

**THE EXPERIENCES OF CAREGIVERS CARING FOR CHILDREN DIAGNOSED  
WITH ACUTE LEUKEMIA**

**BY**

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## Declaration of originality

I, Makopano Sara Mothiba, student number 23085411, declare that this research report titled: 'The experiences of caregivers caring for children diagnosed with acute leukemia' is my own work and the report has not been previously submitted by me at any institution for the degree purposes. All the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

M.S. Mothiba

June 2011

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Signature

Date

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All the participants reacted in the same way when they were first informed about their child's diagnosis. The participants explained that the first emotions they experienced was hurt and shock. This was possibly because they all had to wait for several days while tests were performed on the child to determine the actual diagnosis. For other participants, the anxiety emerged when they were informed that their child was no longer in remission and the cancer had returned. Sternberg (2001:411) describes fear as an emotion characterized by being afraid of harm focused on a particular experience. All the participants said they were shocked when the doctor broke the news. The other common reaction was crying. It seemed that all the participants, when informed about the diagnosis for their child, also experienced feelings of shock or disbelief. This may have stemmed from the lack of information that they had at that time. According to Chapman (2006), people find it difficult to accept facts, information or reality when they are in a state of shock or denial. This may explain why the participants, when informed about the diagnosis, did not comprehend the information (this aspect will be discussed in detail at a later stage). Sternberg (2001:593) says that the first phase, when people are facing psychological challenges, is shock. During this phase the person is stunned and often feels detached from the situation (Sternberg, 2001:593). The researcher is of the opinion that the participants felt shocked when they were informed that their child had leukemia, so they were not able to recall everything that the doctor said to them.

All the participants said the doctor had informed them about the diagnosis. However, it emerged during the interviews that some of them had not understood the actual meaning of the diagnosis, even after the doctor's explanation. Six (6) of the participants knew that their child had leukemia but confessed that they did not really know what the condition or the treatment meant.

- **Participants' perceptions of acute leukemia**

This section focuses on what and how the participants perceived and understood the term 'leukemia'. The participants' responses to the researcher's question "What do you understand by the concept leukemia?" follow:

*“Bangitshelile ngayo kodwa angikayazi kahle hle ukuthi iyini (They told me about it but I am not really sure what it is).”*

*“Eish ga ke tsebe gabotse gore ke eng (I am not sure what it is).”*

*“I know it’s cancer, but how you get it... I am not sure.”*

*Three of the participants responded by saying:*

*“Ke kankere ya madi. (It is cancer of the blood).”*

*“I can’t really explain what it is.”*

*“Angazi. (I do not know).”*

*“My son has leukemia and he is on chemotherapy”.*

When the researcher asked this participant to elaborate on what chemotherapy is the participant responded by saying:

*“There is a drip on my child, they say it is chemotherapy. I don’t even know what this chemotherapy is. What is chemotherapy? ...but at least he is looking better... and he can play in the ward because he can now manage to walk.”*

All the participants acknowledged that they had heard of the term *cancer*. Three (3) of the participants were able to say that leukemia was a cancer of the blood. Four (4) of the participants had sufficient knowledge about leukemia and the chemotherapy treatment their children had to endure. The participants who did not understand the diagnosis admitted that, when the diagnosis and treatment options were discussed with them, they were still in a state of shock. This correlates with Adams (in Holosko & Taylor, 1994:125) who states that most parents are in shock and absorb very little information during the first week or second week after diagnosis. It is therefore essential to clarify the reasons why most of the participants reacted the way they did. Davis

(1993:19) states that being told that a child has a chronic disease such as leukemia will have little meaning for most parents. Davis further points out that people face a state of uncertainty varying from ignorance to some limited knowledge. Hence, the majority of the participants were not able to fully explain what leukemia was about.

Given their limited knowledge about their child's condition, the researcher posed another question to determine how the participants thought their children felt about always being in hospital. The reason for posing this question was to further explore the explanation which the caregivers provide to their children when they ask them for the reason for hospitalization. This was in an effort to find out whether the participants discussed things with their children, as the researcher is of the opinion that being in and out of hospital may be confusing for a child. Here are some of their responses:

*"He always asks me when are we going home."*

When the researcher asked this participant whether her son knew why he was in hospital, she responded by saying:

*"He knows he is sick but doesn't know from what."* (This participant's child is seven (7) years old.)

*"He doesn't know what is wrong with him, I also don't know why he is getting side effects, like now he just vomited."* (The participant's child is five (5) years old.)

*"Indodakazi yami iyazi ukuthi uyagula, kodwa usesemncane ukuthangazwisisa (My daughter knows that she is sick but she is too young to understand)."*

This participant's child is 4 years old. The participant understood what the diagnosis entailed. She stated that:

*"Umntwana uzolashelwa i-chemotherapy izinyanga eziyisithupha, sizozakaningana la esibhedlela (The child is going to receive chemotherapy for six months, we will be at the hospital a lot)."*

*“Ngwana ga a tsebe gore gobaneng a le mo sepetlele, yena o no nyaka go ya gae. (The child does not know the reason why he is in hospital, he just wants to go home).”*

*“Ngamtshela ukuthi icancer ibuyule, wakhala, kodwa ubengazi ukuthi uzongena ephuma kambalwa esibhedlela (I told him the cancer had come back, he cried... but he did not know that he would be in and out of hospital several times).”*

The researcher asked only the participants who have slightly older children about what they may be feeling about hospitalization. The participants thought that the children did not realize what was going on, as they were still young. Only half of the participants interviewed had children older than five (5) years of age. The Adherence Networking Group (2006:119) explains that younger children will not be able to understand fully what the illness and its implications are and they may feel confused and afraid. It is evident that most of the participants did not fully understand their child's diagnosis, so were unable to explain it to the patients. The children would most definitely have been confused about their frequent hospitalization.

- **Future prospects of the child**

The participants felt uncertain about their child's future. This in turn added to the stress of caring for the child. Some of the participants who confirmed this said:

*“Ke tshwenyegile ka bophelo bja ngwanake ko crecheng ka gobane dijo tša gagwe di šwanetše go fetoga. (I am concerned about my child's future at the crèche as his diet will have to change).”*

*“I am scared that my child can get infections when she is not at the hospital, I am even scared to take her to crèche”.*

*“Ngwanake ga se a kene crèche, o thomile go kula a ne le mengwaga e mebedi... bjale ba re cancer e boile gape o tlo fiwa chemo ya dikgwedi tse selela gape (My child has*

*never attended crèche as he started getting sick when he was two years old... now they said the cancer has returned, and he has to receive chemotherapy for another six months).*”

(This participant feels uncertain about her child’s future, as the cancer cells keep returning. As a result, the child has never been to the crèche with other children and now he has to spend more time in and out of hospital.)

*“Ngikuthola kunzima ukumelana nendaba yalo mntwana, futhi kwesinye isikhathi ngiye ngizibuze ukuthi uzoshona noma uzophila na (I find it really difficult to deal with my child’s relapse and I sometimes ask myself whether he is going to die or survive).”*

*“We will just wait and see what will become of my child, but I believe he is getting better.”*

*“Ke tla no rapela gore a fole ka gore nako yengwe wa kaonafala (I will pray for her cure as sometimes it seems she is getting better).”*

*“Indodakazi yami ibangcono futhi nodokotela uthi sesizophuma maduzane la esibhedlela, bese uyoqhubeka nge chemotherapy yakhe izinyanga eziyisithupha njenge sigulane sangaphandle (My daughter is getting better and the doctor informed us that we will be discharged from the hospital soon and she will proceed with chemotherapy for the next six months as an outpatient).”*

The participants were pleased with the support they received from the nursing personnel. It became apparent to the researcher that the participants required much more assistance on a therapeutic level. This could be provided by the social worker, who was able to alleviate the participants’ sadness and the stressors. It seemed to the researcher that the participants felt uncertain about the future of their children because they did not know what to expect and were placing all their trust in the doctor for a good prognosis.

The WHO (2008:82) states that family members are confronted with a number of distressing emotions and experiences. These include fear of death and uncertainty about the nature and prognosis of the disease (WHO, 2008:82; Barnes, 1998:83). This reflects what the participants in this study reported.

- **The participants' level of acceptance regarding the diagnosis**

Another aspect which emerged from the interviews was the level at which the participants had accepted their child's leukemia diagnosis. The following responses illustrate the different levels of acceptance of the diagnosis by the participants:

*“Ke amogetše gore ngwanaka o a lwala le gona o tla fola, gape ka nako yela ya mathomo e be ke ke neetše, ke no ke potša gore dingaka di tla mo thuša (I have accepted that my child is sick and he will be cured. When I first found out about the diagnosis I was scared and reassured myself that the doctors would help him).”*

*“I am happy because my child is getting better, now he can walk.”*

*“Sengamukele ukuthi uyagula, ekucaleni ngangikhathazekile kodwa manje sengehlise umoya njengoba udokotela engicela ukuthi ngimlethe azothola ukulatshwa. (I have accepted that he is sick. At first I was worried, but now I am feeling more at ease as the doctor requested me to bring him for chemotherapy treatment).”*

*“Ke amogetše gore o na le leukemia mara ga go bonolo ka gobane ka morago ga sebakanyana o boa a kula gape. (I have accepted that he has leukemia but it is not easy because after a while he starts getting sick again).”*

*“I have accepted. What can I do?”*

*“Ngisamukele isimo sakhe njengoba esetshelwa okwesibili (I have made peace with his condition, as this is his second diagnosis).”*

Some of the participants said that they had accepted their child's condition. The participants said this was because they could see evidence that their child was improving medically because s/he was receiving the appropriate treatment following the correct diagnosis. This was not the case for one participant who had recently been informed about her child's diagnosis. She was afraid that the child would have to continue treatment over a long period.

This seemed to indicate that some of the participants had adjusted to their situation, as they had been undergoing this process for weeks or months, taking the child home for several days and then returning to the hospital. When people accept their condition, they make whatever adjustments are necessary to live with the reality of the disease (Shotz in Sternberg, 2001:593). This explains why the participants seemed to have made peace with the fact that their children had cancer. The researcher is of the opinion that the participants had accepted their children's diagnosis because they had been in and out of hospital for months. As a result, the participants had acknowledged the diagnosis, but felt helpless about what they could do to improve the child's illness. The researcher also attributes the participants' acceptance of the diagnosis to the fact that they did not fully understand what the disease entailed, so they could more easily adjust and accept the situation.

The researcher could argue that the participants' understanding may be attributable to the nature of their profiles, as indicated earlier on. For instance, the participants had a low socio-economic status, and depended on social welfare grants. Their school qualifications were below the tertiary level. The researcher is of the opinion that there may be a link between the two aspects, the socio-economic status and their level of understanding of the diagnosis. However, this remains to be explored in further studies.

From the above theme and sub-themes the researcher can deduce that the initial reaction of the participants is disbelief and they look to the medical team for reassurance. Although the participants had been living in the hospital with their children

for several weeks or months, it seems this arrangement still did not provide answers to their question about what leukemia entails. This is in terms of the diagnosis, symptoms, treatment and further management. This calls for social work intervention, where the social worker plays the role of educator and advocate to ensure that the caregivers understand what they are dealing with. For instance, “social workers can serve as context interpreters by providing an explanation of the disease from the medical perspective to the patient (in this instance the caregiver) and interpreting the patient’s/caregiver’s perspective of the disease to other interdisciplinary team” (Gregg, 2009:112). Gregg (2009:112) states that reaching consensus on understanding the disease contributes to effective treatment, as social workers become the voice of individuals.

- **The participants’ experiences as lodger-mothers caring for a child diagnosed with acute leukemia.**

➤ **Daily activities**

All the participants have to be in the ward with their children at 7h00 every day. They bath and feed their children, and remain in the ward with them until 22h00.

The researcher asked the participants how they experienced the schedule of being in the ward for the whole day. None of the participants seemed to have any problems with the schedule. At 7h00 they had to be in the ward to bath and feed their child before ward rounds. From there they remained in the ward with the child to feed him/her during meal times, to provide the doctor/nurse with any other information they may require and to sit with the child. The participants said that they were content to be part of the child’s recovery and were able to see the child’s improvement.

The researcher is of the opinion that the participants would do anything for their child. However, she also thinks that the participants were not getting any mental stimulation by sitting in the ward for the entire day, which could affect their mental health status.

➤ **Support system/s**

The support systems which emerged were the families and the medical personnel. The following responses illustrate the participants' experiences of family support:

*"No-one has come to visit me and my son. But I console myself because my sister and aunt are looking after my children".* This participant had been lodging at the hospital for four (4) months.

*"My family doesn't visit us, but I have been here for three (3) months and I go home bi-weekly".*

*"My child's father came to visit once".*

*"Ga gona motho o a tlang go re bona mo sepetlele, Kgale re le mo sepetlele ka November 2009, ga ba re founle gomme le nna ga ke na tšhelete ya go ya gae (No one has been to visit us since November 2009. They don't even phone. I cannot afford to go home as I have no money)."*

*"Usisi wami wayesazi ukuthi ngiletha ingane izothola usizo nemithi, kodwa akazange abuze ngesimo se ngane. (My sister knows that I bring the child for treatment, but she does not ask about the child's progress)."*

*"His father can't come to the hospital but he phones to check on us."*

*"Ko gae ba fela ba lekola gore re tsogile bjang. (My family sometimes phones to find out how we are doing)."*

As stated by the South African Government Services (2009), "families are faced with challenges and need support to function optimally, thus risk factors within the family situation can leave families vulnerable and unable to fulfill their roles and responsibilities

towards family members”. Seven (7) of the participants reported that they had not been visited by their family members while in hospital.

The participants who received no visits from family members said there were financial problems at home, so they did not expect the family to come to the hospital. This is understandable, given that most of the participants were living far from Pretoria. Traveling can be too expensive, specifically for families living below the poverty line. The Adherence Networking Group (2006: 119) stated that the extent of the burden for children would be heavily dependent on how much support there is from the extended family. The researcher is of the opinion that the participants had been in the hospital as lodger-mothers for such a long time that they had accepted the lack of physical support from friends and family. The majority of the participants had more than one (1) minor child who had been left in the care of their extended families during their absence. The seven (7) participants who had not received visitors said that they yearned for the physical presence of the family. The researcher maintains that receiving emotional support from the family members may contribute to the participants’ ability to cope better during this difficult period. The family should therefore be included in the treatment plan for the patient as a way of preparing them for when the patient is continually being admitted and discharged from the hospital. Instead of excluding the family, the social worker ought to ensure that provision is made for them to meet with the nurses and doctors to ask questions and to receive information about the patient’s medical progress (Sulman & Verhaeghe, 1994: 53). The researcher infers from the above that psychological and social problems are associated with leukemia as a childhood cancer and that the participants require general emotional support. All the participants said that the medical team was courteous and made their stay at the hospital bearable.

➤ **Financial implications**

Another consideration that emerged during the interviews was the financial strain experienced by the participants on account of the child's illness. These are the participants' experiences of caring for a sick child:

*“When we go home I sometimes manage to get a job but I can't take the job because after one or two weeks I have to bring the child for chemotherapy. There is no-one to look after her.”*

*“Ngangi sebenza kodwa manje sekudingeka ukuthi ngimnakekele. (I used to work but now I have to take care of her).”*

*“Ke na le business e nnyane ko hae jwale ha kea sebetsa koo kgwedi kaofela (I have a small business at home now, I have lost one month of business).”*

*“Ke be ke šoma ka emiša ka June go hlokomela ngwana (I had a job and stopped in June to take care of my child).”*

*“Ga ke šome gomme ka dinako dingwe ke hlatswetša batho diaparo gore ba mphe tšheletenyana (I am not working but I sometimes do laundry for people to earn some money).”*

*“Ngidayisa ama-vegies no-ayisi ekhaya kodwa manje angenzi mali njengoba ngilana. (I sell vegetables and ice cubes at home but now I am not generating any income because I am here).”*

*“Bengingasebenzi okwesikhashana, nginomndeni wami nama social grants okuyiyona angisiza ukuthola imadlana. (I've been unemployed for a while. I have my family and the social grant as a means of income).”*

*“E be ke bereka ka emisa ka ge ngwana a kula. (I had a job but I lost it when my child started getting sick).”*

As indicated in the participants’ statements, it is evident that the majority of the participants had to leave their jobs, which means that when the child was discharged from the hospital there was no additional income per household. Among all the participants, only one (1) is married, and the other nine (9) are single parents. Two (2) of the participants said they had supportive partners.

One (1) participant mentioned that she was uncertain about her employment prospects as she was away from work for one (1) month. Six (6) participants said they had been employed prior to their child’s illness. As a result, they had to leave their jobs. Three (3) of the participants had been unemployed prior to lodging at the hospital. Moreover, nine (9) participants had more than one child and they received child support grants for the children below age 14. A child support grant is a form of social relief paid out monthly from the South African Social Services Agency to children whose parents or primary caregivers are unable to support them financially (Blacksash, 2010). At the time the interviews were conducted, the grant was R250 per month. All ten participants were receiving child support grants.

Based on the above information, the researcher can deduce that there are negative financial implications for the caregivers. This in turn contributes to the caregivers’ /participants’ inability to return home regularly, as the transport cost is high. Owing to the low socio-economic status of the participants, the family members were unable to visit the participant and her child at the hospital. The participants who had to resign from their jobs will now be faced with the challenge of finding employment in a country where there is a significantly high unemployment rate. This means that the participants will have to work harder to obtain a job. CIA World Factbook (2010) reports that 24% of the labour force is without jobs as of February 19, 2010. In a survey released in the first

quarter of 2010, 4.3 million South Africans were unemployed, so the prospect of these participants securing any employment was very limited.

The other major issue relating to the financial implications was that even when the child was discharged from the hospital s/he had to come back for follow-up treatment as an out-patient. This meant that each participant would have to return to the hospital a number of times. Some of the participants would have to make use of public transport to get to the hospital and other participants would use the planned patient transport from their local hospitals. The researcher can therefore deduce that even if the participants were to find another job they would be absent from work frequently, which might jeopardize their successful period of employment.

➤ **Family implications**

All the participants had to be away from their families in order to be at the hospital with the sick child. Nine (9) participants also indicated that they had to take their other children to live with extended families. This, in turn, places a huge burden on the relatives who take the children into their care. When children are hurt, ill or disabled, they need physical and personal attention and this has consequences for all members of the family (Davis, 1993:11). It explains why the participants had no problem with the relatives not visiting them at the hospital. Some of the participants' responses relating to the help they received from their extended families are cited here:

*“My one child is with her aunt and the other child is with my grandmother in Rustenburg”.*

*“My sister is taking care of my son”.*

*“Bana baka ba babedi ba šetše le koko wa bona. (My two children are with their grandmother).”*

*“Mošemanyana waka o šetše le bomma. (I left my son in my mother’s care”).*

*“Ga go bonolo ka gore ngwanaka o na le mme waka, o nagana gore ga ke mo rate. (It’s not easy because my other child is staying with his grandmother, now he thinks I don’t love him).”*

*“I go home whenever I can and my 14 year-old son is at home with my family.”*

*“O mongwe o šetše le bomma- tatagwe, o mo nnyane o ile ko sesi le rakgadi. (The other child is currently staying with his paternal grandmother and the young child went to stay with my sister and aunt).”*

These statements are consistent with literature, as family disintegration may occur due to the illness of one of the family member. Barnes (1998:174) states that therapists have to move beyond the systemic concept to acknowledge that traumatic events can impact on all individuals within the family. What needs to be done when therapists go beyond this acknowledgement is to include the entire family system from the first day the patient is admitted to the hospital. This inclusion can focus on the process the patient will undergo and what the diagnosis means. Goldenberg and Goldenberg (1996: 73) argue that therapists who adopt the systems theory view a symptom developing in one person as meaning that the system such as the family, community or society, has become dysfunctional. Davis (1993:11) emphasizes that problems vary according to the nature, frequency, severity of symptoms and the demands of the necessary treatment. Davis (1993:11) further states that diseases cause stresses such as physical and psychological adaptations and make particular demands upon the resources of the child and family. Adams (in Holosko & Taylor, 1994:127) adds that when children have cancer, siblings are affected by everything that transpires. The author also points out that, at diagnosis, siblings may be sent to stay with relatives or friends and they are often excluded from discussions about the illness, so they often do not understand what is happening.

The findings of this study are consistent with the above statements by Davis and Adams because they indicate that siblings are divided amongst relatives, but the latter cannot always afford to take care of more than one sibling owing to financial constraints. As indicated earlier, one sibling can be taken to an aunt and the other sibling to a grandmother or sister. This accentuates the statement that there will be some form of change within the family as the caregivers are absent from the family environment. The researcher is therefore of the opinion that there may be role changes in the family, as someone else has to assume the responsibility of the mother/caregiver. Barnes (1998: 83) states that role changes occur after the diagnosis of cancer, as parents often focus on the cancer patient and the siblings may begin to assume the role of the emotional caretaker.

In contrast to the positive family implications mentioned above, there seem to be some negative aspects. To emphasize this point, when the researcher inquired about the participants' support structure, half of them gave optimistic responses as they experienced a supportive family, but the other half had had negative experiences, which were expressed as follows:

*“My sister doesn't want to help me with my child, she thinks her illness is due to witchcraft... only if someone could explain to them what is really wrong with my child”.*

*“My family doesn't come to visit me, they don't even call. Since the child and I were admitted no one has come. I can't afford to go home anytime as I don't have money.”*

*“Yimina omuletha la esibhedlela ukuzothatha amaphilisi ne mithi, kusukela ngenyanga ka- March (I am the one who has brought him to the hospital for treatment, since March.”*

This participant is married and she alone had been bringing her son for chemotherapy treatment for almost six months at the time of the interview in September 2010. Her husband had never helped with bringing the child for treatment. This participant was

unemployed and used several taxis every time she had to bring the child for chemotherapy.

*“Kua gae gaba kgone gotla go nketela, mara sesi waka wa nfounela ge a kgona. (My family cannot come to visit but my sister phones whenever she can afford to).”*

When the researcher asked this participant how she felt about the fact that her family could not come to see her and her child, she responded by saying:

*“Ke a kwešiša ka gore ba hlokometše bana baka. (I understand because they are looking after my children).”*

*“Ubaba wakhe wangempela ungisola ngokuthi angimunakekeli lomntwana, kodwa ubaba lo esihlala naye uyazwisisa futhi uwusizo kakhulu ngokuthi ngize la esibhedlela (Her biological father accuses me of neglecting her, but her step-father is supportive and understands that I have to continually come to hospital).”*

The researcher observed that the participants' concerns related mostly to the family, which seemed to be causing them stress. Although the participants were grateful that their family was taking care of their other children they still yearned for the family to visit, as some felt alone during this difficult period. Powell and Johnston (2007:114) say that children and their parents have to cope with a variety of stressors, such as changes in family interactions, physical discomfort and anxiety caused by strange surroundings and separations from family and friends. The participants said that if only they could get emotional support from the family, they would feel better. The researcher maintains that the participants needed their family to visit them because being with someone that they emotionally related to may have made them feel that they were not so alone. The hospital setting is much different from a home environment.

- **The participants' experience of the role of the social worker**

The researcher asked the participants how they experienced their interaction with the social worker. They gave the following responses:

*“Social worker o tlike mara ga a mpotšiša dipotšišo tše wena o mputšišang. (The social worker came but she did not ask me the questions that you are asking).”*

When the researcher asked this participant what questions had been asked, she said:

*“O no mpotšiša gore ke dula kae, ke na le bana ba bakae... fela. (She asked me where I stay and how many children I have and that's it).”*

*“I saw the social worker talking to others.”*

*“Social worker wa tla mo mara ga mpotšiša gore ke ikutlwa bjang, o no mpotšiša gore re dula kae le bomang. (The social worker comes to the ward. She didn't ask me how I feel, just where we stay, family composition, and those kinds of questions).”*

*“Angizange ngithole icounseling. (I did not receive counseling).”*

*“Social worker o tla go bona fela ge o mo kgopetše. (The social worker will attend to you if you ask to see her).”*

*“Ngilana esibhedlele, inyanga ezimbili, kodwa angikatholi isikhathi soku khuluma nama social worker. (I have been in and out of the hospital for two months but I have not had the opportunity to talk to the social worker).”*

The researcher told this participant to ask to see a social worker if she felt she needed counseling. The social worker was contacted to this effect and she said she would attend to the case.

One participant told the researcher that she had received counseling. She said:

*“Social worker o fela a tla a nkgothatsa, go bolela le yena go dira gore ke be bonolo. (The social worker comes to talk and encourage me. Speaking to her makes me feel much better).”*

This is the participant whose child who was first diagnosed in 2007 and has now relapsed. This participant reported that discussing her concerns with the social worker made her feel more at ease, so she was benefiting from counseling.

Some of the participants stated that they had only been in contact with the social worker once since their admission to the ward. However, it seems that the participants did not receive any form of counseling. “The primary social work focus is on helping children and families adapt to illness and treatment, increasing their ability to cope, facilitating their learning and personal growth as part of coping and helping them communicate with the health care team” (Adams, 1994: 129). Dimond and Jansen-Santos (1994:509) maintain that one of the major components of the social worker’s work in health care is to provide post-hospital planning for patients and families.

One of the most important social work roles is that of educator. In this study it was very clear that the social worker should provide education for the participants, as they needed such a service. This contributed to the fact that the majority of them lacked sufficient knowledge about acute leukemia. Counseling services should include helping children and families by providing information or referral to community resources (Adams, 1994:130). To expand on the importance of education, Campbell, Jackson and Jeglic (1994: 473) maintain that “education of clients, families and other health professionals in order to increase social support of rehabilitation of clients is a major aspect of social work”. It seems that the above obligations of the social worker were not fully implemented at the hospital.

The researcher is of the opinion that the participants could benefit from counseling sessions, as this could alleviate their anxiety. In the researcher’s opinion, if the

participants were given an opportunity to talk about their feelings, they might also be able to better understand acute leukemia in relation to its diagnosis, treatment and management.

### **4.2.3 SUMMARY**

This chapter addressed the findings of the empirical study. The researcher obtained these findings by using unstructured interviews. The focus was on the caregivers who brought their children to receive treatment at the Steve Biko Academic Hospital. Most of the participants had to remain in the hospital as lodger-mothers. The participants were thus selected according to their availability.

The factors identified included the support systems of the participants, financial implications, family implications and the role that the social worker played during intervention with the participants. These factors formed the themes of the findings, as they highlighted the experiences of the caregivers in-depth.

The findings revealed that some of the participants had unsatisfactory support systems, while others had good support. The support network includes the immediate family members and relatives. The researcher found that the participants were living far away from the hospital, which prevented the family from making regular visits to the hospital. The findings revealed that the participants clearly yearned for the support of their family. However, they said they understood why the family was unable to visit them. The majority of the participants had telephonic contact with their family instead.

Another important factor to consider is the financial implications of caring for a sick child. The majority of the participants had to leave their jobs to care for the ill child. The findings revealed that owing to the children's prolonged chemotherapy treatment the participants often had to often go to the hospital, this made it difficult for them to sustain a job because of regular absenteeism. The findings on this aspect also revealed that all the participants received a child care grant as part of social welfare relief. Owing to the

low socio-economic status of the participants caring for a child who had been diagnosed with leukemia it is evident that the disease had negative financial implications for the participants, as they sometimes had to spend weeks or months at the hospital.

The findings revealed that the participants' families did not understand the diagnosis. This could be explored in further research.

The study revealed that the participants had to leave their other children at home or with relatives, which disrupted the family as a system, because the focus fell mostly on the sick child.

The findings revealed that the role played by the social worker was minimal. During the interviews it emerged that only half of the participants understood what the diagnosis entailed. The researcher therefore maintains that the role of the social worker was not clearly defined to the participants, and as a result it seems that they do not know what the social worker in a paediatric oncology ward should be doing.

## **CHAPTER 5**

### **SUMMARY, CONCLUSION AND RECOMMENDATIONS**

#### **5.1 INTRODUCTION**

This chapter will present a summary of the entire research report. A brief discussion of the research methodology will be presented. Conclusions from the literature study and the research findings will also be addressed in this chapter. Lastly, the researcher has provided recommendations for improved social work service delivery and future research.

#### **5.2. SUMMARY**

##### **5.2.1 CHAPTER 1**

This chapter consists of the general orientation to the study with special reference to problem formulation, the goal and objectives, the research question and ethical aspects of the study. The goal and objectives of the study were formulated as follows:

- Goal: To explore the experiences of caregivers caring for children diagnosed with acute leukemia.

The abovementioned goal was achieved because the participants discussed in detail how they experienced having a child who had been diagnosed with acute leukemia. The participants were able to disclose their feelings and explain the impact that this condition had had on the self, the child and their families.

The objectives of the study that were indicated in Chapter 1 were achieved. They were presented as:

- To provide a broad literature overview on acute leukemia as a childhood condition.

The researcher was able to discuss in detail the condition of acute leukemia. This was achieved in Chapter 2.

- To explore the experiences of caregivers caring for the children diagnosed with acute leukemia.

This objective was accomplished in chapter 4, as all the caregivers willingly shared their story. The caregivers discussed in depth their feelings when they were first informed about the diagnosis and how caring for a child with this childhood condition had impacted on their lives and the lives of their significant others. As a result, the researcher was able to understand their world, through the experiences they shared.

- To draw conclusions and recommendations for improved social work intervention with regard to caregivers caring for children suffering from acute leukemia.

The above objective was accomplished in this chapter, as the researcher was able to identify areas where the social work profession could improve. The research question for the study is as follows:

What are the experiences of caregivers caring for children diagnosed with acute leukemia?

The research question was clearly answered, as indicated in the findings of the study.

## **5.2.2 CHAPTER 2**

This chapter formed the theoretical overview of the topic under study. Acute leukemia as a childhood condition was discussed in detail. The researcher described the two types of acute leukemia, ALL and AML. This was in terms of the diagnosis, symptoms

and treatment of acute leukemia. Chapter 2 established the role of the social worker when s/he is dealing with the caregivers who are experiencing dealing with this challenging condition. The impact of acute leukemia was discussed with the focus on the patient and the caregiver. Overall, Chapter 2 served as a basis for understanding what acute leukemia entails. When one understands the diagnosis, it makes sense to comprehend the emotional and psychological aspects attributed to acute leukemia as a childhood condition.

### **5.2.3 CHAPTER 3**

This chapter provides a detailed description of the research methodology that was used to conduct this study.

### **5.2.4 CHAPTER 4**

This chapter focused on the findings of the research. The information provided by the participants is discussed and analyzed. The findings are also verified by literature.

### **5.2.5 CHAPTER 5**

This chapter presents the conclusions of the study according to the themes and sub-themes identified.

## **5.3 The profile of the participants**

The purpose of identifying the participants' profile was to attempt to realize the full impact of the participants' experiences.

### **5.3.1 Factors that influenced the participants to bring the child to the Steve Biko Academic Hospital**

This theme discussed the reasons why the participants had decided to bring the child to the hospital. The purpose was to determine events which occurred to facilitate this process.

### **5.3.2 Aspects impacting on the participants' experience after being informed that the child had been diagnosed with acute leukemia**

This section focused on the first reaction of the participants after the doctor informed them that their child had a childhood cancer, acute leukemia. The purpose was to understand what feelings occurred and how the news had changed their world.

### **5.3.3 Perception of acute leukemia**

This theme was developed after the researcher transcribed the interviews and came to the realization that some of the participants did not understand the medical condition of their child.

### **5.3.4 The participants' experiences as lodger-mothers caring for a child diagnosed with acute leukemia**

This section covered the broad experience of the participants. Sub-themes were identified to explore in depth how the impact of leukemia had influenced their lives.

- **Financial implications**

This category identified the tough responsibility with which the participants are faced. It also covered the consequences of being in the hospital for a long period of time.

- **Family implications**

This sub-theme exposed the results of the caregiver/participant staying in the hospital for a prolonged period, with specific reference to the family members who remained at home without physical contact with their primary caregiver.

### **5.3.5 The role of the social worker**

This section covered the involvement of the social worker dealing with the participants.

## **5.4 CONCLUSIONS**

An account of the conclusions based on the literature review and the empirical findings follows:

### **5.4.1 Literature review**

- Acute leukemia is a condition that mainly affects children before the age of 18.
- There are two main types of acute leukemia, ALL and AML, with ALL being the most common in children.
- It is not yet clear what the real causes of the disease are.
- The symptoms of acute leukemia include fatigue, easy bruising, excessive bleeding and aches in the joints and bones.
- Early detection of acute leukemia is paramount as this leads to a good prognosis.
- It is imperative for the caregivers to seek medical assistance as soon as the child has been diagnosed with leukemia.
- There is no standard staging system for ALL and AML, as risk factors are used depending on the metastasis of the disease.

- Several tests such as the physical examination, imaging studies and laboratory tests are conducted before a diagnosis can be reached.
- Treatments such as chemotherapy and stem cell transplantation are essential for acute leukemia patients.
- Chemotherapy drugs are used to treat cancer by destroying cancer cells.
- The phases of chemotherapy include induction, consolidation and maintenance.
- Chemotherapy treatment may last for several months or years depending on the malignancy of the cancer in the body.
- The prolonged treatment for the child necessitates lengthy hospitalization. This may disrupt the family system financially and psychologically.

#### **5.4.2 Empirical conclusions**

- The majority of participants did not have a clear understanding regarding what leukemia entails.
- Subsequent to the participants being informed about their child's diagnosis, the majority of the participants still did not understand what acute leukemia entailed.
- There are negative financial implications for the caregivers and their families.
- The families of the caregivers were disrupted by their absence and their remaining minor children had to be taken to the extended family for care.
- The majority of the participants were found to be single parents and this affected the care of their other minor children.
- All the participants who were employed prior to being admitted to the hospital as lodger-mothers terminated their contracts, thus making them unemployed single parents.
- All the participants obtained child support grants for the patient and their other minor children.
- Half of the participants had poor support systems and the other half had good ones.

- The participants had to continue treatment for their children as out-patients. This meant that they would attend the hospital weekly or monthly. In turn, the participants' chances of getting and/or sustaining a job were limited.
- The participants' children were between ages of two (2) and seven (7). This means that their scholastic development was being delayed as they were not in a crèche or a pre-school.
- The children were struggling to understand why they had to be in hospital.
- The participants required thorough counseling.
- The family members of the participants should be involved in the entire process of managing the child and the caregiver.
- The role of the social worker working with the participants was not clearly explained to the participants.

## **5.5 RECOMMENDATIONS**

The recommendations discussed below are based on the empirical findings, the social work profession and recommendation for further research study.

### **5.5.1 Recommendations from the empirical study**

- The caregivers need a thorough explanation of their child's diagnosis. This includes the probable predisposing factors, treatment options and further management of the child's treatment. This might help address the caregivers' fears. Discussing the child's diagnosis with the caregiver should be done once the medical team can see that the caregiver is no longer in a state of shock. If it emerges that the caregiver is tearful or emotionally affected, a social worker should be called immediately to provide crisis intervention.
- The researcher recommends that social workers should provide continuous education for the caregivers/parents of the child. As the caregivers are so often at the hospital the social worker should provide continuous counseling.

- The researcher recommends that a fund or sponsor be identified by the hospital board to provide some form of financial relief for the caregivers. This entails purchasing toiletries and assisting with transport for the caregivers. The researcher identified that some of the participants had to use taxis to bring their child to the hospital, weekly or bi-weekly. The participants receive child support grants for their children and they are thus reliant on this form of social welfare relief of R250 in 2010, which is not even sufficient for the basic needs of the patients.
- It is further recommended that a system should be developed whereby a family member is helped to visit the hospital to provide emotional support to the mother and child. In this instance, the researcher proposes that the planned patient transport from various provinces be used to this effect. For instance, when the planned patient transport from Mpumalanga Province or Limpopo Province comes with patients, a family member should be permitted once or twice a month to use the transport system. The researcher established that the majority of the participants yearned for the physical presence of the family, who are not always in a position to afford the transport fees.
- The caregivers/mothers spend most of their time in the ward with their child. The researcher recommends that during their prolonged stay at the hospital, a support group be established for the lodger-mothers. This action will be a beneficial platform where they can share their experiences and talk about any issue they deem necessary. Support groups may be used for educational purposes where the caregivers would be provided with the necessary information pertaining to the diagnosis.
- The community resources should be used. It is therefore recommended that once the caregiver and her child have been discharged from the hospital, they

should be referred to the social worker in their community for continuous counseling or psychotherapy. The paediatric social worker in the hospital should liaise with other social workers to this effect.

### **5.5.2 Recommendations for the social work profession**

- The majority of the participants had only been in contact with the social worker once. It is recommended that as soon as the diagnosis of the child's illness is known, the social worker should provide first phase intervention. The social worker could obtain the history of each lodger-mother during their early stay at the hospital.
- Thereafter, the social worker should establish a support group for the mothers who wish to be included. Support groups can provide both caregivers and children with support from others who face similar challenges.
- Thorough counseling should be provided for all the lodger-mothers, as this would clarify any concerns they may be experiencing.
- The family of each lodger-mother should be consulted to determine whether they require any form of support. Should the social worker identify a family in need, it is further recommended that the area/local social worker be informed to provide supportive services. Moreover, the family members, with the consent of the caregivers, should be called in to the hospital by the social worker, who would explain the child's condition to them. As it is, when the caregivers return home there is no form of support from the family. This may be due to their lack of information, which, when given, may be more effective coming from a professional such as a social worker.

- Once the lodger-mother and child have been discharged from the hospital, the social worker should ensure, by initiating further management that they do not get lost in the system, maybe due to financial problems, as all of the participants in this study were dependent on social security. This is important, as some of the children will have to continue treatment as outpatients for several months to a year. One of the important responsibilities of the health-care social worker is to compile a discharge plan. The social worker could examine issues that may arise when mothers and children leave the hospital, the personal strengths of the individual, their psychosocial needs, personal resources (for example, substitute caregiver, family support) and co-operation of community resources.
- In conclusion, the social workers should play an active role, where they would be visible and available every time they are needed.

### **5.5.3 Recommendations for future research**

**Based on the above information, the following recommendations for future research are made:**

- The short- and long-term effects of caring for a child diagnosed with a childhood cancer could be explored further.
- The psychological and psycho-social impact on the family members who are faced with a child who has cancer and is undergoing chemotherapy could be explored.
- More research should be conducted comparing the primary caregivers who receive counseling after being informed about their child's diagnosis of leukemia (or any type of childhood cancer) and the primary caregivers who do not receive any form of counseling. The purpose would be to evaluate whether counseling services had any substance.
- Finally, the future requirements of the child should be considered in an attempt to identify precise services in the community in respect of the child.

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Eskom wellness newsletter.



UNIVERSITEIT VAN PRETORIA  
UNIVERSITY OF PRETORIA  
YUNIBESITHI YA PRETORIA

Faculty of Humanities  
Research Ethics Committee

30 August 2010

Dear Prof Lombard

**Project:** The experiences of caregivers caring for children diagnosed with acute leukaemia  
**Researcher:** SM Mothiba  
**Supervisor:** Dr J Sekudu  
**Department:** Social Work and Criminology  
**Reference no:** 23085411

Thank you for your response to the Committee's letter of 12 August 2010.

I have pleasure in informing you that the Research Ethics Committee formally **approved** the above study on 27 August 2010. Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should your actual research depart significantly from the proposed research, it would be necessary to apply for a new research approval and ethical clearance.

The Committee requests you to convey this approval to the researcher.

We wish you success with the project.

Sincerely

**Prof. John Sharp**  
**Chair: Research Ethics Committee**  
**Faculty of Humanities**  
**UNIVERSITY OF PRETORIA**  
**e-mail: john.sharp@up.ac.za**

Research Ethics Committee Members: Dr L Blokland; Prof M-H Coetzee; Dr JEH Grobler; Prof KL Harris; Ms H Klopper; Prof E Krüger; Prof A Mlambo; Dr S Ouzman; Dr C Panebianco-Warrens; Prof G Prinsloo; Prof J Sharp (Chair); Prof E Taljard ; Dr J van Dyk; Dr FG Wolmarans

Faculty of Health Sciences Research Ethics Committee  
24/06/2009

**Number** : S111/2009

**Title** : The experiences of caregivers caring for children diagnosed with acute Leukaemia

**Investigator** : M S Mothiba, Department of Social Work and Criminology, University of Pretoria (SUPERVISOR: DR J SEKUDU)

**Sponsor** : None


**Study Degree:** MSW (Health Care)


**This Student Protocol has been considered by the Faculty of Health Sciences Research Ethics Committee, University of Pretoria on 23/06/2009 and found to be acceptable.**

Prof AG Nienaber	(female) BA (Hons) (Wits); LLB (Pretoria); LLM (Pretoria); LLD (Pretoria); Diploma in Datametrics (UNISA)
Prof V.O.L. Karusseit	MBChB; MFGP (SA); M.Med (Chir); FCS (SA)
Prof J A Ker	Deputy Dean: MBChB (Pretoria); MMed (Int) (Pretoria); MD (Pretoria)
Prof M Kruger	(female) MBChB.(Pretoria) M. Med.Paed.(Pretoria) M. Phil. (Applied Ethics) (Stell) PhD.(Leuven) (Special Advisory Member)
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Snr Sr J. Phatoli	(female) BCur (Et.AJ); BTech Oncology
Mr Y M Sikweyiya	MPH (Umea University Umea, Sweden); Master Level Fellowship (Research Ethics) (Pretoria and UKZN); Post Grad. Diploma in Health Promotion (Unitra); BSc in Health Promotion (Unitra)
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Prof TJP Swart	BChD, MSc (Odont), MChD (Oral Path)
Dr AP van der Walt	BChD, DGA (Pretoria)

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**DR L SCHOEMAN**; BPharm, BA Hons (Psy), PhD;  
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DEPARTMENT OF HEALTH  
DEPARTEMENT VAN GESONDHEID

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To  
Miss M. S. Mothiba  
Department of Social Work and Criminology  
University of Pretoria

**REQUEST TO CONTINUE RESEARCH STUDY AT STEVE BIKO ACADEMIC HOSPITAL**

Your request to continue and complete your research study in "The experiences of caregivers caring for children diagnosed with acute leukemia" that was commenced in Kalafong Paediatric Oncology Department, now relocated at Steve Biko Academic Hospital is approved.

*Yours Sincerely,*

Handwritten signature of Hansa Tanna in cursive script.

*Dr. H. Tanna  
Senior Superintendent  
Pretoria Academic Hospital  
Dated: 26/4/2012*

Pretoria Akademiese Hospitaal, Privatsak x169, Pretoria, 0001 / Pretoria Academic Hospital, Private Bag X169, Pretoria, 0001



Faculty of Humanities  
Department of Social Work & Criminology

## INFORMED CONSENT FORM

Researcher's Name: Makopano Sara Mothiba

Address : P.O Box 296, Kempton Park, 1620

Name of institution :University of Pretoria

### Title of study

The experiences of caregivers caring for children diagnosed with acute leukaemia.

### Purpose of the study

To explore the experiences of caregivers caring for children diagnosed with acute leukaemia.

### Procedures

The researcher will use an in-depth interview to collect data. I am aware that the audio tape will be used and I give consent to that, to ensure that all the information is captured.

### Risks and Discomfort

Due to the nature of this study, specifically that I will be expected to talk about my experiences, it is possible that I could be emotionally affected. The researcher has promised to provide me with a debriefing session immediately after the data collection process has been completed. If I should be found to be in need of further counselling, the researcher has promised to refer me to the social worker at Steve Biko Academic Hospital.

### Benefits

The findings of this study will assist in the improvement of the service delivery by professionals in this field, at SBAH and as a result I am confident that I will benefit.

University of Pretoria  
Pretoria, 0002  
South Africa

Telephone : 012 420 2325/2030  
Facsimile : 012 420 2093/5256

[www.up.ac.za](http://www.up.ac.za)

**Participant's Rights**

I am willing to voluntarily participate in this study after I was informed about the purpose, advantages, disadvantages and risks involved. I have been informed that I may withdraw from the study at any time, should I find it unbearable to continue and this will not be used against me. I am aware of the fact that the data will be stored for 15 years for archiving purposes. Should the data be required for further research purposes, I will be contacted before utilization of the data, for my consent.

**Confidentiality and anonymity**

My identifying particulars are not going to be used in the research report and only the researcher and her supervisor will have access to the information that I will provide during the interview. Should I decide to withdraw from this study, the information that I would have already provided will be destroyed.

**Person to contact**

Makopano Sara Mothiba : 0727317814

**Declaration**

I, ....., understand my rights as a research participant, and I voluntarily consent to participate in this study. I understand what the study is about and how and why it is being conducted.

-----  
Date Place Participant's signature

-----  
Date Place Researcher's signature

-----  
Date



Faculty of Humanities  
Department of Social Work & Criminology

## TUMELELO YA BATLHOKOMEDI BA BANA

**Leina la Monyakišiši :** Makopano Sara Mothiba

**Lefelo la madulo :** P.O Box 296, Kempton Park, 1620

**Leina la thutelabogolo :** Yunibesithi Ya Pretoria

**Hlogo ya nyakišišo :** Maitemogelo a bahlokamedi ba bana bao ba tshwereco ke bolwetši ba kankere ya madi.

### Lebaka la dinyakišišo

Go nyakišiša maitemogelo a bathlokamedi ba bana bao ba tshwerweng ke bolwetši ba kankere ya madi.

### Ditshipidišo

Monyakišiši o tlo butšiša diputšišo tše mmalwa gore a kgone go kgobakantšha dinyakišišo. Nna bjalo ka motlhokamedi wa ngwana ke a tseba gore go tlo šomišwa setšeamantšu go tšea tšeo ke tla be ke di boletšego. Ke fa monyakišiši monyetla wa go šomiša setšeamantšu gore a kgone go boloka mantšu ka moka.

### Dikgobalo le go se dudušege botse

Mo dinyakišišong tše, ke loketše go bolela ka maikutlo a ka le gore ke phela bjang le ngwana woo a tshwereng ke bolwetši ba kankere ya madi. Ke a tseba gore go ka direga gore ge ke bolela ka maikutlo, nka tswenyega moyeng. Monyakišiši o tshepiša go nkgothatša ka morago ga nyakišišo. Ge monyakišiši a ka bona gore ke sa nyaka kgothatšo o tlo nkiša go social worker wa sepetlele sa Steve Biko Academic Hospital.

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UNIVERSITY OF PRETORIA  
YUNIBESITHI YA PRETORIA

Faculty of Humanities  
Department of Social Work & Criminology

### **Monyetla**

Dikarolo tša dinyakišišo tše di tlo thuša ge ke kgopela thušo mo bašoming ba sepetlele sa Steve Biko Academic Hospital, kudu kudu social worker. Ke tshepha gore ke monyetla o mogolo go tšea karolo.

### **Maikarabelo a batlhokomedu ba bana**

Ke tshepiša go tšea karolo mo dinyakišišong tše. Lebaka ke gore ke boditšwe ka botlalo gore gobaneng ke swanetše go tšea karolo, le mathata ao a ka diregago le tše botse tšeo di ka tšwang. Ke boditšwe gore ge ke sa tihwa ke nyaka go tšea karolo nka tlogela ka nako ye nngwe le ye nngwe. Ga go se sebe seo se tlo diregang ge nka tlogela. Ke a tseba gore dinyakišišo tše ditlo dula Yunibesithi Ya Pretoria mengwaga ye lesome-hlano pele di ka lahlwa. Ge go kaba le dinyakišišo tše dingwe gape tše di ka dirwa, ke lokelwa go tsebišwa gore ke fe tumelo yeo.

### **Khupamarama le boemo ba go se tsebege**

Leina la ka le ka se šomišwe mo dinyakišišong tše. Ke a tseba gore ke monyakišiši le morutiši wa gagwe bao ba tlo tsebang ditaba tša ka. Ge nka hwetšwa go le boima go tšwela pele ke dumeletšwe go tlogela go tšea karolo, gomme nkase bonwe molato. Monyakišiši o tshepiša go se šumiše ditaba tšeo ke tla be ke mmoditše tšona.

Ge o na le diputšišo leletša Makopano Sara Mothiba mo 072 7317 814

### **Boipobolo**

Nna.....ke kwešiša ditokelo tša ka bjalo ka motšea karolo mo dinyakišišong. Ke fa monyetla wa go tšea karolo. Ke a kwešiša gore dinyakišišo tše ke tša eng le lebaka leo.

Letšatši

Lefelo

Motšeaakaralo

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