMS, phone calls or return visits to hospital. This relates to what Spiegel (In Ross, 2010) terms "domestic fluidity," a concept Ross attributed to the ways in which extreme poverty leads to household

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<sup>23</sup> According to Statistics South Africa, 24% of the South African population were unemployed during the 4<sup>th</sup> quarter of 2010. High unemployment cannot be understood in isolation from the state of PHC system. The more people are unemployed, the higher the demands on PHC but the fewer people can contribute taxes. Demand for PHC thus far outweighs supply (Statistics South Africa, 2011).

functions being “spread over a variety of social configurations” (Ross, 2010:91). As Tanja and Gccobisa’s relationship illustrates, the relationships born in the hospital took on some of the characteristics of a household through the reciprocal and affectionate nature of the relationships, in the ward and outside.

The children displacement from the activities of daily life, became apparent in their schooling, or rather lack thereof.

*“School is excellent medicine for a child with cancer who is well enough to go. Modern cancer treatments mean that many children can continue with their schooling” (Parker et al., 1979:67).*

This quote is from 1979, since which time cancer treatments have developed even further. Most cases of CHC diagnosed in developing countries are relatively easy and cheap to treat when diagnosed early. Unfortunately the children who participated in my research did not have this option. The distances they lived from home meant that most of the school-going children were at the hospital without caregivers, who had either to work to support the family or look after younger siblings. My child participants share some characteristics with IDP children who, according to Mooney, are frequently separated from their families and experience a disruption in education and normal development (Mooney, 2005).

The way in which ‘normal development’ and the effect of separation from family are interpreted is a matter of social context. But the point of focus here is the way in which a CHC diagnosis removes a child from their home environment and renders them incapacitated to fulfil their work or schooling. Of course their schooling could and possibly would be disrupted by a cancer diagnosis due simply to the biological nature of the illness, but in my participants’ cases it was a complete removal from their school environment for a months at a time.

The children had cancer but they rarely looked or acted ill. While they were playing outside Diana remarked: *“If anybody sees these children, they would say ‘Why are these children in hospital? They are healthy!’.”* The children’s illness was not what kept them from their schooling. Although the hospital had a teacher to visit the paediatric wards, usually for an hour or so a week, these classes were severely lacking in both quantity and quality. The children received workbooks and many of them, especially the girls, would spend *hours* at a time trying to make some sense of the instructions (which were sometimes in English) and doing exercises. I tried to explain the instructions as best as I could, making use of one of my participants’ limited English skills to translate, with lots of gesturing and the odd isiXhosa word. The children mostly followed the same ‘syllabus’ despite their varying ages, and many of the children were not on a par with their school-going peer group, with many unable to write their own names.

My participants were not only displaced from their home environment where they would have been surrounded by family and friends, but were displaced from one of their occupations as children in South Africa. On returning home, my participants could experience a further displacement due to the social rupture an extensive hospitalisation can cause. The daily rhythms of 'home' would have continued without them and would be measurable in very visible forms, such as schooling. As a result they might find their social networks severely ruptured and be left partial strangers in their own homes.

### **A New Place in a New Space**

IDP's trans-location requires them to re-establish themselves in a new society. This re-establishment is a two-way process which involves both IDPs and the host communities they move into by "creating new places and giving new meanings to old places" (Brun in Brun, 2003: 380). It entails a re-negotiation and reallocation of resources which can coincide with abnormal levels of conflict (Harrell-Bond 1986).

Diana had been in the ward only a few days when she told me how she had been reduced to tears when a nurse scolded her for lounging on the lazy-boy. "It's not right," were her distressed words. These conflicts ensued in a space-strapped environment where individuals were trying to make a home in a very un-homelike environment in which spaces and objects had to be multi-purposed to try and 'homify' the space. It was during these times, when members of the 'host' community assumed a misappropriation of resources, that the mothers were described as out of place, a tension shared with IDPs (Brun, 2003). Comments such as "These mothers shouldn't really be here," were few and far between, but there were inevitable moments of conflict in a space- and resource-strapped environment.

Navigating the ward space, usually entailed taking on new roles and the role of mother usually became enmeshed with that of a nurse as Cebisa's story relates.

*Cebisa looked at me proudly as she told me how she had done Nkosazana's (Percutaneous Endoscopic Gastrostomy) PEG feeds from the time the PEG was inserted. She asked the nurses to show her how to change the feed bags, which now held Freedom's daily dietary requirements, and which buttons she could push to stop the machine's nagging beeps. She was nonplussed by my awed responses. "It is my child, I am going to take care of her."*

According to Brun, the process of displacement can completely upset the social and hierarchal structures of the 'home' community (Brun, 2003). In C5, carers took on both mothering and nursing roles and children would 'mother' other children.

Mothers maintained ‘mothering’ roles, making sure their child was fed, had clean clothes and cuddling on the days when tears flowed. They also took on additional roles which extended their ‘normal’ tasks and could be classified as nursing. They could recite the names of complex procedures and medicines, and were a walking nursing report on anything pertaining to their child: signs, symptoms, drugs and procedures. They had learnt to speak the ‘foreign’ language in the host community to negotiate the best possible care for their child in the current space. When I seemed amazed by the detail contained in the medical accounts, the answer was usually along the lines of “It’s my child. I must know what is going on.”

This diffusion of roles was the result of various motivations. There was the natural obligation to care as a mother, assuring quality care in a resource-limited environment, and the need to fill the merging days with some sort of purposeful activity.

This slippage and coalescence of roles is not always a harmonious process. After spending months in the ward, Gcobisa could no longer spend hours sitting next to her child Nesiwe’s bed. She started running errands to other wards and made friends around the hospital. At one point she even had a boyfriend on the hospital grounds. She loved her child dearly, but was very clearly aware of the terminal nature of her child’s cancer and was of the opinion that she needed to think about the future. Yet she was very upset by the gossiping about the lack of time she spent with Nesiwe that she perceived to be going on in C5. Gcobisa is thus an example of the ways in which different definitions and expectations of an individual’s place and role in a community can lead to conflict, as, according to Brun, tensions do when the host community views an IDP as ‘out of place’ or in this case perhaps ‘not in their place’.

*“Cancer is a disease in which close contact with the hospital is essential, but it is not necessary for most children to be actually in hospital for long periods. One of the great advantages of this idea of treating the child and letting him or her go home is that your child will not lose the family feeling for you, and you will still have him or her as part of your family life... this is very important especially if your child recovers from their disease.”* (Merren & Mauger, in Parker 1979:43)

In a context in which health services were not available near the participants, they had little option but to displace their lives from their families’, possible suspending ‘childhood’ to come and live in the hospital. Children would spend hours chatting as equals with the adults. Nolitha, a ten-year-old girl, ‘adopted’ an abandoned baby who came to the ward. One doctor would also remark how ‘adult’ Nolitha was. She

shared how, during ward round one day, Nolitha started crying – a rare occurrence. When asked why, she said that she didn't want her brother and sister, who had come to spend some time with her in hospital, to have to be there. In this she showed almost parental concern for her siblings, one of whom was much older than her. She didn't want them to spend so much time as she had in hospital and to fall behind with schoolwork as a result. Yet I am wary to classify behaviour as 'child' or 'adult'. As James and Prout point out (in Tyrer & Hart, 2006) 'childhood' is a 'social construction' which is neither 'natural nor universal' despite being a "specific structural and cultural component of many societies" (2006:6; See also Jenks, 1996). Children in South Africa have long been part of families that did not adhere to the model of the nuclear family and may include members that are not biologically related. The history of migrancy has ensured that for a child in South Africa the 'family' is a fluid concept (Henderson, 1999).

Yet despite these conflicts the doctor's assertion to Diana that in C5, "We are family," did hold some truth. Mothers would watch over each other's children. Material would be shared. Nurses would chat just as leisurely with the mothers as with each other, with some of the mothers sitting in the nursing station. CHOC would come and sell clothes at the hospital on a Thursday as a fundraising initiative, and the nurses were always buying clothes for children in need in the ward.

The relationships would continue even after discharge. The families would phone or SMS each other or catch up on 'ward news' whenever they returned to the ward for a check-up. The ward did, in some way, form its own 'family' in all its tumultuous glory. The children who were alone were cared for by the other carers, who made sure that their clothes were washed or shared snacks with them.

Discharge was synonymous with home and 'normal' routines. Blake (2007) relates how for her child participants a cancer diagnosis removed them from their 'normal' life-worlds. In most cases 'normal' would prove to be an illusion. As Gcobisa would state after counting of the days to go home: "Home is boring." The majority of her friends were now mothers in the hospital and she had few friends left at home. Cikizwe would give me a weekly inventory of what she was going to do if discharged for the weekend. Her plans for prawn-filled lunches and movie-driven weekends would dissipate when the week's sleepless nights proved too much; she would spend the weekend trying to recover from the chronic lack of sleep in the ward or coordinating watching the children with her family. Yet the dream of home remained a strong one and home the preferred environment.

Many IDPs would like to return home but see it as a process of 'becoming displaced once again.' Some even envisage feeling out of place (Brun, 2003:387). These sentiments are echoed in narratives of journeys with childhood cancer. In a study by Rivero-Vergne, Berrios & Romero (2011) participants

generally found that a return to home did not necessarily (and usually did not) mean a return to normality. Life had moved on and there was also the intermittent pull-back factor of having to return to hospital for check-ups. This disruption from 'normal' life was perhaps even more tangible for my participants due to the extensive time spent in hospital. Check-ups could mean another week or so away from 'normal life'. Specialized treatments, such as radiation of the eye socket, required a trip to Cape Town and some procedures meant a few months' stay in the city, even more foreign to them than East London.

Discharge was by no means a smooth process and could at times be dangerous. The lack of knowledge about CHC can make the return home a potentially lethal exercise, even if home is fairly nearby. During my 2<sup>nd</sup>-last week in East London I was surprised to find Tanja and Jason in the ward. I had seen them off just the previous week and Jason was doing very well. Tanja, though, noticed that something was amiss and when they got to the emergency room she had to explain to the doctors what they should do. Patients from C5 were supposed to be admitted directly to C5 if they became ill, but this protocol was forgotten amidst the halls of Frere as Tanja had to fight the medical personnel to have Jason admitted. As mentioned before, Cebisa didn't want to return to her referral hospital because of the sub-standard treatment Nkosazana had received at the hospital. Healthcare facilities were thus no guarantee that the healthcare services rendered would be sufficient or, even more worryingly, that they might not actually be detrimental to health.

Repatriation means that one needs to return home and renegotiate the relationships one had left. As mentioned earlier, the process of displacement can throw social networks into disarray and IDPs can feel displaced in the very home to which they have dreamed of returning.

Gcobisa had poor relationships with her family before Nesiwe was diagnosed with cancer, but the quality of the relationships disintegrated even further when Gcobisa and Nesiwe left for hospital. I knew that Gcobisa and Nesiwe were occasionally without food and Gcobisa had to make use of the networks she had established in hospital to try and find some food for the two of them. She had told me how every return home was met with accusatory glances when Nesiwe returned unhealed. According to Gcobisa, "They don't understand" how the treatment couldn't be working and some of the blame was placed on her shoulders. Nesiwe's father had initially blamed Gcobisa for the cancer as he believed that it was in her genes – they 'didn't have cancer in the family'. After numerous explanations he seemed to come around was more supportive.

When Nesiwe was readmitted to hospital after another bout of fits, the realisation dawned on Gcobisa that this might be the end. We had spoken about Nesiwe's condition on numerous occasions and Gcobisa spoke openly about life without Nesiwe. Yet as the reality of death became imminent Gcobisa started worrying how she would go on without her daughter. Gcobisa had always held firm that she and her family "only believed in doctors and hospital" as they were church-going people, a sentiment shared by many in the ward. Yet she was now considering another healer, and from what she explained it sounded like a faith healer. She didn't want Nesiwe to die without trying everything to save her life, or risk being blamed for 'not doing enough'.

Nesiwe's and Gcobisa's healthcare journey became, at least in part, a renegotiation of the places they would take upon a return home. The distance between Gcobisa's home networks and the ward space caused a chasm, as her family were not participating in the same health journey and so did not appreciate all the nuances contained in that journey. Gcobisa had to take a piece of the health journey home to involve her family in some way and to re-establish at least some place for herself in her home environment. I am not sure whether Gcobisa consulted the healer she mentioned but, on the last account, Nesiwe was doing surprisingly well.

## **Conclusion**

A cancer diagnosis displaces one from the daily routines from life. Hospital visits, medications and procedures wedge themselves into the daily rhythms of life, resulting an arrhythmia which never quite syncs back into a normal rhythm, even after discharge or a 'diagnosis' of remission.

For many of my participants their displacement involved a physical relocation to a foreign space, with strange people and new routines. They had to leave their homes, social networks and methods of income in order to save their lives as the healthcare they needed was usually not available in the area where they made their life-world.

In the host community, they had to find and negotiate their space and redefine their place. It was not always a smooth process: not everyone accorded with a strict delineation of spaces and roles, but a new, transient community was formed in the ward regardless. Days were filled by sharing stories, sleeping on the lazy-boys, caring for the children and watching television. Curbing the boredom was a challenge in

itself. Cikizwe was quite verbal in her assertion, “I never knew you could be so tired from doing nothing,” and home was always presented as something to look forward to.

Discharge, however, was not always the happy, stress-free experience it had been imagined in the daydreams that filled the hospital day. Friends’ and families’ lives had gone on at home and a return home could imply a renegotiation of your place and function. Gcobisa, although happy to be home, felt that home was ‘boring’ as she realised her friends were now the mothers in hospital. In some cases, such as Gcobisa’s, the renegotiation was a matter of engaging in treatments to ‘prove’ yourself and your intentions.

My participants had come to share many of the journeys and challenges IDPs faced in other countries. Chronically positioned in a disadvantaged sector of the PHC, they had at times to displace themselves from an environment which did not provide them with the necessary treatment. The rupture from the participants’ life-worlds proved to be less a matter of physiology and more a matter of ill-placed health resources unable to cater for people in their own living spaces.

## **Chapter 5: Conclusion**

When I reflect on my fieldwork, I see that two narratives in particular had a profound impact on the way I interpreted and presented my field data.

he first is that of Aviwe who uttered the words, “It’s a hard life, this” in her semi-conscious state – a sentiment shared by Diana when she related her arduous journeys to and from East London. I would come to realise that a diagnosis of CHC had an undeniable impact on the family’s life as well as the child’s, but that implication of the diagnosis was more the symptom of a disjointed social system than that of a biological disease.

My participants’ journeys shared some characteristics with the journeys undertaken by internally displaced people, who had to leave home and the safety it represented to try and make a new life in a host community. My participants left home to locate life-saving treatment, leaving behind lives and livelihoods and reinventing and renegotiating space and meaning within the host community of the hospital ward and its staff.

The second very significant narrative during my fieldwork was the phrase, “We are a family,” which was repeated by the doctor on multiple occasions. To me this represented the ways in which individuals manage to make-do within situations over which they have very little choice. Yes, this was “a hard life”, and their lives were fragile and could shatter, but somehow my participants managed to pull the shards together and live in the ward. In small but profound ways, they worked within the very system that had created their present situation.

I do not aim to vilify the PHC system. I have come into contact with many caring and deeply devoted healthcare providers who do life-saving work in sometimes very challenging situations. There are good hospitals and bad hospitals, but what cannot be denied is that for a large percentage of the population, entering a PHC system may not necessarily lead to the resolution of their health issues and may necessitate journeys that take them away from home for long periods.

By showing how my participants internally displace themselves to receive life-saving treatment, leaving behind social networks, work and known routines for long durations of time, I hope to provide a fresh angle on the ways we interact with the information we hear about the deficient PHC system. It is very easy to be blinded by the statistics we receive in press releases on a regular basis, but the tracking of individuals’ health journeys presents us with a less abstract way to understand the very real journeys on which illness can take the individual in a health system that is not always healthy.

While I was writing, I felt a tension between under- or over-emphasising my participants’ agency within a tumultuous PHC. I walked a tightrope between highlighting the structural violence carried out on individual lives by a crippled health system, while at the same time acknowledging the ways in which people ‘make do’. At times that, reflecting on the ways they ‘make do’ seemed to diminish the impact of the inequality in the PHC and social system in South Africa. After much reflection, I came to the conclusion that it isn’t an either-or situation. We need to look at the roots of the structural violence contained in the PHC and how it impacts on individual lives, but also acknowledge that inequality will always exist in some or other format despite the most ardent interventions by the state. Thus, we need to understand how people navigate these inequalities, and not only get by but create lives for themselves that contain joy and heartache, community and isolation – thus life-worlds in different hues, but life-worlds nonetheless. This may not be ‘fair’ or ‘the ways things should be’, but it is the way things are. This should not deny a critical analysis of the processes and structures that give rise to this ‘hard life’, but casting my participants as ‘victims’ will do none of them any favours and will, I believe, even rob them of the agency they have available. To cast someone in the role of victim may bring them to embody that role and no

longer make use of the resources that could aid them in this 'hard life' –that may be the most violent act of all.

In my research I engaged closely with children and adults and I have presented the various interactions accordingly. I have opted not to delve too deeply into categorisations of 'adult' or 'child' for, as the literature has extensively shown, 'childhood' is a mere social construction and the border between what is 'adult' and what is 'child' is permeable and constantly shifting. I also do not see the value in such a categorisation: experiences are not made more or less valuable or real by the experiencer's age. As this beautiful poem by Marcello, a 7-year-old boy dying of cancer, illustrates, children can be very adept at expressing difficult concepts:

I see your eyes  
like fires  
lit in the night;  
they've cried  
they've loved  
they've laughed,  
these eyes of yours.  
They're loving  
they're pure  
they're sincere  
like my special toy.  
I love them  
I feel them  
imprinted in my heart,  
these eyes of yours.  
Today I find them  
tired, yes...  
but as always  
tender  
Believe me, mom.

(Masera et al.. SIOP guideline, 2005: 48)

All experiences that are real to the participant at that point in time and as such carry worth. Arbitrary classifications have little place in this analysis. A cancer diagnosis has an impact on the life-worlds of everybody involved and brings about a displacement which shared traits with IDPs – but it was, at the same time, a unique and highly individual experience.

As I write this thesis I hear the words of an undergraduate lecturer in my memories. On choosing research topics she asked us to ask, "So what?" about the information we were trying to gather. It is a question that has driven both my protocol and now my dissertation. Ethically, I feel a responsibility to present my field data in such a way that it might rewrite the healthcare journeys people in similar situations have to undertake.

By highlighting the displacement children and families experience I hope to add to discourses surrounding the PHC system in South Africa and how it can be restructured to work for the very people it is intended to serve. Most CHC treatments are relatively easy to administer and could be implemented at more local hospitals if health personnel were better trained and supported.

But curbing the onslaught of childhood cancer has no quick-fix solution. Health staff need to be better educated first to identify and then to treat CHC, but this knowledge is thoroughly lacking at the moment. One cannot expect health staff to be educated on every medical anomaly, but CHC is not a rare occurrence. The figures are staggering and South Africa will keep losing children to a relatively easily treatable disease if we do not take measures to educate the people who are supposed to help them. On this point, CHOC needs to be commended for their active education programmes based on the SILUAN signs (SILUAN is a mnemonic which lists the most common signs and symptoms of CHC – please see Addendum B for a copy of the Siluan signs). One can only hope that the increasing emphasis the WHO is placing on non-communicable diseases will trickle down and make a tangible difference the lives of people like my participants.

Ideally education should extend beyond the medical fraternity to include the general population. As my data has shown, it was usually the mothers' recurrent insistence that something was wrong which finally brought about a cancer diagnosis. When equipped with knowledge, people are able to act as agents of their own health. This can prove invaluable in a resource-strapped space, where essential health services may not reach all available sectors of the society.

There is no quick cure for the displacement the health journey with cancer brings about. Segregation of the population is still evident in the PHC system of South Africa in a climate of mismanagement. Although the government is trying to push through an NHI programme which theoretically should put quality healthcare in the reach of more South Africans, the jury is still out as to whether it will attain these high ideals.

To reiterate: there are dedicated healthcare providers working in the PHC, but as long as they remain under-supported and deprived of the necessary tools, their numbers will continue to dwindle. We are at risk of hearing the echo of nothingness in the halls of flashy new hospitals, with would-be patients' health journeys extending even further over the desert land of inefficient health services.

**In Remembrance of:**

**Nkosazana & Jason**

*Fly (Written by Jean-Jacques Goldman & Philip Galdston; Performed by Celine Dion)*

*Fly, fly little wing*

*Fly beyond imagining*

*The softest cloud, the whitest dove*

*Upon the wind of heaven's love*

*Past the planets and the stars*

*Leave this lonely world of ours*

*Escape the sorrow and the pain*

*And fly again*

*Fly, fly precious one*

*Your endless journey has begun*

*Take your gentle happiness*

*Far too beautiful for this*

*Cross over to the other shore*

*There is peace forevermore*

*But hold this mem'ry bittersweet*

*Until we meet*

*Fly, fly do not fear*

*Don't waste a breath, don't shed a tear*

*Your heart is pure, your soul is free*

*Be on your way, don't wait for me*

*Above the universe you'll climb*

*On beyond the hands of time*

*The moon will rise, the sun will set*

*But I won't forget*

*Fly, fly little wing*

*Fly where only angels sing*

*Fly away, the time is right*

*Go now, find the light*

## **List of Abbreviations and Acronyms:**

AAA: American Anthropological Society

AORTIC: African Organisation for Research and Training in Cancer

CHOC: Childhood Cancer and Haematology Clinics.

CHC: Childhood Cancer

IDP: Internally Displaced Persons

NGO: Non-Governmental Organisation

NG Tube: Nasogastric Tube

NHI: National Health Insurance

NMAH: Nelson Mandela Academic Hospital

PEG Tube: Percutaneous Endoscopic Gastrostomy Tube

PHC: Public Healthcare

SAIRR: South African Institute of Race Relations

SIOP: Societe Internationale D'Oncologie Pediatrique (International Society of Paediatric Oncology)

UN: United Nations

WHO: World Health Organisations

WWE: World Wrestling Entertainment

## **Glossary:**

**Bone Marrow Biopsy:** The removal of the soft, inner part of the bone which forms blood cells. It is usually done on the hip bone and the test is done to determine the patient's complete blood count, which is used, among other things, to diagnose blood disorders or to determine whether cancer has spread (Pubmed, 2010).

**Enucleation:** A treatment option (usually when other treatment failed or diagnosed very late) in which the eye with the tumour is removed (Pubmed, 2010).

**Lumbar Puncture (Spinal Tap):** A medical procedure to collect cerebrospinal fluid (the fluid in and surrounding the spinal cord and brain), which is tested for abnormal proteins which may indicate cancer. It is done by inserting a needle into the spine in the lower back and extracting the fluid from the spinal cord (Pubmed, 2009).

**Medullablastoma:** The most common brain tumour found among children. They are more common among boys around the age of 5 and are almost always diagnosed before the age of 10 (Pubmed, 2010).

NG Tube: A feeding tube inserted through the nose to assist feeding. Usually for short-term use. (Oral Cancer Foundation, 2011).

Palliative Care: According to the WHO, palliative care for children rests on the premise of active care of the body, mind and spirit of the child and support of the family. It is a multidisciplinary approach which includes the family and occurs in an appropriate setting (WHO, 1998).

PEG Feeding: A feeding tube inserted through stomach wall for long-term assisted feeding (Oral Cancer Foundation, 2011).

Retinoblastoma: A tumour in the retina of the eye. It is usually diagnosed in children under six years of age and is most common in children between the ages of one and two years of age (Pubmed Health, 2010).

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### Addendum A: List of Children and Mothers

Nokukhanya, the mother of Anathi.

Cebisa, the mother of Nkosazana.

Diana, the mother of Nocwaka.

Gcobisa, the mother of Nesiwe.

Fundiswa, the mother of Aviwe.

Cikizwe, the mother of Buhle.

Tanya, the mother of Jason.

### Addendum B:

<b>For the children and families:</b>	<b>For the specialised treatment centres:</b>	<b>Generally:</b>
<ol style="list-style-type: none"><li>1. Support groups to assist families to cope with the stress that the diagnosis brings</li><li>2. Information and items of immediate practical use, to be made available to all newly diagnosed families.</li><li>3. Accommodation close to the treatment centres for</li></ol>	<ol style="list-style-type: none"><li>1. In close liaison with the medical staff, to ensure that the medical and physical facilities in the specialised units are of a high standard.</li><li>2. To ensure that the units provide a warm, child friendly environment.</li><li>3. Support for the medical and nursing staff to maintain and</li></ol>	<ol style="list-style-type: none"><li>1. Children with cancer have special needs due to the often lengthy treatment and the uncertain future the diagnosis brings. The organisation aims to advocate and lobby on behalf of children with cancer; to ensure that</li></ol>

<p>families from out-of-town, and assistance with transport costs where necessary.</p> <p>4. Transport aid, to enable families to complete treatment.</p>	<p>improve their levels of expertise in the specialised field of childhood cancer.</p>	<p>the medical authorities provide the specialist units required nationally, and appreciate the ongoing problems and trauma that the families experience.</p> <p>2. A Scholarship programme to provide financial assistance to children with cancer who require extra tuition through disruption of education, or who suffer effects of the disease and its treatment.</p> <p>3. Funding into research and studies investigating the causes and treatment of childhood cancer.</p>
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Fig 1.1 The Services CHOC aim to provide. Available: [www.choc.org.za](http://www.choc.org.za) [23.06.2011].

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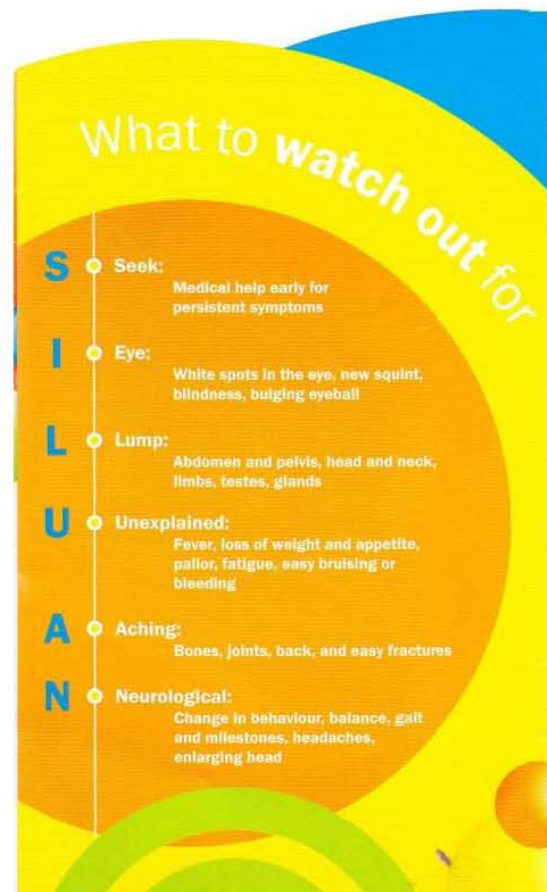


Fig. 1.2. Early childhood cancer warning signs. The above image forms part of CHOC's CHC education campaign.

### **Addendum C.**



Fig 1.3 Map of the Eastern Cape. Available: [http://www.southafricaholiday.org.uk/images/mapdetail\\_easterncape.jpg](http://www.southafricaholiday.org.uk/images/mapdetail_easterncape.jpg) [4 August 2011]



Fig 1.4 CHOC House, 'Home of the Brave'; East London: Front Aspect



Fig 1.5 High School Musical Room 1, one of the themed rooms.



Fig. 1.6 My Room: The Teddy Bear Room.



Fig. 1.7. Participant Observation in action.  
Having my hair braided, one of the main pastimes in the hospital.

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