BODIES OF KNOWLEDGE

CHILDREN AND CHILDHOODS
IN HEALTH AND AFFLICTION

Edited by EFUA PRAH AND SUSAN LEVINE

CHAPTER 6

LIVING WITH MORTALITY: HOW BELIEFS AND DAILY ROUTINE ARE EXPERIENCED IN A PAEDIATRIC ONCOLOGY WARD

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*The names of patients and parents have been changed to protect their identities.

Early one Thursday morning, the paediatric oncology ward was a hive of activity. Parents were sitting with children in the waiting room and there was constant traffic with nurses walking up and down and parents and children entering and exiting. Outside the yellow doors, the hospital was a fairly somber environment with neutral-coloured walls and long echoing passages. Inside the ward, however, it was bright with the walls of the long passage covered with beautiful artwork including a bear on a slide, monkeys hanging in trees, children playing in a field and other characters and spaces meant to be enjoyed by children. The atmosphere in the ward was warm and welcoming. The children were often playing and fairly talkative, and parents who were there daily, conversed amongst themselves and with the nurses as most of them had gotten to know each other over time.

During one of my first visits to the ward, a young boy of about 3-years old returned to the ward where his mother who had accompanied him to the hospital was nowhere to be found. His confusion and angst was apparent. He raced up and down the ward, his face wet with his tears. What had not been conveyed to him by the staff was that the Magnetic Resonance Imaging (MRI) scan that he had been for, required her to leave as she was pregnant and the radiation of the scan would have serious consequences for her unborn child, his unborn

sibling. The absence of information provided to him, illustrates the tendency of withholding particular details from young people due to the assumption that they will most likely not understand. This later became more evident in the way that children aged around 8-years old and younger were given a basic understanding of their conditions and procedures. While the younger children's parents were informed of their progress and the steps that would follow, older children were also afforded this courtesy in relation to their own cases. This is not only linked to the assumption of their stunted ability to comprehend the situation, but also a reference to their emotional immaturity. What was not adequately shared with the young boy of 3-years old, was that before he returned to the ward, his mother had felt faint and needed to be carried out and put under observation to ensure that both she and her unborn child were fine. Explanations from the nurses that she would return did little to calm him and he refused to change from the hospital gown in which his mother had left him. A nurse then requested that I watch him until his mother returned. This was my introduction to this medical environment. What is outlined in the remainder of the chapter are my observations gleaned from three weeks of fieldwork conducted in June 2011 in a public hospital in the Western Cape. I had entered into this space to better understand the experiences of children living with cancer. Themes explored examined the provision of support for ill children and the roles and responsibilities parental figures occupied in their lives.

The experience was unlike any other that I had ever known. During the time that this boy's mother was away, he had to receive further treatment and I found myself comforting him while a needle was being inserted into his hand and he was crying and yelling that he would be a good boy if the nurse just stopped. While it was by no means pleasant for any of the parties involved (myself, the nurse or the boy), in a way, it was a good thing to witness as it provided me with a sense of one of the routine aspects of being a child or playing a parental role in the ward during cancer treatment. To comfort a child in that state can never be an easy task for a parent or doctor. As introduced above, it also became clear to me that he in fact did not understand much of what was happening as he believed that his treatment was a form of punishment for not being a good boy. The assumption that a young child would not be able to comprehend any sort of negative situation seems to be a common one, for example, when someone dies and a child is told that the person is up in Heaven watching over them. This

particular example also ties in with the notion that religion is a way to provide meaning when things are difficult to explain (Geertz, 1973), an idea which will be elaborated upon later on in this chapter. Alternately, this lack of sharing could also be seen as a form of protection, again though, most likely based on a fear that the child could not fully understand his or her diagnosis, thus leaving them in a realm of uncertainty. While the worry and fear that this uncertainty creates in children with cancer is a reasonable reaction to an immense threat, it also takes a toll on the emotions of the children, the effects of which are said to remain well beyond treatment (Yi, Kim & Sang, 2016). Since there is no way of hiding the fact that a child with cancer receiving treatment is ill, it begs the question of who decides when a child is old enough to be completely informed of their condition.

A cancer diagnosis has several ramifications, including but not limited to copious numbers of bills for treatment and spending lots of time commuting to and from hospital and/or clinics. For the duration of my research process, I became part of this world in which every person involved played a role: the doctors played an over-arching role in that they examined the patients and recorded progress and instructions for treatment; the nurses administered the treatments and resultantly spent more time with the patients; and the parents were there to comfort their children and interacted with the nurses regularly. Each of these people has to call on their own identities, understandings, beliefs and knowledge in order to participate in the daily activity. For example, a female doctor who is also a mother might draw on that identity and relate to the mothers of her patients in their interactions. Similarly, the Christian nurses identified with the mothers discussing God's plans for their children. The discussion of anthropological researchers by Behar (1996) as needing to be vulnerable, supports the claim that in order to gain meaningful insight, the researcher needs to be open to the experiences presented to them. In this instance, I needed to be a compassionate and caring individual who interacted with the parents, children, doctors and nurses, as though I too was an occupant of the ward. I therefore found myself helping and playing with the children, watching television programmes with the parents during quieter times, and joining in general discussions when in the rooms with the parents, children and nurses.

Schooling, routine and coping with illness

In their research into the coping mechanisms of family members of children with cancer, Reay et al. (1998) established that the process of coping with illness causes disruptions to the 'normal' way that the family functions. Williams (1995:583 cited in Garro, 2010:473) asserts that "health-related behavior" is itself a routinised feature of everyday life; "something which is woven into its very fabric". It is important to notice and understand how this disruption is evidenced through the formation of new routines and rituals, using the constraints and constructs, including modes of support, provided by the hospital environment, as it illustrates the aforementioned core knowledge and understanding by which all of the various elements related to this illness are held together. An almost taken for granted aspect of the daily life of a hospitalised child is that of attending school, the place where children are said to truly begin to build their identities independently from their parents (Lydia & Aurora, 2013). What follows is a discussion of the role that school plays in the daily routine of a child and how the hospital provides for this need despite the disruption.

Under South African law, every child has a right to an education and it is the duty of the state and institutions to ensure that those rights are met. "Hospital schools stimulate children and give some normality to the day's routine" (Eiser, et al., 2003:4 cited in Carstens, 2004:4). The school at the hospital in which I conducted my research, is based on the lower ground floor and follows the national curriculum. It caters for all grades accordingly. Mrs Potgieter, the principal at the time, was kind enough to provide me with a tour of the school, which was well-maintained and seemingly an invaluable asset for the patients at the hospital. Today, hospital schools are no longer unique in nature, but rather well established proper institutions (Lydia & Aurora, 2013).

The major difference between this school and schools not at hospitals was that all of the pupils were hospital patients with varying illnesses ranging from mental illness to physical illness. The students would be collected from the wards in the morning and returned in time for lunch, except when they were not feeling well-enough to attend. While the doctors would stipulate whether a child was allowed to attend the school or not in the general sense, for example, if the child's immune system was not compromised, the child could also say that they were not feeling up to attending school on any particular day. Their progress would also be communicated to their regular schools at which they were still enrolled, thus

allowing them to keep as up-to-date with their education as possible under the circumstances. This is one clear example of how the treatment phase is a liminal one. On the one hand, the hospital school is a way of ensuring that the children continue to progress normally in terms of their education while the harshest part of their treatment takes place, allowing them to transition back into the general school system as smoothly as possible. In essence, the normal contexts are simply shifted. Furthermore, the concept of the hospital school illustrates that the whole situation is temporary, that life will continue as per normal thereafter. As the length of stay in the hospital of each child varied depending on the nature of their illness, so did the length of their attendance at the hospital school. With a cancer diagnosis, the children sometimes spent months at the hospital with short breaks in between due to the ongoing treatment. In addition to the general disruptions to the life of a child and his/her family (for example, aspects relating to social relations and usual daily activities), this dislocation of attending two schools can be particularly distressing and interferes with the developmental tasks that take place during this period (Zebrack, 2011). Essentially, inasmuch as the hospital school provides the structure and coursework that is required, they are still being uprooted and forced to shift between schools as their conditions change. For a child, creating meaning and making sense of things in such an environment is not an easy task.

In a thesis investigating the inscription and resistance of chronically ill children, Jennifer van Heerden (2009) notes that the Special Needs Education policy in South Africa has created a situation where chronically ill children are included in special needs schools in order to compensate for the impact of their illness on their ability to attend school regularly. While this is intended to mitigate the disruption of the children's education during their illness, the provision of the school also provides a sense of 'normalcy' for the children in the sense that they attend school in the same way as other children their ages. Given the interjection of treatments and other hospital requirements, this normalcy is somewhat limited in that classroom time would be disrupted in order to attend treatments, there is only one school that they can attend, and so forth. In other words, the provision of school facilities allowed the children a routine similar to what they might have experienced before, at a high level, that is, attending school, having homework and so forth, but within the hospital context this routine was an adjusted version of what they had had before. While some of the younger children in the ward

were excited to go to school, the older ones displayed less of an interest and tended to simply want the hospital time to end so that they could go back to their lives as they knew them before the diagnosis.

Re-integrating back into their lives post-treatment can pose some additional challenges. The immune systems of cancer patients undergoing treatment are severely compromised as a result of their treatment, thus making them highly susceptible to illness or attack by germs. As a result, they are required to refrain from visiting shopping malls and other places where people gather, in order to avoid contracting any illnesses that others might be carrying. Most other students within the hospital school are, by virtue of a need to be in hospital, not well, thus also posing a risk to the cancer patients.¹

Accounting for the impact treatment has on children and parents

The paediatric oncology ward has ties with Childhood Cancer Foundation South Africa (now known as CHOC)² that has branches across the country with a specific interest in providing support to children with cancer. It does so by recognising the impact that treatment has on children and parents and, amongst other things, aims to provide a space where children can be treated without losing the sense of a home environment, thereby reducing adverse effects (where possible) of the disease on their experience of childhood.

Adri Maritz of CHOC compiled a book for schools that contains useful information on cancer and the mental and emotional impact that it might have had on the children. Similarly, it includes general support and guidelines to ensure that the environment is as safe and comfortable as possible. The book highlights the fact that cases of fellow children being ill, especially with contagious children's diseases such as chicken-pox and measles, need to be reported to the school principal immediately. She also provides a template of a letter that the non-hospital school might find useful to be sent to the other parents in order to inform them of

1 My reasoning for using the words 'most other students' is due to the fact that not all suffer from physical and/or contagious illnesses and therefore do not necessarily pose a health risk.

2 What started out as a group of parents coming together to provide each other with support following their children's cancer diagnoses, CHOC (initially an acronym for Children's Haematology Oncology Clinics) is now a national organisation that assists parents of children with cancer all over the country. They obtain most of their funding through corporate sponsors, along with conducting fundraising projects (CHOC, 2010).

the situation and various precautions that they might need to take. Essentially, childhood cancer results in long-term after-effects that require a great deal of attention, including but not limited to, the need to protect the child with a compromised immune system from potential sickness and ensuring that he/she is not taunted as a result of any aspect of the illness, as there is often stigma around cancer and other life-threatening illnesses.

There are many reasons for the existence of the stigma, some of which include fear of the unknown, similarity, beliefs and religious ideas, and association with death: fear of the unknown refers to the uncertainty of the development of cancer and how and why it occurs, especially since it manifests in so many different forms; similarity relates to age and gender – a fear of it happening to you because you can relate to that person; beliefs and religious ideas include that the diagnosis is a punishment from God or that it is the result of witchcraft; and the association with death makes reference to cancer as a death sentence (Wagstaff, 2013). Some children do not want the existence of their illness disclosed to others due to the possible reactions and subsequently lose confidence as a result when people are informed (Zebrack, 2011). Once again, the uncertainty for children becomes prominent and can result in the alienation of the child with cancer due to stigma resulting from a lack of awareness. This would also result in additional stress for the child and his/her family.

Being under a great deal of stress and trying to find suitable coping mechanisms, such as talking to friends or family about things that are bothering us, are all part of the daily practice of coping with stress. For the parents of children with cancer – in line with Koocher and O'Malley's (1981) assertion – the daily stresses and the effort to cope is multiplied, thereby becoming that much more difficult. The mother of a 10-year-old boy with leukemia, Mrs van Niekerk, spoke of a need to have other parents who had been "in the same boat" to tell her how *they* had gotten through the difficult time and to advise her how *she* could get through the difficult time. This also ties in with the notion that she and other parents experience of having to maintain a façade for the sake of their children. For all of the mothers, the support from each other was said to have been invaluable and unrivalled. Mrs van Niekerk took this a step further and explained that while the parents spoke to each other in the ward, it was often in front of the children, which prevented them from being able to speak about certain topics, specifically the ones that were really bothering her and taking an immense emotional and psychological toll. She would have preferred to have special times allocated to group sessions with the fellow parents.

Psychological support is catered for by the hospital in the form of a social worker. While this is, in most cases, not someone who has gone through or is going through what the parents are, this type of support has also proved to be immensely helpful to certain families

Other mothers felt welcome and able to consult and support each other in ways beyond talking, such as acting as pillars of strength for the children while mothers went and took a moment. In this way the hospital context provides a surrogate support to parents currently separated from their usual channels of support, such as other friends or family that they might confide in, in the form of a social worker. The examples above show how the meaning and comfort found in this coping mechanism does not change within the different context, but adapts in order to make use of the substitute available. Meaning is therefore retained despite the challenge of the context.

Home away from home

"Health behaviour in daily life is predicated upon taken for granted routinised knowledge and practices which, for the most part, we carry out unthinkingly and unreflectively" (Williams 1995:598 cited in Garro, 2010:473). While there were those everyday aspects of life that the informants may have considered to be routine and/or "normal" from their perspectives, prior to coming to the hospital there were also several aspects that became routine in the hospital itself and had to be adapted to while others were constructed through informant interactions. Some examples of this would be of a precocious 3-year-old nephrology patient in the ward³ shouting "hier ko' die kos!" (here comes the food) every time that the food trolley was brought into the ward or "muffins!" whenever the man selling muffins would enter the ward with his box under his arm. This behaviour became established as a norm in the environment due to the difference from their home life in that food in the hospital is delivered and not prepared by the parents. In other words, the context provided the opportunity for the establishment of the norm.

3 Despite it being the paediatric oncology ward, one of the bigger rooms was used for paediatric nephrology and cardiology patients.

Many informants expressed that the hospital had become a “home away from home” and parents and children adapted to this new environment in order to minimise their coping difficulty. The nurses worked in shifts and the day staff handed over to the night staff at certain times and vice-versa. The doctors arrived between 08:00 and 08:30 every morning of the weekdays and would hand over to the weekend doctors on a Friday afternoon. Similarly, the doctors would do their rounds every morning in the form of coming to each room and discussing each case at the bed of each patient in the larger rooms and in the passageway outside single rooms. Every morning, a mother, Mrs Mtwla, would put her baby, Asanda, into her cot once she had fallen asleep and every morning she would wake up and cry when examined by a doctor. Essentially, there were certain routines within the ward which its occupants grew accustomed to and came to expect. While these aforementioned routines allowed for a more relaxed atmosphere within the ward, these routines also functioned under certain constraints, resulting in the creation of expectations that could not always be satisfied.

CHOC is also well known for the accommodation that they provide in the form of CHOC House in Plumstead (a suburb in the Western Cape) and CHOC Lodge on the hospital premises. I make mention of these two that are located in the Western Cape, but they also have locations elsewhere in South Africa. Where a child might not need to stay at the hospital, that is, be admitted as an inpatient, but it is necessary for them to be there daily, they would organise for that child and his/her parent to stay at CHOC Lodge. For example, Justine Mitchell – a 7-year-old girl – was not able to go home to Piketberg, a distant rural community, as the pipe of her brovia⁴ needed to be cleaned at the hospital daily in order to ensure that it did not become septic. She and her mother therefore stayed at CHOC Lodge, while her father and half-brother stayed at home on the farm – CHOC does not take responsibility for the children nor their parents and it is therefore necessary that a parent stay with their child. Similarly, Janet Solomons, an 11-year-old girl from Ceres, was not able to go home as she needed to be at the hospital daily. At the same time, it was not necessary for her to be at the hospital all of the time. As she and her mother would travel to the hospital by ambulance, bus, or farm

4 A catheter that is inserted into the large vein that leads directly to the heart. It allows for the infusion of medication, blood and fluids without having to repeatedly insert drips or inject the patient. It is also used for the convenient drawing of blood samples (California Pacific Medical Center, 2011).

transport, it was arranged that they stay at CHOC Lodge. However, she initially remained an inpatient as her mother had to go home and she was therefore unable to stay at CHOC due to being by herself.

Two things really stood out for me throughout my field research in relation to CHOC: firstly, there was an undeniable awareness of the Lodge's existence and the convenience of it as an option; and secondly, while the children wanted to go home, there was always an element of excitement around going to stay at CHOC. When there was a possibility that Damian Baatjies would be allowed to leave the hospital and go to CHOC Lodge for the weekend, I witnessed a spirited conversation between some mothers with regard to the nice rooms and which one he and his mother hoped that they might be allocated. It was also as though CHOC Lodge was simply an extension of the ward with questions such as "bly julle nou in CHOC?" (*are you staying in CHOC now?*) and "gaan julle nou CHOC toe?" (*are you going to CHOC now?*) and variations thereof often being heard. Janet and her mother would also come to the ward to socialise in the afternoons when things became a bit too quiet at CHOC Lodge. In essence, it formed part of their ritual and routine. In addition, it held meaning for the children which was evidenced through their excitement at going to stay there.

Where transport and/or accommodation are often taken for granted, even when arranging with another to share private transport or for public transport, it served as quite an obstacle for many in this context. With hospital treatment as a necessity, reaching the hospital was in itself also problematic at times. None of the outlying areas that many of the patients lived in had the resources to cater for the necessary treatments. Similarly, this lack of resources is evident in the stories that parents relayed on how their children had been diagnosed. The experience of perceived inaccurate diagnoses being made, being treated accordingly and having to travel from one place to another for further examinations when each treatment was as unsuccessful as the last, was a common story. This by no means negates the experiences of the families that live in closer proximity to the hospital as they too had similar experiences. It is, however, for the most part, generally easier to find someone to be able to assist with transport locally than for a long distance. It is also much more affordable to use public transport for shorter distances. During the period in which I conducted my research, I encountered only two parents who had their own transport.

As far as transport in general was concerned, many parents spoke of the ambulance as their transport to the hospital during my initial conversations with them. It was not until later, however, that I was informed that the ambulance went and fetched the parent and child in areas that were further away, most often those that fall under the umbrella of the *Platteland*. This was arranged with hospital administration. As one of the doctors informed me, it was therefore a matter of having the ambulance bring the parent *and* child from home or vice versa. However, it was much more difficult to justify transporting the parent by themselves. It was not without its challenges, such as when the ambulance was fully booked for a given day or, as previously stated, a parent needed to be transported without their child. For the most part, however, it was a very helpful method of support to many. While a lack of transport was not the only reason that parents and children stayed in the hospital, it was the reason that some stayed at CHOC Lodge. As mentioned earlier, the parents would socialise within the ward whether they were staying at CHOC Lodge or in the hospital. This is because the hospital could be seen as a “home away from home” due both to the familiarity of the space as a result of living there for certain periods of time and also to the ties that were formed within the space. Essentially, relationships that characterise family life were formed within the space, ties that the parents could associate with their home environments (Coser, 1956).

The role of religion in normalising care

Another form of support takes the form of religion and the comfort that it provides parents such as church groups praying or raising funds for them, or parents turning to whoever God might be to them in order to survive the process. Geertz (1973) explains that the core function of religion is to act as a framework through which people make meaning of their life experiences. My experience in Ward G3 taught me that it is impossible to ignore religion as a form of support in that particular space as it was often a topic of conversation and regularly introduced by the informants. My intention in this instance is not to debate or discuss the accuracy of people’s religious beliefs, but rather to note, through various experiences which I will elaborate upon hereafter, the critical role that religion and, in some instances, notions of death play.

As Diane Komp (1992:73) pointed out, it is commonplace for people to describe experiences with cancer through the use of metaphors related to change or religious conversion, illustrating this with the example of a woman who had survived cancer, but had no religious background, describing her survival as “passing from death unto life” and having been “saved for a purpose”. Similarly, in studies of parents who have lost a child or children to illness, it was found that their religious convictions were a great source of support both throughout the process as well as following the death(s) (Cook & Wimberley, 1983:225; Bluebond-Langner, 1980). In times of childhood chronic illness such as cancer, parents and their children seek various types of support from others and in the form of routine.

Geertz’s (1973) assertion that religion plays a key role in individuals making meaning of everyday life suggests that religious socialisation is a strong influence in how individuals interact with their environment and with one another. Consider the anthropological understanding that differences in culture, religion, ethnicity and so forth are based on making sense of the world in terms of perceptions of us (those like us) and them (those different from ourselves). The combination of these two entrenched premises at face value suggests that where people from various religions gather, this distinction is likely to be highlighted. It was therefore particularly interesting to observe that the inhabitants of Ward G3 not only interacted with one another regardless of their varying ideas of faith and belief, but that they also welcomed prayer and support through whichever channels possible. For example, a Christian man had asked one of the mothers, Mrs Abrahams, a Muslim woman, years ago whether he could pray for her. Mrs Abrahams expressed that “it all goes to the same God” and she therefore welcomed his prayer efforts despite him being from a different religious background. With her daughter, Zubeidah, having been unable to walk at the time, her mother maintained that that man’s prayers had been answered because Zubeidah stood up and had been able to walk ever since. Similarly, a man came around to the ward and handed out pamphlets for us to read that contained inspirational scripture-based messages which were accepted by people regardless of faith. Essentially, the important part was not who followed which traditions as a result of their beliefs, but rather that belief in a ‘higher’ or ‘divine power’ existed and was available to everyone for support.

During some of the tests and procedures, the children were required to be sedated. Each one seemed to emerge from this sedated state in a different way – some would be quiet, some would cry, some would be exceptionally talkative and

others would even sing. One day, Michael van Niekerk awoke, took his mother's hand and said that they needed to pray, before proceeding to pray for everyone in the room. A few days later, he revealed his reasons for doing so to his mother. She was leaning on the side of his bed and he was quite cheerful as he was feeling better than he had in a while. He told her that he had gone to heaven while he 'was under'. He had been "playing with angels" and after ending up in a circle, they were each tasked with something to do. His task had been to pray. After looking at me in wonderment, his mother smiled and encouraged him to find out more the next time. She later relayed this story to nurses and parents both proudly and with a continued sense of wonder.

On a subsequent occasion, when Michael was brought back to the ward, his father was present. He had been informed of the earlier conversation. Michael then told him that he had visited heaven again and that one of the angels, Gabriel, had told him to say hello to his father on his behalf. Mr van Niekerk thanked his son and then told him to rest out of concern that his experience was a side effect of the sedation or a further symptom of his illness. Devine and Deneulin (2011) discuss the important correlation between religious values and the behaviours and attitudes of individuals who follow them. Therefore further understanding of their religious practices provides context for this difference in the parents' responses. Mrs van Niekerk considered herself to be quite religious as she firmly believed in God, would talk about her beliefs regularly and would often sing hymns while we were in the lift/elevator. Mr van Niekerk, unlike Mrs van Niekerk and many of the other parents, did not openly display or relay any religious ideas or beliefs during his time in the ward.

Following Geertz's (1973) assertion of religion as a tool for creating meaning, Devine and Deneulin (2011) discuss religion as not occurring in isolation within social environments and the socialisation experience, particularly focusing on the interaction between religious principles and the impact of social norms on how these principles are lived or exhibited. Michael lived with his mother as opposed to his father, providing the premise that his daily socialisation outside of the hospital includes a home environment where Christian beliefs and principles played a strong role. Belief systems, including Michael's and Mrs van Niekerk's, "allow individuals to give meaning to the world around them and to their experience" (Silberman, 2005:644-645). Michael's indication that he experienced these 'visits',

as a comfort and knew that he need not have been afraid as a result illustrates his interpretation through religious belief. Considering that prayer was welcomed in the ward, as mentioned above, his efforts to pray for others was also construed as being within the social norms of the environment. Considering Mrs van Niekerk's prioritisation of her faith, and Michael's experience of the hospital context as well as his home environment, both were comforted by Michael's experience under sedation, illustrating how a religious frame of reference and meaning was able to provide comfort and support.

While sitting in the waiting room with mothers of both inpatients and out-patients, a discussion ensued about one of the other mothers in the ward, Mrs November. Mrs November had elected not to speak with me about her experiences or consent to me spending time with her daughter, a nine-year-old girl who was in palliative care.⁵ Both mother and daughter had been in the ward since before I began my visits. During the discussion, I pointed out that I had noticed that the room in which they had been staying had been empty for a few days. At this stage, it was said that, while at home, the girl had requested to be brought back to the hospital as a result of the amount of pain she was in and that was why they had returned. The consensus in the ward was that it was likely that she would pass away that day or the next, but by the end of that week for the latest. The discussion in the waiting room revolved around her mother's response to the idea of these final days, particularly her refusal to allow anybody else to pray for her daughter. This caused great distress to the other mothers as they felt that she was "not letting go" as she needed to. This further illustrates the idea that religious beliefs, such as the mothers' beliefs about praying, interact with what Geertz (1957:33) describes as the "ongoing process of interactive behaviour, whose persistence we call social structure". In other words, the mothers had established a common set of behaviours within the ward regarding their support of one another, including praying for each other's children. Devine and Deneulin (2011) discuss this interaction as inevitable in the creation of meaning. The mothers' raising of this concern illustrates a response to behaviour outside of these established and shared behaviours, or norms, but it also indicates the strength of the support that the parents find in using religion to "make sense of their experiences" (Taylor, 1989:175).

5 When there is no longer anything that can be done medically to help cure someone, he/she is kept comfortable for the remainder of his/her life through medical assistance with pain management without any further attempt to treat the underlying cause.

Mrs November continued to pray for her daughter's recovery and believed that it was not possible that she would pass away. At the same time she would not see family off that had come to visit over the weekend as she feared that her daughter might die while she was out of the room. When people entered the room with a Bible with the intention to pray for the little girl, her mother refused to allow them to do so and took the Bible from them saying that she alone would pray for her daughter. When Mrs Baatjies went into the room, she took the girl's hand in hers and asked how she was doing. Her mother then pulled her hand away from Mrs Baatjies'. The mothers in the ward expressed outrage and confusion as to why this mother was pulling away from them and their support at this time. In addition, they feared for how the mother would respond upon the girl's death and also that she was not allowing them to pray for her safe passage into the afterlife by administering her "last rites".⁶ There seemed to be a consensus amongst the mothers that this mother needed to release her child and that "it is not for us here on earth to try to keep a child alive – when God decides that it is your time, it is your time; your children are merely on loan to you".

It was mentioned earlier that support had been established and entrenched among the informants within the hospital context. In most instances, while the parents discussed, with me and each other, their concerns around the seriousness of their children's illness, it was not until this stage that they spoke about or openly acknowledged the possibility of their children's deaths. The concept seems to have its own impact on the norms of the ward G3 environment. During the abovementioned expressions of concern, Mrs Baatjies spoke of times when Damian had been very ill and the fact that she would pray for God to take his pain away and that if that meant that he be taken from her, let His will be done. Her husband would then tell her that she was bad luck for praying for that and it is also this type of prayer that the mother of the girl in palliative care did not want for her. Kotarba (1983 cited in Park, 2005) furthers the notion of religion as a meaning system by postulating that it plays a particular role in making sense of death and pain in order to provide a sense of comfort to those who believe. For Mrs Baatjies, although she would have preferred her son to be alive and with her, her belief was that if it was "God's will" for him to pass away and that

6 In the Christian faith, the last rites, also known as the anointing of the sick, is administered when one is close to death by reason of illness or old age, based on the book of James in the Bible, Chapter 5, verses 14 to 15.

would put an end to his suffering. This was a notion that she could accept and come to terms with. The complexity arises regarding the belief that prayers are answered expectations of outcomes met (Silberman, 2005). Using this logic, if you are praying for the ending of someone's suffering and accepting "God's will if it is for them to be taken", there is almost a sense that you are requesting their passing, as evidenced by Mr Baatjies' interpretation of his wife's prayers to end suffering as "bad luck".

Mrs van Niekerk, while sharing similar beliefs, was not a part of this conversation as Michael had been allowed to go home for a few days and she was therefore not at the hospital on that day. On a separate occasion, however, she conveyed these same ideas to me and said that she needed to "let [her] son go [as] he belonged to God" and that she was grateful for the time that he had been allowed to spend with her. Interestingly, Michael was doing quite well at that stage and the doctor had told her that matters were looking rather promising. This, to me, showed how prevalent the idea of a potential death is under these circumstances and in this context.

I also observed that where someone might not think about death because a child is doing much better and a full recovery looks almost certain, the mothers seemed to hold firmly onto the idea that things were not looking promising until they were certain that the illness was in remission. This seems to be at odds with the religious assertions above but somewhat in line with Mr Baatjies' interpretation of "bad luck". There seemed to be a sense that if you stopped praying, assuming that the child is now well, you might be tempting fate to prove otherwise. The phrase which most aptly describes this fear to me would be "counting your chickens before they are hatched". Considering that many of these parents had taken their children home before, only to have to return, it is understandable that they would fear assuming the best for fear of reprisal. If we include Sontag's (1978) notion of illness as metaphor, where the language-use (particularly 'remission' instead of 'cure') provides the illness with an identity of its own, we uncover the implication that recovery is not necessarily permanent. Within this setting, the combination of these factors, both religious and anthropological, provides strong evidence for the fears expressed by the parents.

While sitting around in one of the bigger rooms in the ward and having conversations with some of the older children, both Zubeidah and Damian recounted their experiences of having dreamt that they were in attendance at

their own funerals. Where one might expect such conversations to have an air of heaviness or despair, those present always seemed to just be intrigued by the fact that similar dreams had been had by other children, thus reassuring them of an element of normalcy. They seemed to find such things interesting rather than disturbing or odd. In conversations regarding dreams, death was seemingly always seen as something normal without any negative connotations, especially when it came to the older children. I say the older children (9 years and older) because the younger ones (8 years and younger) never brought up any thoughts or ideas of death. The older ones, especially Damian and Zubeidah, spoke openly about it as though they knew that it was a possibility, had made their peace with it, and were just carrying on as per usual. Bluebond-Langner (1980) found similar evidence in her research into what she titled *The Private Worlds of Dying Children*, as did Clark (2003), where it became evident that although parents tried to shield their children by avoiding discussing the seriousness of their illness and its possible implications with them, children seem to be aware of these factors. In fact, Bluebond-Langner (1980) discusses how children may not share their understanding with their parents in order to avoid causing sadness or distress to the parents.

However, in the same space with some of the same people, but on a different day, fears surrounding death in general surfaced through a conversation about "the Angel of Death". Following a telephone call with her daughter, one of the nephrology patients' mothers opted to share with the group that her daughter had seen a man dressed entirely in black clothing standing behind one of the doors in a room in her house and that when she had looked at him, he had simply looked back at her before coming out and subsequently disappearing. At this point, a nurse joined in by saying "nee, dis mos die doodsengel!" (*no, that is the Angel of Death!*). She had seen him for herself one day in a room where her father and brother had been sitting. "Hy kom soek vir mense om saam met hom te vat, maar bewaar jou siel as hy spesifiek vir jou kom" (*He comes to search for people to take with him, but beware if he searches for you specifically*). In contrast to the conversations about dreams of death and funerals and the reactions to these, this conversation resulted in Mrs Baatjies shivering and saying that such things just scare her too much. The other mothers also reacted in a similar manner. For some reason, the idea of death in the form of a person coming to fetch

you was terrifying, while death when it was “your time” and “willed by God” was comforting. Despite the label, the Angel of Death was seen as a being of darkness rather than something or someone sent by God or related to religion.

As mentioned earlier, religion is itself a mode of support that is available, promoted and often (as found in my research) welcomed and appreciated. Given that each of the informants seemed to subscribe to some form of religious belief system, the introduction of topics regarding, or opportunities to exercise, religious beliefs merely became an extension of the norms and values incorporated into the environment of ward G3. While there are those who provide access to this as evidence by literature (for example the man who brought pamphlets with supportive passages and Bible verses to the hospital), it is also something that people bring with them across contexts in order to make sense of their experiences. Thus, it is available wherever they are and they can seek it for themselves if they so desire. What is perhaps of more consequence to this particular context is that there seemed to be a common ground across the different belief systems which allowed for the development and embracing of high-level norms, such as praying to an “overarching God”.

Concluding remarks

Backgrounds, beliefs and circumstances are shown to play a bigger role in that they impact everyday life. I explored the aspects of the informants’ everyday lives in terms of what components were “carried across” from their home (‘normal’) environment into the hospital environment and how these interacted with one another to establish and socialise a common set of norms. As a result, it is made apparent that parents need modes of support that allow them to live their everyday lives in and according to the differing contexts that illness sets up. This includes education for their ill children, transport, accommodation, financial assistance, and emotional and psychological support. The circumstances do not present a dilemma as differences are put aside for a greater over-arching idea, namely the welfare of the children and their future health. Religion itself was shown to be a mode of support that extends to all facets of life, including and especially death given its key role in creating meaning in everyday life.

While there is an overarching focus on the roles that the parents, doctors, nurses, and even religious leaders play in making this transition a smooth one for the

children, the most important factor is the children themselves and how they make sense of things. Yes, everyone spoke and acted as though the treatment phase was a liminal one and that life would continue as per usual after, but it was not always that simple. There were children whose initial treatment worked and their follow-up appointments were just that, but there were also those who repeatedly had very strong treatments and spent long periods in hospital on several occasions.

In summary, there are several modes of support on offer that have been and continue to be immensely helpful to many. While what is needed is not always provided, there are people and organisations, such as CHOC, who provide what they can, when they can, in order to make this process slightly less stressful and taxing than it already is for all of those impacted. Similarly, while backgrounds, beliefs and circumstances vary, the tendency to overlook this with regard to support is often a positive thing. In addition, the general responses to the struggles, experience, and modes of support were *"hulle raak gewoond daaraan"* (*they get used to it*) and *"'n mens raak gewoond daaraan"* (*people get used to it*), illustrating that people do find a way through, with the establishment of a network or community (*"we've become like a family"*) playing a large role in this.

As stated earlier, there are some aspects of everyday life, such as attending school, that were transferred from one context to another. At the same time, additional rituals are created and routines become part of everyday life as a result of living within a specific context or environment, such as the 'announcement' of food arriving. Either way, these norms create expectations that, given the constraints of the environment, are not always sustainable. A great deal of resources are required to support the patients and their families, some more necessary than others. What is clear, however, is that those who travel further have an additional obstacle to overcome than those who live nearby. This by no means implies that either group has things easy, but it illustrates how different backgrounds and resources can exacerbate or reduce the stress experienced in adapting to new routines. While it is especially difficult to provide for the needs and help maintain people's usual routines and what they deem 'normal' in a changing context, it is also difficult to begin to provide and then keep up with expectations by maintaining these actions. In this sense, new norms are continually being established, impacting the routines and rituals of the occupants. When these modes of support are removed, these norms and the subsequent routines which incorporated them, have to shift and change yet again.

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