# Sickle Cell Disease

## *Experiences of the caregivers in managing the disease in children living in the Western Region of Jamaica*

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Abstract

The aim of the study was to find out the experiences of caregivers in managing sickle cell disease in children under the age of six year old living in the Western Region of Jamaica.
The purpose was to bring forth information about their lived experiences, on how the disease has affected their lives and their attitudes in coping with the disease. The study seeks to raise awareness for healthcare professionals on the psychological needs of the caregivers.

It was a qualitative research using a focus interview with a convenient sampling. Data collection was done on the 28th of June 2006 at the Cornwall Regional Hospital. Content analysis was considered suitable for this method.

Results: The research showed awareness of the caregivers where sickle cell disease is concerned. The study also suggested that the disease caused financial strains as well as psychological stress to the caregivers and their families. In knowing that they could produce another child with the same disease, some mothers have been reconsidering their reproduction behaviours. Religion is seen as a major coping mechanism because it offers some sort of hope and comfort to the caregivers in the facing up to a disease where they feel powerless.

Further study is recommended on the issue of reproduction consideration in young couples who have tested positive for sickle cell trait.

Keywords
Sickle Cell Disease, management, psychological, socioeconomic aspects, coping mechanism reproduction consideration

Miscellaneous

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SIRPPISOLUANEMIA –SAIRAUS
Perheiden kokemuksia sirppisoluanemian hoidosta alle kuusivuotiailla Jamaikan länsiosissa elävillä lapsilla.

Koulutusohjelma
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Tiivistelmä

Tutkimuksen tavoitteena oli selvittää sirppisoluanemiaa hoitavien perheenjäsenten kokemuksia työssään alle kuusivuotiaden Jamaikan länsiosassa elävien lasten parissa.

Tarkoitus oli tuoda esiin tietoa heidän kokemuksistaan, kuinka sairaus oli vaikuttanut heidän elämäänsä ja heidän asenteistaan sairauden hallitsemisessa. Tutkimus pyrkii lisäämään terveydenhoitohenkilöstön tietoisuutta perheenjäsenten psykologisista tarpeista.

Kyseessä on laadullinen tutkimus keskittyen edustavanotoksen haastatteluihin. Tiedot kerättiin Cornwall'in aluesairaalassa 28. kesäkuuta 2006. Sisältöanalyysi katsottiin sopivaksi tähän metodiin.

Tulokset: Tutkimus esitti perheenjäsenten tietoisuutta sirppisoluanemian suhteen. Tutkimus myös kuvasi sairauden taloudellisia yhteyksiä sekä henkistä stressiä perheenjäsenillä. Tietoisuus mahdollisuudesta saada toinen sirppisolanemiaa sairastava lapsi vaikutti joidenkin äitien asenteeseen koskien jälkeläisten hankintaa. Uskonto nähtiin keskeisenä selviytymiskeinona, koska se tarjosi jokin verran toivoa ja mukavuutta perheille näiden kohdatessa sairauden jonkaedessä he tuntuivat voimattomilta.

Jatkotutkimus on suositeltava koskien jälkeläisten hankinnan harkitsemista nuorten sirpisoluanemia alttiiden parien piirissä.

Avainsanat (asiasanat)
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Muut tiedot

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## 1. INTRODUCTION

Sickle cell disease is a disorder that affects red blood cells. The name of the disorder indicates that the cell shape is sickle or crescent, which means that the red blood cell turns from its round and soft shape into a sickle shape due to decrease of oxygenation and that causes difficulty in passing through small blood vessels. The person is born with the disease due to genetic inherited disorder but it is usually revealed in early postpartum months. Sickle cell disease runs in families and it is transmitted from one generation to the next. It should be noted that sickle cell anaemia is a chronic, painful and potentially life threatening illness (Bloom 1995, 5)

About 5% of world's population carries the genes responsible for haemoglobin disorders. Each year about 200 000 infants are born with sickle cell anaemia only in Africa (World Health Organization, 2006). The largest number of sickle cell disease cases occurs among the blacks from Africa, as well as in countries with the slave trading history such as the Caribbean and Latin America. However, the sickle cell disease is also present among the whites from Middle East, India, and Mediterranean. The gene is common for Israeli Arabs, Saudis, Turks, Greeks, Sicilians, and the Cypriots (Bloom 1995, 22).

The study aims at bringing forth the experiences of caregivers on the management of Sickle cell Disease children living in the Western Region of Jamaica, because 10% of the population in Jamaica carries the sickle cell genes.

The study will provide information on the disease for health professionals in those countries that are not familiar with the Sickle Cell Disease. The experiences of the parents however, will provide information for those who are familiar with the illness but are not totally aware of the psychological effects of the disease on caregivers and immediate family members. The result of this study will be send to the Sickle Cell Clinic in Jamaica in the hope that there

will be appropriate steps taken to organise a support group in the Western Region.

We begin the study with an overview of the Sickle Cell Disease via its acquisition, and clinical manifestations. We will focus more on clinical manifestations in order to give a clear picture about the symptoms that patients with sickle cell disease are going through. This is very important since the quality of life and well-being of these patients are often impaired. The other very important part of the study will focus on psychological and socioeconomic aspects of the illness on the caregivers of children with chronic illness because they are related. The study will also reveal some of the common coping mechanisms of caregivers when facing up with the chronic illness of their child.

## 2. HISTORY OF SICKLE CELL DISEASE

### 2.1 The first mention of sickle cell disease

Sickle cell disease went unreported in African medicine until the 1870s even tough the gene is most common in Africans.
In 1846, in the USA a paper titled “Case of Absence of the Spleen” was probably the first one to describe sickle cell disease. The case that was mentioned in the paper was about a runaway slave who has been tried and executed for murdering another runaway slave. A physician, who autopsied the body one hour after the execution, noted the unusual body builds of the murderer describing it as a strange phenomenon of a man having lived without a spleen (Bloom 1995, 24-25).

The first formal report on sickle cell disease came from Chicago in 1910 when Dr. James Herrick reported “peculiar elongated and sickle shaped” red blood cells in “an intelligent Negro of 20”.
Dr. Ernest Irons was the first to examine the patient’s blood and sketched the strange shaped cells. In 1922, after 3 more cases were reported, the disease was named “Sickle cell Anaemia” (Bloom 1995, 24-25).

### 2.2 The presumptions of the sickle cell’s origin – malaria hypothesis

Bloom (1995) stated that the first presumptions on relation between sickle cell disease and malaria begun in 1940 when British colonial medical officer stationed in Northern Rhodesia, nowadays Zimbabwe, noticed that blood from malaria in those with the sickle cell trait (one HbS and one HbA gene) had less malarial parasites than blood from the patients without sickle cell trait. However, following this observation, physician in Zaire reported that there were fewer cases of severe malaria (parasites affected the brain) among the people with sickle cell trait then among those without it. Some 14 years later from the first observations, Anthony C. Allison hypothesized that sickle cell trait offered protection against malaria. This hypothesis was supported by

geographical distribution since malaria and sickle cell disease share the same geographic distribution (Bloom 1995, 25-28).

## 3. OVERVIEW OF THE DISEASE

### 3.1 Sickle cell disease, its acquisition and life expectancy

Sickle cell disease is the genetic blood disorder which is caused by abnormal haemoglobin. The abnormal haemoglobin leads to damaging and reforming red blood cells. Therefore the red blood cells break down causing anaemia and because of its ability to transform or turn into sickle shaped cell and obstruct the blood vessels the patient will experience the recurrent manifestations of pains and multi-organ ischemic damage.
(Creary, Williamson, Kulkarini 2007, 575-578).

There are few types of sickle cell disease and the most common are: Sickle haemoglobin S disease, Sickle haemoglobin C disease, Sickle beta thalassemia. This means that haemoglobin consists of four protein subunits and two of them are called alpha haemoglobin and two are called beta haemoglobin.
The function of haemoglobin beta gene (HBB) is to provide instructions for making beta haemoglobin. However, when the function of the HBB gene is impaired it leads to mutations making various versions of beta haemoglobins (Muscari 2005, 207).

Sickle cell disease is the most common form of sickle cell disease. Sickle cell disease occurs when the person inherits two abnormal genes, one form each parent. The person is said to have the sickle cell disease. However, if the person inherits one sickle cell gene from one parent and inherits a normal gene from the other parent, then the person is said to be born with sickle cell trait (Muscari 2005, 207-209)..

Having sickle cell trait (one copy of sickle cell gene) does not mean having sickle cell anaemia. People with sickle cell trait do not have a condition but have a gene that can cause the condition. All this means that if both parents have sickle cell traits the child is likely (25%) to inherit the two traits (one from each parent). Two copies of sickle cell genes further more means sickle cell anaemia (Hill 1994, 16-17).

The median age for life expectancy of a person with sickle cell disease is between 45-55 years old. Now with all the possible treatments, people have been living past well their 60's. Those who died from the disease did not die due to organ failure but due to acute episode of pain, chest syndrome or stroke (British Medical Journal 1995). The life expectancy of sickle cell patients have improved over the past two decades due to better understanding of the disease. However, even though there is much better understanding of the illness nowadays, the cure has not yet been found (Bloom 1995, 67)

### 3.2 Clinical manifestations

Sickle cell disease is a chronic, painful and potentially life threatening illness. The first crisis usually appears when child turns six months after the birth. Usually the crisis is precipitated by infection, possible dehydration, fever, and exposure to cold.(Muscari 2005, 207-208).There is no cure for this blood disorder (Brunner & Suddarth 2004, 887-888) but there are few regular ways of treatment. Treatment of sickle cell disease is the focus of continued research.

Clinical manifestations in patients with sickle cell disease may vary.
The most common symptoms are: Enlarged spleen from congestion with sickle cells, enlarged and tender liver form blood stasis, hematuria, inability to concentrate urine, necrotic syndrome, bone weakness, swollen hands or feet , frequent infections, especially pneumonia , pain in any organ or joint , stroke, myocardial infarction (Griffith 2006, 599) .

Sickle cell crisis may occur in different forms, the most common crisis is: vaso-occlusive which is the most common and very painful episode resulting from obstruction in blood vessels (Muscarri 2005, 208-209) that causes fever, abdominal pain, tissue hypoxia (Brunner & Suddarth, 2004, 887-889) and necrosis due to lack or inadequate blood flow to the specific region of tissue or organ.

Acute chest syndrome results from sickling in small blood vessels in the lungs and the reason may be either vaso-occlusive crisis or infection. Overwhelming infections result particularly from streptococcal pneumonia or haemophilus influenza type b pneumonia. These are major causes of death in children with sickle cell anaemia younger than 5 years of age (Muscari 2005, 208-209).

Splenic sequestration (Muscari 2005, 208-209) results from spleen pulling a large amount of blood that may cause severe drop in blood volume and causes shock. This is life threatening condition characterized by irritability, abdominal distension, pain, hypotension and tachycardia. This condition requires transfusion and splenectomy. The spleen is the most common organ responsible for sequestration in children. By the age of 10 years most of the children experienced splenic infarction. In adults however, the liver and more seriously lungs are the most common organs responsible for sequestration. A stroke may result form sickle cell blocking major cerebral blood vessels that may lead to various neurological impairments (Brunner & Suddarth 2004, 887-889).

### 3.3 Medical management in sickle cell disease patients

Majority of the patients experience pains nearly on a daily basis. The severity of the pain may vary from mild and moderate to very severe. Sometimes painful episodes can be managed at home but very often due to severe pain the patient must seek immediate care in health care centres, emergency units or crisis centres. This means that sometimes the pain cannot be overcome even though that the patient is using pain killers prescribed by doctors (Hill 1994, 20-21).

In one of the studies done by Karen, Ready, Workman, Sedway, Anthony (2000, 228-238) that has been made on pain management during two weeks study in sickle cell patients suggested that the majority of children experienced at least one painful episode. It was also found out that the pain interferes with everyday activities even though majority of them did not miss any day of school while 40% of them missed some days from school. This basically means that if a child is in pain and cannot attend the classes at school one parent or caregiver must stay with the child at home (Karen, Ready, Workman, Sedway, Anthony 2000, 228-238).

Pain Management will be depending on the frequency and severity of the painful episodes. There are few alternatives in pain management such as: aspirin which seems to be very useful in mild to moderate pain (Brunner & Suddarth 2004, 887-889).However, when it comes to children, aspirin is not recommended for children below 12 years of age due to possibility of developing Reye's syndrome ( symptoms of encephalitis combined with the evidence of liver failure). In that case there are alternatives such as Panadol, Paracetamol (Griffith 2007, 148). Aspirin is very useful because of its ability to diminish the inflammation and possible thrombosis. The above mentioned medicines belong to the group of Non-steroidal anti-inflammatory drugs (NSAID) that are usually used for moderate pain but also combined with opioid analgesics in severe painful episodes. Patient –controlled analgesia is

often used as pain management method also. The preferred opioid analgesic is morphine. Patients who frequently use NSAID should be in regular renal control because in some cases the regular use of NSAID may precipitate renal failure. (Brunner & Suddarth 2004, 887-889).

### 3.4 Types of therapies during hospitalisation

Hydroxyrea (Hydrea) is a chemotherapy agent whose function is to increase haemoglobin levels by decreasing the permanent formation of sickled cells. As such it is proven to be effective and the patient with this type of therapy appears to have fewer painful episodes, a lower incidence of acute chest syndrome and less need for Red Blood cell transfusions. (Brunner & Suddarth 2004, 887-889).

Red blood cells (RBC) transfusion is proven to be highly effective in acute exacerbation of anaemia in for example aplastic crisis situations. Aplasia means total or partial failure of development of an organ or tissue. Aplastic crisis in sickle cell disease means that body cannot produce new red blood cells. This condition is usually precipitated by infection. (Brunner & Suddarth 2004, 887-889).

Bone marrow transplant is the method that is seen as a potential for cure of the disease. Unfortunately, this treatment is not available for most people with the disease because of lack of compatible donor or possible organ's damage (liver, kidney, and lungs) already exists, and it is also an expensive procedure (Brunner & Suddarth 2004, 887-889).

### 3.5 Improving the quality of life by continuing management of sickle cell disease

Besides medical care and attention, it is important that patient takes good care of him/her self at home as well. It is also very important that patient or families and caregivers do follow the instructions given by their physicians. The continuous of a positive life style will certainly contribute to the improvement of a life quality (Bloom 1995, 69-73). The patient should have:

*Diet* consisting of fruits and vegetables rich in vitamins and irons is very important because the body of children and adolescents makes additional demands in order to make new red blood cells (Bloom, 1995). The diet should also includes Vitamin E because of its beneficial function in protection of the membranes of the red blood cells and further more Folic Acid and Vitamin B12 as a prevention of coronary artery disease (Graham & Borgstein 2000, 94-109)

*Adequate fluids* is needed because of the high concentration of HbS and the more there is concentration the haemoglobin molecules are then more closer to each other and more likely to come into contact with each other. Any clear fluids will make a good benefit, such as water, milk, fruit juices, soft drinks… It is also important to drink as much as possible on a daily basis, especially great amount of fluid intake is recommended if there is fever or painful episodes (Bloom, 1995). The basic objective of fluid therapy is correction of fluid and electrolyte deficits and maintenance of normal serum electrolyte concentration. The fluid intake will be based when it comes to children according to their weight and for adults the recommendation is 3 L / day if cardiac status is normal (Reid, Charace, Lubin 1997, 38).

## 4. FAMILY FACING CHRONIC ILLNESS OF THE CHILD

### 4.1 Family functioning when chronic illness occur

Bradford (1997) believes that there is constantly growing awareness of the need to treat the whole family when it comes to chronic illness in family member. By increasing attention to the psychological needs of the childhood chronic illness has also served to highlight the importance of involving the whole family into the treatment. When this is recognised as of crucial importance it was widely accepted and nowadays parents are encouraged to stay in the hospital and take care of their child. By taking active role in care, parents will help child to cope better with the illness. However, this way of treatments is not possible to establish everywhere especially in countries where sickle cell disease is a major public problem.

Treating childhood chronic illness requires the integration of medical, nursing and psychological care. For better coping with illness the whole family should be involved in structural family therapy. Bradford (1997) underlines the importance of early involvement of the family therapist. This is essential because it help reduce the possibility of families and medical professionals focussing only on the physical elements of the illness (Bradford 1997, 95).

Davis (1993) says that each disease presents the specific problem to the child and family. The problem may vary according to nature of the illness, severity of the symptoms, frequency, disability and life threatening. Each chronic condition brings stresses and makes certain demands upon the resources of the child and family. Consequently, the common for all of them is the need to adapt physically, psychologically and socially to the new situation (Davis 1993, 1-5).

However, Bradford (1997) claims that integration of the family assessment and therapy at least when it comes to paediatrics is often problematic.

The reason can be that during medical admission staff focus on the physical condition and amelioration of the symptoms. The second problem is that for integration of systemic thinking, the medical team needs to change the concept. The existing and prevailing medical concept has to change in order to incorporate psychological dimensions in treatment. The third problem is, that medical staff is not the only one to change the system and its belief, but also the patient and the family. This is mentioned because very often when health care professionals attempt to incorporate psychological dimensions parents are confused because they are mostly concerned and focused on the organic problem. Therefore, family may have difficulties in accepting the notion of psychosomatic illness (Bradford 1997, 94)

### 4.2 The characteristics of families under stress

Wilkinson (1998) underline the chronic illness within the family may contribute to suffering from severe stress. He further more reveals that the degree of reorganization of the family required by the illness is often profound; affecting issues such as finances, time, school, peer group as well as emotional and interpersonal ones. Boss & Mulligan (2003) pointed out that chronic illness leads to disruption of normal family process such as routines and rituals. In their efforts to meet the demands related to illness very often family members must restrict some activities or even give up. The family system also have to think and establish the role for accomplishing the basic tasks such as earning the family income, child care, meal preparation and household maintenance. Families vary in how segregated they are. Some family may share the tasks according the gender meaning tat each gender will perform separate roles which are presumed to be typical for certain gender, and in some family both genders share the most of the roles. The aim is however, to make family talk to each other openly and split or share the tasks. This will avoid family falling apart. The family should also speak openly about the chronic illness between each other and about the impact of the illness on their lives (Boss & Mulligan 2003, 110-113)

Barakat & Kazak (1999) conclude that strains of childhood chronic illness on the family are unlimited. There is actually no list of potential stressors that can do justice to its impact. Among the stressors described by families are: facing uncertainty about the future well-being, mortality of the child, as well as dealing with emotional, academic and occupational limitations of the child, financial strains, and communication breakdown in the family, friends and neighbours, lack of leisure time. Low socio-economic status in the family with the member suffering of chronic illness, and low levels of social support or integration into community are stressors that make the burden of chronic illness difficult to carry. But despite all these stress factors experienced by the families of children with chronic illness, families have been found to be incredibly competent in adapting (Barakat & Kazak 1999, 333-336)

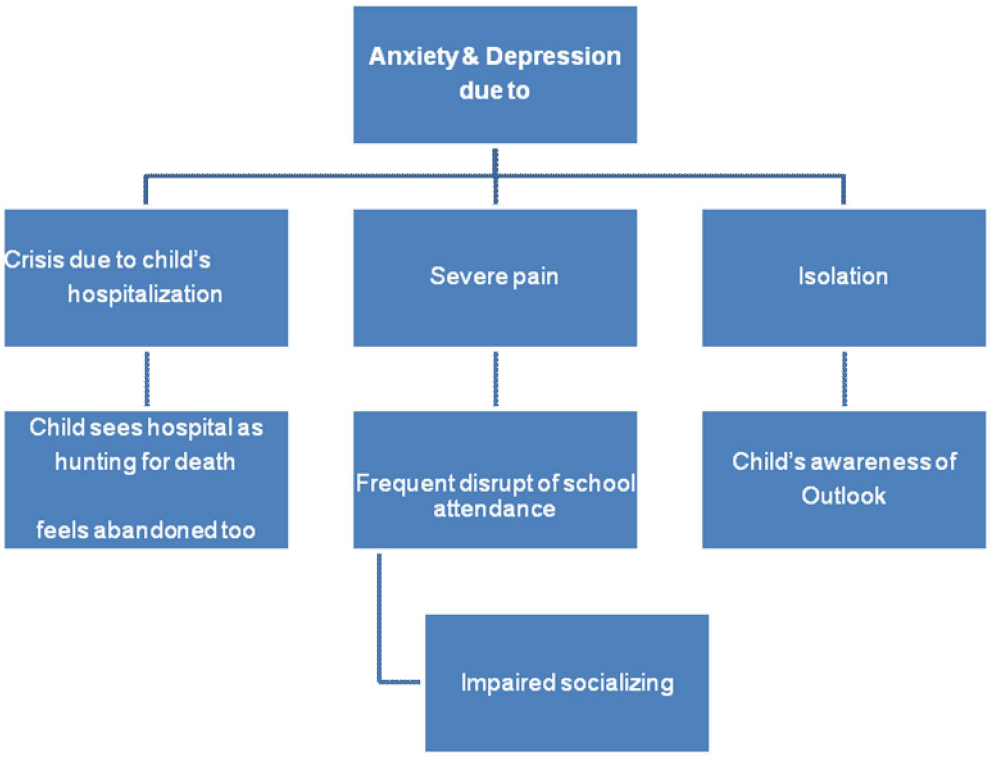
## 5. PSYCHOLOGICAL AND SOCIO-ECONOMIC ASPECTS OF THE CHRONIC ILLNESS

The first real crisis moments for both, child and family is separation due to child's hospitalisation time. Bloom (1995) says that children must separate from their parents during hospital stays and some children fear that they are being abandoned by their parents. Severe pain, isolation, disability can take their psychological toll and therefore anxiety and depression become common. For some children the hospital may be seen as hunting for the death. Furthermore, Bloom (1995) states that sickle cell children are often smaller and thinner than their healthy peers and they might feel themselves less intellectually competent because of the frequent school missing and suffer academic consequences. When sickle cell children turn to adolescent years the result is often low self-esteem. This may lead to social withdrawal and depression (Bloom 1995, 62).

Painful episodes which are typical for sickle cell disease may have a significant impact on the individual's psychological adjustment throughout the life span. Painful episodes are especially difficult for children who may experience fearfulness and helplessness. Another difficult moment in painful episodes when it comes to children of young age is their inability or limited ability to describe pain to their parents and health care professionals (Nash 1994, 20).

The next important element that may influence psychological state of sickle cell child is socializing with peers. This is usually happen when child starts the school and painful episodes frequently disrupt school attendance and social activities with peers

The crucial point of quality of life in chronic illnesses is certainly maintenance of mental stability. Mental stability is key element for the patient and for the family. Therefore, having a psychological support is as important as medical treatments. The psychological support will help patient and their families to adjust better, to overcome crisis and help in positive thinking (Nash 1994, 20).



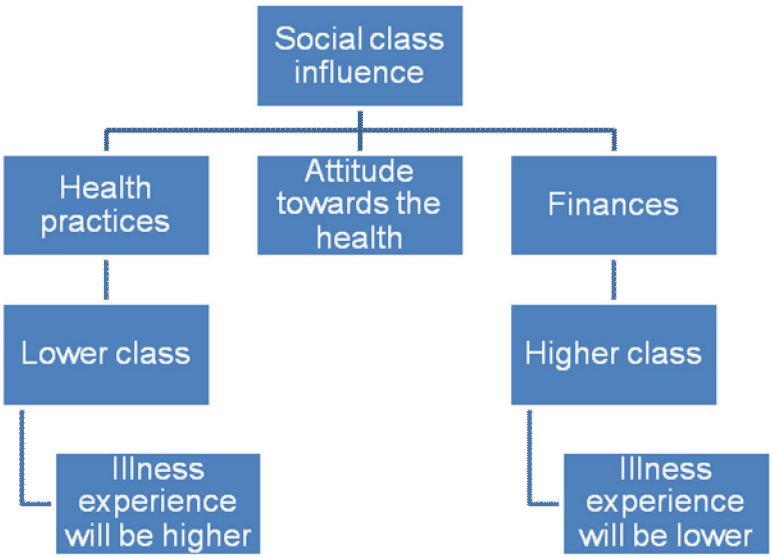

(Illustration 1. refers to psychological aspects of the chronic illness)

Furthermore, the illness may produce a drain of energy and money within the family which can lead to some sacrifices so that siblings may not get for example new toy, or new shoes, or go to some filed trip (Bloom 1995,76). Drotar and Crawford (1985) claimed at that time that impact of chronic illness on healthy siblings is a sadly neglected area since brothers and sisters of ill children experience very often a number of psychological problems such as mood changes, attention-seeking behaviour, changes in academic performance, withdrawal, somatic complaints etc.(Drotar and Crawford 1985, 355-362).

Muscari (2005) states that social class and its establishment has great influence due to differences in child practices and attitudes toward the health.

Children are raised in different ways by the parents whose education may vary as well as communication skills, occupation and income. It is also well established that low socio-economic status has adverse influence on health and this may be due to escalating health care costs and unaffordable health insurance, Eating unbalanced and insufficient food, no health visits due to lack of funds or lack of value in the importance, inadequate housing that may result in overcrowding, poor sanitation and greater chance to expose to communicable disease, the child may be homeless (Muscari 2005, 5-6).

The basic assumption of the chronic illness in socio-structural approach is that the illness is biological circumstance which forces individual to live differently adapting the new way of living. Chronic illness results in a state of economic, social and psychological being. From the sociological point of view health and illness are differently distributed along social classes, meaning that in lower classes the level of the illness experience will be higher than in higher class (Field & Taylor 1998, 3-5).




(Illustration 2. refer to socio-economic aspects of illness)

## 6. COPING MECHANISMS

Coping within context of health is a term used to describe a strategy for living with the chronic illness. Coping mechanism has been defined as constantly changing cognitive and behavioural efforts to manage internal or external demands of a people's personal resources (Hitchcock, Schubert & Thomas 2002, 709-7109).

### 6.1 Psychological support, knowledge on the illness, culture and religion as coping mechanisms

World Health Organisation defined health as a state of complete physical, mental and social well-being and not merely, the absence of disease or infirmity. In that context people's well being will be observed as a whole and therefore treatment will focus so that holistic approach is applied. This basically means that treatment cannot exclude mental status from physical status. One is closely related to another. Also, we can not exclude physical and mental status from social status. Why is this all important? First of all, having psychological support in support groups or individually will contribute in changing attitudes towards the illness, to learn that the person is not the lonely in her/his illness, it may help people better socialize to each other and adjust better over the situation. Positive attitudes may greatly contribute to the better quality of life. However, by having a chronic illness the patient is not the only one affected by the illness but the whole family. Psychological support will prevent family from falling apart and ideally gives the strength to face the illness as best as they can.

While the medical support is taking care of physical conditions, the psychological care which has to considered will be taking care of a mental stability. Combined medical and psychological support will contribute in establishing the balance between physical and mental well-being. The balance between mental and physical is the most important attribute in the patient suffering from chronic illnesses (Bloom 1995, 75).

Different coping mechanisms may help persons to adjust better to their new conditions and follow recommendations. Coping mechanism can be also detrimental to positive patient or caregiver education. One of the coping mechanisms is need to know every detail of the condition and treatment. This coping style may help reduce anxiety of unknown and helps person to feel of having the control over the condition (Falvo, 2004, 57-58)

Knowledge is powerful tool in coping with a chronic illness. Besides acquiring the knowledge from different sources the knowledge may come in the form of learning experience through normalization. Coping mechanisms are directed towards personal adaptation. The more they know about the illness the better adjustment to the situation will take place (Hill 1994, 174-177)

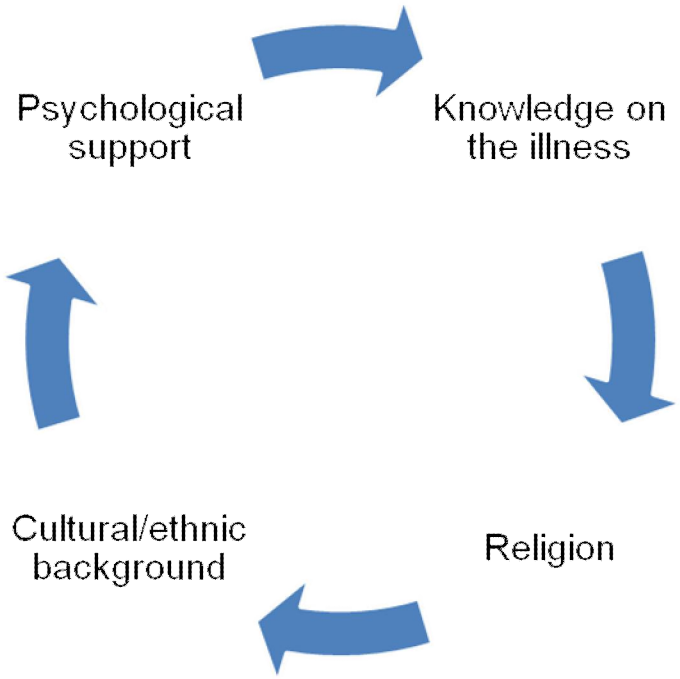
Cultural and ethnic background helps people to shape their own values and beliefs. However, like religious beliefs, all persons from particular culture may not share and practice the same values and beliefs (Morof, Lubkin & Larsen 2006, 438). Cultural aspects of health remain an important factor in developing countries despite an emergence of Western curative health approaches. A system is developed so that Western medical approaches have been incorporated alongside traditional approaches (Hitchcock et al 2002, 709-7109)

The influence on health/illness and the quality of life will be also related by culture and religion. Culture and religion beliefs may influence the post marital residence, household rules, family obligations, family interactions, dietary customs, health beliefs and practices. This means that some family may rather use folk healers believing that they are more powerful. Many cultures use home remedies of which are some compatible with medical treatment but some may be harmful and these remedies usually have no scientific basis (Muscari 2005, .5-6).

Coping through religion has been seen as multidimensional and many coping mechanisms have been identified in earlier studies on religion as a coping

mechanism. One of the examples would be seeking spiritual support is a spiritual/religion coping mechanism that achieves coping via searching for comfort through God's love and care (Pendleton, Cavalli, Kenneth, Pargament & Nasr 2002, 1).

Religion helps individual to develop effective mechanisms for coping with personal difficulties and stress. This means that religious coping include obtaining personal strength or support form God or Higher Being. After the conduct of clinical studies on religion as a coping mechanism in chronic illness it has been concluded that chronic illness may lead to renewed faith in God or higher power or might in some case even have devastating impact on individual's spiritual growth and sense of emptiness. (Young & Koopsen 2005, 231-232)




(Illustration 3. refer to coping mechanisms in facing the chronic illness)

## 7. SICKLE CELL DISEASE IN JAMAICA

### 7.1 Prevalence of the disease

Jamaica is the third largest island in the Caribbean with a population of 2.6 million inhabitants (World fact book, 2007). The island is one of a former slave colony under the British rules with imported Africans during slavery times. The population is made of 90, 9% West African origins, therefore like any other country with African descendants; Jamaica is very much vulnerable to the Sickle Cell Disease genes.

An issue of the national newspaper, the Jamaica Gleaner reported that there are about 375,000 people in Jamaica living with Sickle Cell Disease genes, and 15% of the population is at risk of having a child born with the disease. A person diagnosed with full blown Sickle Cell Disease is known in Jamaica as a sickler. (Jamaica Gleaner, October 2006).

### 7.2 Awareness of the SCD in Jamaica

Jamaica is now aware of the disease than larger countries around the world, because of the disease's prevalence. Parents and caregivers are wiser that they were few years ago in managing the disease. However, Dr. Graham (Sickle Cell week awareness, October 2006) pointed out that Jamaican teachers still have a long way to go where awareness of the disease is concerned because of lack of knowledge on the disease management in the schools; children are being sent home from school when a crisis starts. If there is no one at home to take care of the child at home, it can prove to be a fatal case. In the early days when a person was diagnosed with SCD people used to believe that it was like a death sentence because they know that there was no cure for the disease and the sickler was often sick, they felt that the person could not live long. Recent researches have revealed that many SCD's patients are now living well past their fifth decade which has produced

a change in the thinking and attitudes towards life expectancy of a sickler. (Jamaica Gleaner, October 2006)

When a child is diagnosed with SCD, parents are taught preventive measures in order to avoid certain complications such as: getting wet so the child does not catch cold because of weak immune system, pain management, fever controlling, importance of fluid therapies and eating a well balanced meal that is consist of plenty of fruits and vegetables. They are also taught the importance of palpating the size of the spleen on a regular basis because if the spleen is enlarged it can be due to blood sequestration which can easily lead to shock. They are also advised when to seek medical help during a crisis. Some parents may spend little time in reading the brochures, but when they visit the clinics, education is reinforced by health professionals as what to do and not to do. They know that complications associated with the disease can be fatal to their children if quick actions are not taken during crisis. (Sickle Cell Unit brochure acquired in 2006)

To prevent streptococcus pneumonia infections, babies are given prophylaxis: Penicillin V, the dose is 125 mg twice a day from four months to under 3 years old and 250 mg twice a day for above. Another alternative is to take injection of 1.2 IU of Bacillin every 3 weeks. Those allergic to Penicillin can be given erythromycin ethyl succinate at 20 mg/kg twice a day and this treatment can continue until the age of 14 years old depending on the effects of the illness on the individual. Pain management is also crucial at home.

### 7.3 Controlling the spread of the disease in Jamaica

In order to control the spread of the disease, the Ministry of Health along with the Sickle Cell Unit Trust of Jamaica are conducting a campaign educating the younger generation about sickle disease and about reproduction patterns. Their aim is to control the spread of the disease and eventually eradicate it so that sickle cell disease will be a thing of the past. The campaign involves brochures, leaflets, video presentations in schools, clinics and any other

relevant sectors that are associated with sickle cell disease. People of child bearing age are encouraged to get tested and find out if they carry the genes or not and if yes, what kind of help is available to them.
Pregnant mothers are also being screened for sickle cell traits and once the babies are born, they will be screened early enough to avoid fatal complications.

The laboratory of the Tropical Medical Research in Kingston, Jamaica is now carrying out genetic research using the umbilical cords of all the babies born at the University Hospital of the West Indies and at the Victoria Jubilee hospital for Sickle Cell Disease. (Jamaica Gleaner, June 1, 2006).

In a cohort study done by Dr. Graham Serjeant between 1973 and 1981, 307 babies born with SCD were studied and followed for survival rates. It was found that 61 of them have died before the age of 15 due to complications of crisis arising from SCD. It was concluded that the most feasible way to improve survival rates among sicklers is to establish a clinic where there are specialists who have knowledge of the disease and that SCD patients will have easy access to care and treatments at the clinic. (British Medical Journal. 1995, 1600-1602)

The Sickle Cell Unit clinic at the University of the West Indies in the Mona Campus in Kingston, Jamaica operates like a day hospital where sicklers come when they are experiencing crisis, they are treated and given medication at no cost during the day with the best Sickle Cell specialists in the island. If crisis arises during the night, patients have to be admitted to one of the major hospitals around the island or to the University hospital in Kingston.

In the Montego Bay area, Jamaica second largest city where our study took place, there is a monthly Sickle Cell clinic for the Western region. The same team of specialist from Kingston travels throughout the island and hold clinics once a month in different parishes.

## 8. AIM AND PURPOSE OF THE STUDY

The aim of the study was to find about the caregivers experiences in managing Sickle Cell Disease in children under six years old living in the Western Region of Jamaica.

The purpose was to provide information about some of the issues that affect caregivers in facing up to sickle cell disease. Hopefully the revealed information will create awareness for appropriate steps to be taken by health care professionals to help the caregivers cope better with the illness.

## THE RESEARCH QUESTION

What are the experiences of caregivers of children diagnosed with sickle cell disease in the Western Region of Jamaica?

## 9. IMPLEMENTATION OF THE STUDY

### 9.1 Method of Data Collection

Qualitative method was used in this research, Morse (1992) stated that qualitative research is appropriate to use when describing a phenomena about which little is known, and this method emphasises the understanding of phenomena from the individual's perspective. Qualitative research relies on reasons behind various aspects of behaviour such as the why and how for decision making, in contrast to quantitative research which relies on what, when, and where. The difference between the two is that qualitative is explanatory while quantitative relies on analysis of numerical or quantifiable data. Hence the need in qualitative study for a small but focussed sample (Fain 2004, 225).This research seeks to present the lived experiences of parents in relation to a chronic illness in the hope that the outcome will be a full, rich descriptive view of their experiences in relation to the phenomenon. It can be a journey of discovery for both the researcher and the informants revealing areas and ideas that were not anticipating at the outset of the research.

The data collection was taken from five families who were attending the monthly clinic held at the Cornwall Regional Hospital in Montego Bay which is situated in the Western Region of Jamaica. Convenience sampling was used in this research because of the ready availability of the informants for the researcher. In using a convenience sampling, data collection can be obtained from whoever is available to take part in the research once they fit the criteria required; it saves time and money (Fain 2004, 112). Therefore, it was the best way to obtain information needed on spot when patients and caregivers came for their monthly check up at the clinic

The research was conducted on June 28$^{th}$ 2006 in one of the room assigned to the monthly sickle cell clinic at the Cornwall Regional Hospital in Montego Bay. The data collection was done using focus interview. Interviews and

observations are common method of data collection in qualitative research (Fain 2004, 163). This type of interview will allow the informants to speak freely and describe what is important to them using their own choice of words. A focus interview will allow the researcher to probe for more details and make sure that the questions are interpreted the way they are supposed to (Fain 2004, 162-165). According to Radcliff (2003), the interview does not have to follow a strict pattern as long as the researcher can obtain valid qualitative data from the interviewees.

The interviews were done face to face using a mini video camera, and each interview was scheduled to last between 25 -30 minutes , time was of essence due to the fact that the informants were waiting to see the doctor. The informants were informed at the beginning that their interviews will be taped recorded. But the researcher unintentionally failed to tell them it will be with a video camera. According to Radcliff (2003) video-taping can be used to document a qualitative research, in this case it will provide evidence that the research was actually conducted or document reactivity to the researcher's presence. But this was not the case because the mini video camera was used more as a voice recorder than a filming device.

Due to the fact that the camera was so small, it did not intimidate the participants. The researcher explained to each informant at a time when they took place at the interview table that filming is not a part of the interview process; the camera will be placed near their mouth so that it will record their voice clearly during the interview. The camera filming lens will be turned to the wall so their identity is not revealed. The researcher explained to them that the mini camera was the only available tool that she had for her interview. If they feel like the researcher is not respecting her part of the bargain, they can ask to stop it or be excused from the interview. There also was a portable computer on the other end of the table which was used to transfer data from the camera to the computer once the memory card from the camera was full.

The formulation of the questions for the interview and the gathering of the data were done by only one of the three researchers because she was the one on location and has been doing her practical training at the Cornwall Hospital in Montego Bay, Jamaica. That particular researcher has taken an interest in the Sickle Cell Disease due to the fact that she has been working on a medical children ward at the Hospital where she became familiar with the disease, and has also been observing the reactions of the caregivers in relation to the diagnosis of certain chronic illnesses.

The interviews took place in the quietness of one of the hospital clinic rooms assigned to the Sickle Cell Unit team during their monthly visit from Kingston. The room was a well equipped examining room which suited well for the interview because of the privacy that it provided to conduct the interview.
It was not without any noise but, according to Patton (1987) there could be pitfalls such as: outside interruptions which can create distractions during the interview; it is up to the interviewee to overcome those pitfalls; rephrasing or repeating the questions can lead you back on track; whatever the informants were saying could not be heard outside of the door. During the interview, pitfalls came in the forms of children accompanying their parents in the room getting restless; therefore those parents tend to be side tracked if the interviewer did not repeat the questions over for them.

### 9.2 The Informants

While a group of about 30 patients and caregivers were waiting for the clinic day to begin, the researcher went to the waiting area, introduced herself and gave a brief description of the aims and the purpose of the research and the research's criteria for participation. The group was informed about the length of the interview, the place and the manner in which the interview will be conducted. It was a voluntary choice, no pressure and they are free to withdraw from the interview at any time.

The criteria for taking part in the interview are as followed:

- The child must be in the range of 9 months to less than six years old.
- The child must have been hospitalised at least two times due to crisis resulting from the disease.
- The informant must be primary the caregiver for that child.
- The family must be resident of the Western Region.

The criteria are based on the fact that the first crisis usually appears when child turn six months after the postpartum. Strokes in Sickle Cell Disease are the most serious complication associated with the disease and that it affects the youngest children. The highest incidence of stroke occurs in the first 10 years, but the most critical are between 2 and 5 years of age and many trips have been made to the emergency room due to crisis. The crises are precipitated by infection, possible dehydration, fever, exposure to cold (Muscari 2005, 207-208).

Comments presented on ethical consideration was reviewed in the Workgroup of European Nurses researchers (1998) ,study which was presented in the works Benociel (1988), Latvala et Janhonen (1998) suggested that essential ethical questions are concerned with personal privacy, respect for self determination, and informed consent. Our informants were introduced to the topic for the research in a group and it was their free choice to take part in the interview or not.

Participants were given about half and hour to think and decide whether or not they would like to take part in the interview if they felt that they fitted the criteria mentioned above. They could name themselves as participants and sat on chairs provided outside the interview's room door.

Once the participants had decided that they would take part in the interview, the Sickle Cell Disease clinic's staff was notified of their participation in the interview so that when their turns to see the doctor came there would not be a problem. If the informant was being interviewed while their child's name was called, then the doctor would take the next available patient, providing that the informant after completing the interview will be next in line to go in the doctor's

room. If their name was called while waiting to come to the interview they would go in to see the doctor and come to the interview afterwards.

Morse (2002) stipulated that participants in a study must be willing and able to provide information about the phenomenon after informed consent is obtained. In the waiting group, the researcher was fortunate enough to have one married couple and four female caregivers as voluntary informants. The researcher had not met the four mothers before the day of the interview. She, however had met the couple before while working on the children medical ward when their son was being treated for sickle cell crisis, ant it was a good occasion for her to get their views and feelings where the disease is concerned.

## 10. DATA ANALYSIS

Data analysis was done using content analysis which is the procedure of analysis and organizing non structured information into a standardized format. Holroyd (2001,1) stated that it is important that researchers read carefully over and over the entire data to gain a wholistic view which will allow them to understand better the lived experiences of the subjects. It is good to examine units for redundancies, clarification, or elaboration and, relating meaning units to each other will help the researcher acquire a sense of whole (Fain 2004, 230) in relation to Giorgi's (1970) method of analysis. The refined data will be an essential source to pick up themes relevant to the study.

The three researchers had set a date, time and place to listen to the said data recording. Throughout the listening, the three researchers were trying to analyse the data in order to reveal themes that were important to the study. Due to the fact that the data was recorded in the Jamaican language half patois and half English, it was difficult for two of the researchers who were not used to the Jamaican language to understand certain terms. So the researchers decided to analyze the data when it is transcribed. A week later the data collection's researcher presented the verbatim transcription to the other two researchers. This time the raw data provided a clearer picture on the interview. The transcription of the raw data generated 8 pages which were in 1 pt line space.

After the researchers have read the material into the Standard English language and decisions have been agreed on the steps to follow in analyzing the material. (1) Read the material to obtain an overall impression and bracketing previous conceptions; (2) identified essential features of the data and described interrelationships among various themes discovered (3) condensing and summarizing the contents of each of the themes; (4) generalizing descriptions and concepts concerning the experiences on managing the disease and coping mechanisms, quoting exact words in their lived experiences, (5) focus on the usefulness of the findings which can be useful for clinical practice.

Each one of the researchers have had a copy of the raw data collected, therefore after careful  and intensive reading, the researchers met to discuss their feelings about the material and how they perceived it. It was not easy for all of them to agree on the themes that are relevant to the research, but after much discussion a consensus was reached as to what is good to focus on.

In analyzing data, researchers have to bracket out any prejudgement, or ideas that they have had before in order to eliminate biases. Cohen (1987) stated that by bracketing out prejudgement, the researchers can be accurate receptors of the phenomenon.

Only one of the researchers had a good knowledge of the population under study, because she has lived into the Jamaican society for over 10 years which could allow for some biases in the study. The researcher knew about their lifestyle and what are their common coping mechanism could be in a powerless situation. This could fall into agreement with the argument presented by Bergum (1999, 55-60) about “bracketing out” prejudgments and ideas, he quoted that “a researcher’s own experience is an important source of data and a guide to analysis. But the researcher chose to put aside any preconceptions and ideas about the phenomenon and let the data speak for itself in order to facilitate reflexive awareness.

Although the Jamaican patois is not standard English language however, all of three researchers were able to grasp the meanings of the words expressed after it was transcribed. The Jamaican language used into the findings will provide the readers with an idea of the exact words used during the interview. Elimination on redundant or repetitive words that are not important was done throughout the process such as manifestation of the disease in the child, workplace policies, or the kind of help that they are expecting. Yet, this did not alter the essentials of the description.

At first, to facilitate order during the transcription, each interview was sorted using coding techniques such as: interview# 1, interview #2 and so on. Later on, they were grouped as family unit than as objects referrals. The transcripts were then divided into discreet segments of expressions of the participant's experiences. The elimination of redundant or repetitive words which were removed did not alter the essentials of the descriptions.

Major Themes have been identified and under each theme they were sub categories which came from the informants answers to the thematic heading. The Major themes arising from the analysis are:

Knowledge of Sickle Cell disease

Management of the disease

Perception of the disease

Psychological effects on the caregivers and family

Emotional coping mechanism

Ability to cope financially

Reproduction Consideration

## 11. FINDINGS

### 11.1 Knowledge of the Disease

When attending the sickle cell clinic for the first time, caregivers are given a very clear and printed brochure about the disease and how to manage the disease at home. Therefore with that, one is expected to know the basic facts about the disease and how to prevent some unwanted complications.
Parents reported that they are aware of the disease since their child has been diagnosed. Their knowledge comes mostly from education and reinforcement from doctors and nurses at the clinics.

*"Well.....a dont know much about the disease, but when a took him to the clinic, i try to get more information from di dokta about the disease".*

We however found that some caregivers had a need to get more informed about the disease besides what the advices they received at the clinic. One said that she reads books while the other one said that she used the internet to get more acquainted with the disease. She identified the disease as a problem that needs to be dealt with and therefore she must prepared herself in facing up with the situation.

*"I have searched the internet and read books about it...i have invested expensively on educating myself about the disease...I have done extensive reading as well"*

*"One caregiver admitted that she does not read the brochure, her knowledge of the disease only comes from the medical staff of the sickle cell clinic.*

*"Apart from what they tell me in the hospital about the disease, i have no more resources".*

### 11.2 Management of the disease at home

Education is essential in helping to improve the quality of life of any sick person; therefore parents are taught how to manage the disease at home before they can seek medical help. Caregivers reported that they give pain killers when the child is in pain whether in liquid form or in tablets. They tried to make sure that the child always has enough fluids to drink and using lots of vegetables in the child's diet. When a crisis arises, the best thing is not to panic just remember what they have been taught at the clinic. If there is a fever of over 38 degrees and home management is not helping, so they have to rush to the emergency room with their child. First aid medication is either the Panadol liquid, aspirin or other children tablets. It is handy to have them at home all the times just in case there is a crisis.

*" When she have the fever, mi mus give har aspirin and some other medicine that them tell me".*

*"When him get sick, i do not panick, I know what to do. The last time him come from school and was complainin bout pain, a know exackly what to do for the pains that him did have, a give me di tablets".*

Other home management included therapeutic remedies such as sponging bath to reduce the fever, massaging the enflamed area. and making sure that the child is very comfortable in bed and has plenty of liquid to drink

*"i sponge her down and take temperature and I write down at what time i take the temperature and what was the result"*

*"... if di feva not getting down..take her to the hospital, if she in pain, a mus give har cetamol and cataflan, she must drink plenty of juice and give her lots of vegetables*

The only male caregiver in the group replied that:
*"... massage in the affected area, a also apply warm water in the affected area, give him fluid as much as he can take".*

Cold is a factor that can precipitate crisis, therefore it is always wise to make sure that the child does not get wet in cold water.

*"dem tell mi she musn't get wet, coz they bawl for pain"*

Besides those therapies, caregivers are also taught how to palpate the spleen. Each morning they would put the child of his/her back or standing position and start to feel for the size of the spleen.

*"Dem tell me if the spleen is larger than normal, mi mus take har to the hospital".*

**11.3 Perception of the Disease**

All the parents reported that they know that there is no cure for the disease. Good management is vital in order to avoid complications. Many of them have the idea that their child lifetime is going to be short. Some of them have reported that friends and families have been talking about other people that they know who have died early from the disease.

*"When mi tell people about it, them tell me that mi child na go live long, coz she ago dead soon. Coz this disease kill people"*

*"Having the disease means that i know it is a possible that she could die before her time especially when she was small...."*

However one mother felt she has to reduce her time at work and focused more on the child and the disease. She needs to be monitoring the disease progress in the child's life.

*"It means that I will have to cut back on the hours at work and make more time for my child...be more vigilant".*

*" I know that there is no cure for blood born disease"*

Since in Sickle Cell Disease patients, haemoglobin level is most is most of the low, one caregiver felt that she must make sure that the son has all the iron loaded food to eat in order to raise the haemoglobin level

*"....mi know that wid dat disease, people have low blood ,so mi give him all green thing such as callaloo, kidneys and some juice things like soursop so him blood can get higher*"

**11.4 Psychological effects on the caregivers and the rest of the family**

Many caregivers expressed fears at the outcome of the disease they do not know what will happen to their child. Depression has been most outlined when it comes to psychological effects. They think about the cost of prescribed medication, the cost of hospitalisation, the financial strains that the illness has put on the family, and also the growth of the child in years to come. The fears come mostly when the child is in the hospital and that mothers are the one who have to take care of them and at the same time maintaining a balance between caring for their sick child, running the household with maintaining a job. They also considered the effects of the illness on the other children at home, therefore they have to be strong and positive to face up to the disease.
Many of the informants expressed their emotions as "depressed" especially when the child is hospitalized, sad because there is no cure for the disease.

This can all be related to fears and anxiety as to the possible worsening of the situation.

*“Uhm..... (pensive).....depressed..depressed. Sometimes.....when mi sit down and think about it, mi get fret, and ask miself, how long she ago live, how wi ago pay for all them treatment.....*

*“..a got scared when she inna hospital, she can get worse, I dont know if she will make it. The last time she was inna di hospital, her blood count was low and dem told me if a she dont get the blood she gonna die”.*

*“ a worry sometime coz she a start school in september .....”*

Or about the child growth, if the child is going to be a normal child

*.”..is she going to be normal like any other child. A worried when she gets sick, she might die”*

The other children at home have to be considered as well, although mothers are concerned for the sick child, but they have to be strong in order to keep the family together and to provide for them.

*“ I have two other kids to care for, she is the last one and she is the only one who has it....i must be strong for har*”.

*“...She have been three times in a hospital since she is born, she is three years old now..... it is as if every year she is inna hospital, the first two times was 8 days.*

### 11.5 Emotional coping mechanism

Prayer is a most common coping strategy that parents have used to help them cope with the disease. Praying provides caregivers with inner strengths, hope and comfort in order to stay positive throughout the course of the illness. They think it is God's will that the child comes across the disease. They feel that any hope for the disease will be coming from above, Therefore families and friends will join up in prayer for the recovery of the child.

*"Me man, mi just pray and trus Gad to help me inna dis situation coz mi no know what fi do".*

*"Well, am tryin to cope as you can see...a pray a lot a hope the Lord will help me. When she is not in a hospital, I am OK.. I cannot say too happy coz I know that anything can happen any time..but I give Gad thanks that she is Ok right now"*

*"Staying positive is not easy. We wait unto God to do what his will. We are depressed when he is in the hospital".*

### 11.6 Ability to cope financially

All of the caregivers interviewed hold some kind of a job, and we found that three of them are holders of a health card. They are all able to buy the non-prescribed drugs such as paracetamols and aspirin among others. But when it comes to hospitalisation's bills associated with prescribed drugs, parents have expressed fears of not being able to cope easily. There are other mouths to feed in the house, bills to be paid, some of them are living in renting houses, therefore the cost of care of the disease do add financial strains on the family budget. Many of the mothers have said that there is a father at home who is working as well, but mothers are the ones who have to time off their jobs in

order to attend clinics with the children and they are not being compensated for their missing days at work.

*"Financially, I can cope with buying the medications at home, but when she ina hospital it is different stories coz when she get release from there, there is always big bill to pay..."*

*"mi no have no choice, where the money is mi must find it".*

*"Financially, a try to cope, the last time a come here, a got some tablets fa him an a pay.....$700JA fi them...not too bad..a try my best to buy dem.*

One caregiver wished that she could register her son with the National Health Funds

*" A try to register him with di NHF (national health funds), but a do not see sickle cell on di form".*

Caregivers who are holder of a health card are able to manage better than the others. The health card covers 80% of the cost of care.

*"Boy!..... it's not easy, tru a work with the government a have the healthcare and that help me..a only pay 20% of the cost of medication with the health card.*

*"Financially, we can cope, I (the mother) use the health insurance card to cover some of the cost, need to have some other resources for back up".*

**11.7 Reproduction Considerations**

Many mothers felt that in knowing their child has the disease, it raised some awareness to them in regards to reproduction. If before their child has been diagnosed they had tried to ignore the fact that they are carriers of the sickle cell genes or have the trait. Now, this situation is like a wake up call for them as to what they should do in the matter of future pregnancies. Some mothers have found out that more than one person in their families have the sickle cell genes besides the Sickler. None of the mothers reported any fact that their partners should be tested, they all felt that the responsibilities fall on their shoulders where having other children is concerned. Those women who have had children with different fathers, did not give much thoughts about their reproduction or family extension.

One female caregiver reported that when you date or fall in love with a man, the last thing on your mind is to ask whether or not the man has the genes or is HIV positive. The consequences for ignoring this health related behaviour can be detrimental to the woman or to her entire family unit. One of the mothers has had children before and after her son has been diagnosed with sickle cell disease. That same mother did not expressed any particular consideration where having more children is concerned.

*"Him a fi different fada, that why him a di disease, mi other children dem not have di disease"*

Two caregivers have reported that apart from the child diagnosed with the disease, they have had another member of their family with Sickle Cell trait. Therefore that prompts them to pay attention to reproduction in the future. One mother thinks that she is now 35 years old, it is a considerable age to stop having kids especially if they are likely to be born with the genes.

*“I do not think that I will have any other one. I already have two. This one has the full disease and I find out that my first son has the trait. I will not take chance anymore, even though the second one has not been test as yet*

Fears of given birth to another sickle cell child also have played an important role in two of the mothers’ decisions not to have other children.

*“And a afraid that the next child might be born with the disease too and a don’t want that”*
*“not putting at risk another gift from God”*

The women are given considerable thoughts about their reproduction behaviours.

**11.8 Satisfaction with the received services**

Caregivers have reported that they were truly satisfied with the service that they get from the heath care teams whether in the hospital or in the Sickle Cell clinic. As a matter of fact they are of the opinions that the staff really takes good care of their kids and that they enjoy a good relationship with them.

*“well mi think dat dem take good care of har here””*

*“They have been so helpful to us since our child has been diagnosed.”*

Even though the caregivers are satisfied with the services of the clinic, there is still room for improvements for reinforcement and better home managing of the disease.

## 12. DISCUSSION

### 12.1 Evaluation of the research

Bennett (2002) stated that data from qualitative studies are subjective and incorporate the perceptions, beliefs of the research and the participants. The aim of this research was to have descriptive facts on the experiences of parents of children living with Sickle Cell disease. This approach was chosen because it was the best way to report the lived experience of the participants. Researchers need to formulate their questions in simple language that is not considered as a jargon to the informants, asking good questions involved specifying good answers. (Fain 2004,147-149)

The guiding sources for the formulation of the topics were the Sickle Cell Unit Trust brochure on Management of the disease, along with an article read from the Jamaica Gleaner - Flair section ( 2004) where a couple who have had their first child diagnosed with SCD mentioned how the counselling and support they received from the staff of the Sickle Cell Clinic of the University of the West Indies in Kingston have helped them to cope in facing with the disease.

Fain (2004, 233) refers to **credibility** of findings as faithful descriptive or interpretation of the lived experience. The findings must be recognized by the informants as an accurate description of their own lived experience. Since there was not time to go over the interviews with the participants and amended their answers if needed, we could not have filled that side of the study. However the interviews were taped recorded, and the researcher has reported the exact words of the participants in the study about their experiences in managing the disease, even some intonations were also reported. The themes were designed using a language that is clear enough to be understood by the everyday people. If during the interview an informant could not understand a question, the researcher was able to clarify or rephrase the question in order to get an appropriate answer.

The researcher has tried her best to put the informants at ease, by making small talk before the interview. Due to the fact that the researcher was wearing a nursing uniform, the informants did not feel like the researcher was out of place, so there was a certain confidence during the interview to express themselves freely. We cannot say that we are a 100% sure of what the participants have said were true because they might said what they thought the researcher would like to hear. But we have to give them the benefits of the doubt.

The **transferability** of a research refers to the degree to which the results from one study can be generalised of apply to other settings (Libarkin and Kurdziel 2002, 197). The data gathered from five families is not sufficient enough to sustain this goal in regards to other settings. Some families have been through a more serious situation than others and we may not have had the chance to meet them. Future research would have to be done with a larger sample in order to support the theory about transferring the data of this study to other settings. We could also argue that most parents with chronically ill children experience the same kind level of stress when it comes to hospitalizations and the cost of care especially in a low income family.

McCartney (2005) suggested that the **dependability** of the research rests on the consistency of the gathered data. Our research took place a year ago, and since then, there have been changes into the health care system in Jamaica. On May 28, 2007. The Jamaican government has decreed that children under the age of 18 years old are entitled to free healthcare, which means that parents do not have to worry any more about paying for hospital bills if their child is admitted to a normal government hospital. However the fact remains financial strains were not the only issues in this study, there was also emotional issues when facing with a disease that could be fatal to your child. Even though the financial burdens would have ease up, but the emotional needs still remain unmet.

Kirk and Miller (1996, 87) suggested that there are three components that are essentials to the reliability of a study: repeatability, stability over time, and similarity between measures. We could try to measure the dependability of the study by repeating it again, it is likely that we would not get the same answers, because it would have been two different studies with two different group of people.

The **confirmability** of a research refers to a certain degree of objectivity to the study and free of potential biases. Trokim (2001, 363) suggested that the researcher can use more than one persons for checking and rechecking of the document. Even one of them can play the devil's advocate role in respect to the study. Our research team is comprised of three persons and all of the researchers were examining the data collection and looking for relevance to the study.

**Ethical consideration** is needed in order to conduct a research in an established institution, permission has to be sought from the Ethical board of directors which has the right to grant request for conducting research in the institution (Fain 2004, 35). In this study the researcher has sought permission from the Cornwall Regional Hospital Ethic Committee and had informed the indented informants about the interview and that it is a voluntary choice.

Two weeks before the interview was conducted, the researcher had an audience session with the Matron of the Hospital discussing her intentions to conduct a research on the sickle cell topic. The Matron in turn asked her to put her request on paper so she can discuss it with the Ethic Committee Board. A week before the interview, the request letter was drafted and presented to the Matron requesting permission to conduct the interview in a said day and time set by the researcher (appendix 1). Due to urgency of the situation, permission was granted verbally by the Hospital Matron who is a member of the Ethical Committee, and then promised that later on the formal undersigned permission letter will follow.

The researcher left without the undersigned returned letter in her country of residence. After many e-mails and phone calls requesting that the undersigned letter be returned by fax to a choice of two fax lines, the researcher was asked to send again the original letter by e-mail to the Hospital Chief Executive Officer, because the original letter was misplaced, could not be found due to the fact that the letter has to be passed from one head of department to the other. So the original letter was again e-mail to the CEO, who weeks later send few words by e-mail saying that permission was granted (Appendix 2).

### 12.2 General Findings

Sickle cell disease affects 10% of the Jamaican population and one in every 150 births are diagnosed with the disease. The research revealed that the caregivers are well aware of the severity of problems associated with SCD.. They know what the first aid management is when the child gets into a crisis at home before they take the child to the hospital. They know that preventive measures and good management of the disease is of vital importance and that complications can result in fatality. Jamaican has long been suffering from the disease and this time they want to be trying to educate more the population about the disease.

The perception of the caregivers to the disease is the stigma attached by “well wishers “neighbours who will fill their heads about the child will die soon. But the healthcare team has tried to erase those thoughts out of their mind; caregivers have learnt that even though there is no cure for blood disorders, regular treatments will help a great deal (Smeltzer & Bare 2004, 887-888).

Educating oneself about a disease makes you better prepared to face up with the challenges associated with the disease as it is stated in one of the studies by Holaday (1989) Lazarus & Folkman (1984), Mc.Curbin & Peterson (1983). The health care team has been doing their best to educate parents and

caregivers about proper management at home. The research showed that caregivers have fears of the unknown, therefore using other sources to gain deeper knowledge of the disease may help them cope better

Pain and fever are the most common form associated with sickle cell crisis in the house, they have been taught that quality of life of the children depends on good management of the disease (Bloom 1995, 69-73).

Proper nutrition and fluid intakes are vital for a sickler (Reid, et. al 1997, 38). The research proved that caregivers understand how important good nutrition and fluid therapies are especially when the child gets into a crisis situation. They make sure that there is always some sort of juice in the house since most children do not like water.

When the child is sick or is hospitalized, the mothers as primary caregivers are worried. They are concerned about their finances, their jobs are being jeopardized, and there is also the mental well being of the family. According to Wilkinson (1998) chronic illness in a household can contribute to family stress, the research reported that caregivers do experience stress and for some of them it has been hard to balance both the healthy children life and the sick child's life. Sometimes siblings can be resentful. Mothers have to be strong enough to support and balance both their family lives and their jobs. The primary caregivers are the ones who would take time off their jobs in order to attend clinic days with their children.

All the caregivers in the study mentioned prayer as coping strategies; whether they attend church or not .It is a source of strength for them during difficult periods. Many of times friends and extended families join into the prayer chain which constitute a form of support. When people are facing with a challenging dilemma the best way to stay afloat is to find some sort of coping mechanism or strategies that could prevent breakdowns Pendleton et al (2002, 1) suggested that it is good for a group of people to seek spiritual guidance as a coping strategies. However the research reported that positive thinking makes them strong and hopeful as well. Parents are hoping for a cure one day. Even though they do not have any idea when that cure will come but they remain

positive that their child will not die from the disease and they are cooperating as much as they can with the healthcare team for the success of a cure.

Other issues in coping with a long time illness is the matter of financial issues, such as direct costs for in patient and out patient medical treatments, transportation, and indirect costs such as a loss of income and career opportunities. All of these factors are enough to put strains on the family finances and causing stress. Whether they live below the poverty line or not they all made the effort to provide for their family and taking care of the sick one as well. The cost of care is very much a matter of concern to the parents.

Aside the fears that their child conditions could take the worst turn when in hospital, there is also lack of abilities to pay the hospital's bill which can amount to high fees that parents without a considerable good income are not able to pay instantly. Many regular workers have a health card which covers a certain percentage of medical cost, but is it enough? Unlike many common chronic illnesses in Jamaica where the NHF (National Health Funds) covers the cost of medication, Sickle cell Disease was not found on the list, therefore mothers with low income salaries were faced with a big problem if there are prescribed drugs to buy while a child is in hospital. Even with the health card, parents were still hoping that it could help a great deal if they could get some sort of financial help.

## 13. IMPLICATIONS FOR FUTURE RESEARCH

The study was conducted primarily as a personal interest and curiosity for the field researcher, but it has revealed itself very useful, because the knowledge on how the parents are managing and coping with the disease will help health are professionals put a bit more emphasis on the parent's psychological status. The small sample study cannot reflect the views of the whole population in the Western Region of Jamaica. A larger sample can be considered and this time using an advanced letter informing the participants of the study in order to give them time to be ready.

Another recommendation for further research could be on the subject of reproduction. Couples who are planning to get married can get screened and find out if they have normal or abnormal genes and in the later what are the choices that they have where reproduction is concerned.

## 14. CONCLUSION

The research had for aim to bring out the experiences of the caregivers in managing and coping with the diagnosis of Sickle Cell Disease in their children. It has showed clearly that parents have a good knowledge how to manage the disease at home efficiently in order to prevent complications. Continuous reinforcement is good for them because caregivers are not likely to forget about the teaching received at the clinics.

This study has also showed that there is a need for medical staff to offer supports to the parents because of family mental well being. The chronic illness of the child has created very difficult situations for parents especially for mothers whether in a relationship or not. There is no way to estimate how the illness has affected the different families, because some families have been through a lot more than others depending on how severe the disease is present in their child. This study has only sought to bring light to the various aspects on how the disease affects the caregivers and their families.

The caregivers in the study are in great need of psychological care and support in order to prevent emotional exacerbation. A support group would offer counselling, advice, and sharing of experiences with each other. The support group could also help to alleviate some of the stress that parents are faced when the future of their child remains unclear. Each member would be able to feel that they not alone in the battle against this disease.

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## 15. APENDICIES

### Appendix 1:

### 15.1 Request to carry out the research

June 19, 2006

To the CRH Ethic Committee
c/o Matron M.V. Byfield

Dear Sirs,

During my training here at the Cornwall Regional Hospital, I have become familiar with the Sickle Cell Disease that is found among Afro Caribbean population. I have learnt that 10% of the Jamaican population are carriers of the sickle cell trait, and that there are a number of people who are born with the full blown disease. With that information in mind, I have decided to conduct a small research on how parents are coping with the disease in the island.

According to the brochure published by the Sickle Cell Trust in Kingston, most serious complications occur in the first 2-3 years of life; therefore parents play a crucial role in the successful management of children during that time. In an article published in the Monday Gleaner dated October 11, 2004; a young couple living in the Kingston area talked about their struggle in facing with the diagnosis that their first born had Sickle Cell Disease.

My aim is to find about the experiences of some of the parents in the Montego Bay area who have children suffering from Sickle Cell Disease; their coping skills and abilities to face the disease which could be life threatening to their child and also their expectations where treatment is concerned.
I would like to interview a few of the families or carers for children in the age range of 6 months to five years old. It would be done on a voluntary basis and the interviewees will be given background information regarding the interview.
It will be a 20 -25 minutes semi structured interview which will be recorded, transcribed and destroy afterwards to safeguard the identity of the respondents. The date chosen for the interview will be on Wednesday the 28th of June 2006.

Thank you in advance for considering my application

Serette Kesola (student nurse)
Jyväskylä University of Applied Sciences)

**Appendix 2:**

**15.2 Permission to carry out the research**

From: Serette Kesola Friday - April 13, 2007 1:01 PM
To: crhospital@yahoo.com
Subject: Vs: Re: FW: Application!

Thank you very much, but I would like to have the request application fax back to me. So I can show it to my project tutors at school.
Best regards
Serette

>>> cornwall regional <crhospital@yahoo.com> 12.04.07 20:06 >>>

Dear Miss Kesola:

With reference to your request to conduct the interview as outlined in your email, please be advised that permission is granted for you to conduct same.

**Appendix 3:**

**15.3 Letter of introduction to parents/caregivers**

University of Applied Sciences
School of Health and Social Care
Jyväskylä, Finland

Dear parents and caregivers,

I am a nursing student of the above mentioned institution who is practicing in Jamaica for a three (3) months period of time. I have practicing on the children's medical ward and I have gotten familiar with the Sickle Cell Disease and I have taken an interest in the disease. I have consulted with two of other colleagues and we have decided it will be a good idea to get some views from parents and caregivers on the disease and how it affects family life. This means that this information will be shared with the other two colleagues who are not present at the moment.

I would like to conduct a small interview with you in order to find out about your experiences and how you cope with the illness of your child and your hopes for future treatment. The interview will last 25-30 minutes, it will be taped, transcribed and afterwards destroy in order to safeguard your identity. The interview will be conducted in the quietness of one of the room that is assigned to the sickle cell clinic or at your convenience.

Sincerely yours,

---

Serette Kesola on behalf of Biljana Milosavljevic & Tin Min Shain

**Appendix 4:**

**15.4 Themes questions:**

**Knowledge of the disease**

- For how long has your child been suffering with Sickle Cell?'
- How much do you know about the disease?
- How often is your child hospitalized?

**Management of the disease**

-Do you know what to do when one of the crisis arise?
-Do you know what to do in order to improve the outcome of the disease?
-Have you been taught how to assess your child before you take her/him to the hospital?

**Perception of the illness**

-What was your first reaction when you leant about the diagnosis?
-What does having the disease mean to you?

**Emotional coping mechanism and emotional weakness**

-How do you cope emotionally when the child takes ill?
-Describe your feelings about the whole situation?

**Financial strain and financial coping**

-Financially, how are you able to cope with the cost of medications?

**Reproduction consideration**

**-**Would you consider having another child knowing that the next child risk having the disease as well?

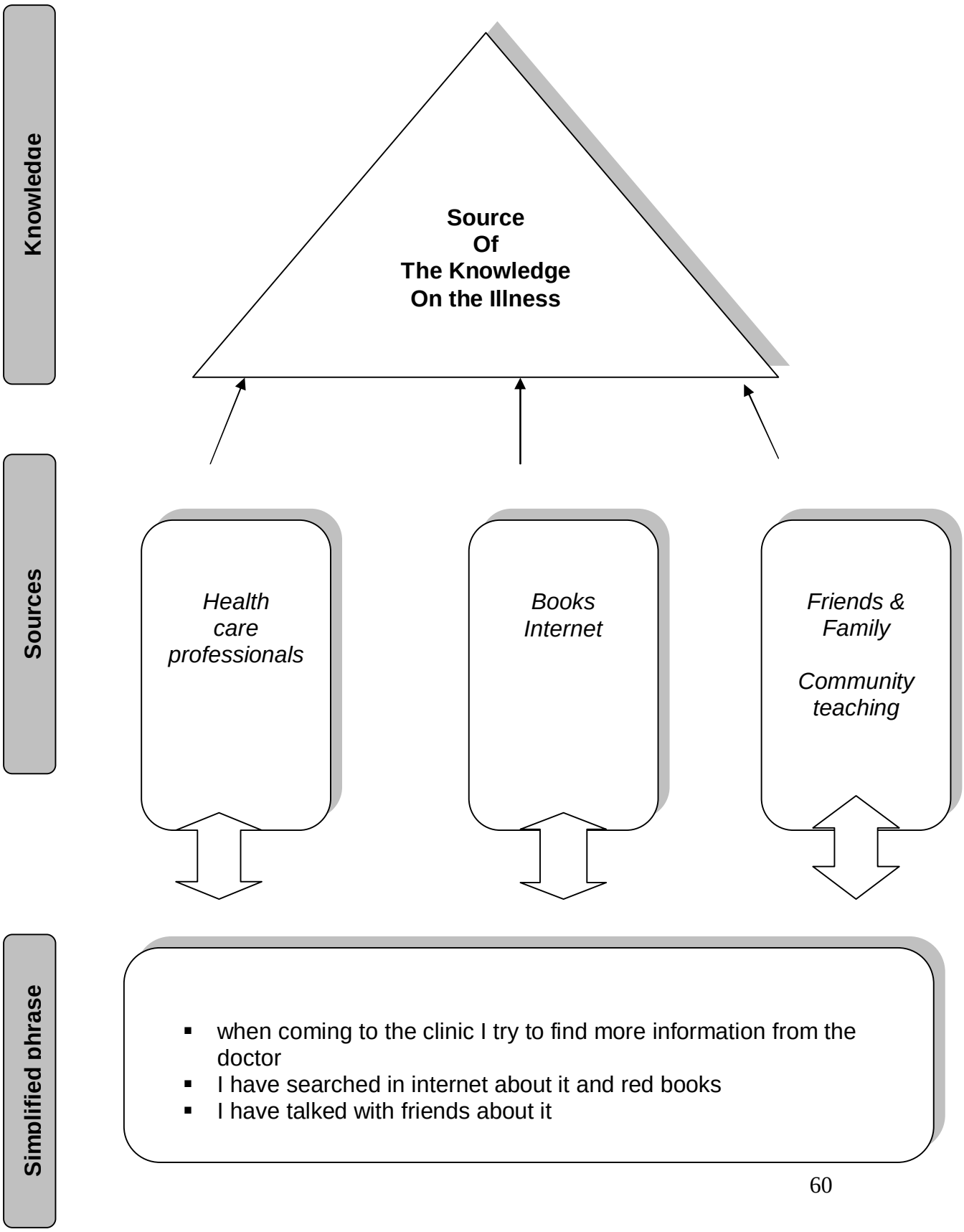
**Satisfaction with the Service received from the health care team**

-What is your opinion about the level of treatment that your child gets at the hospital or at the clinic?

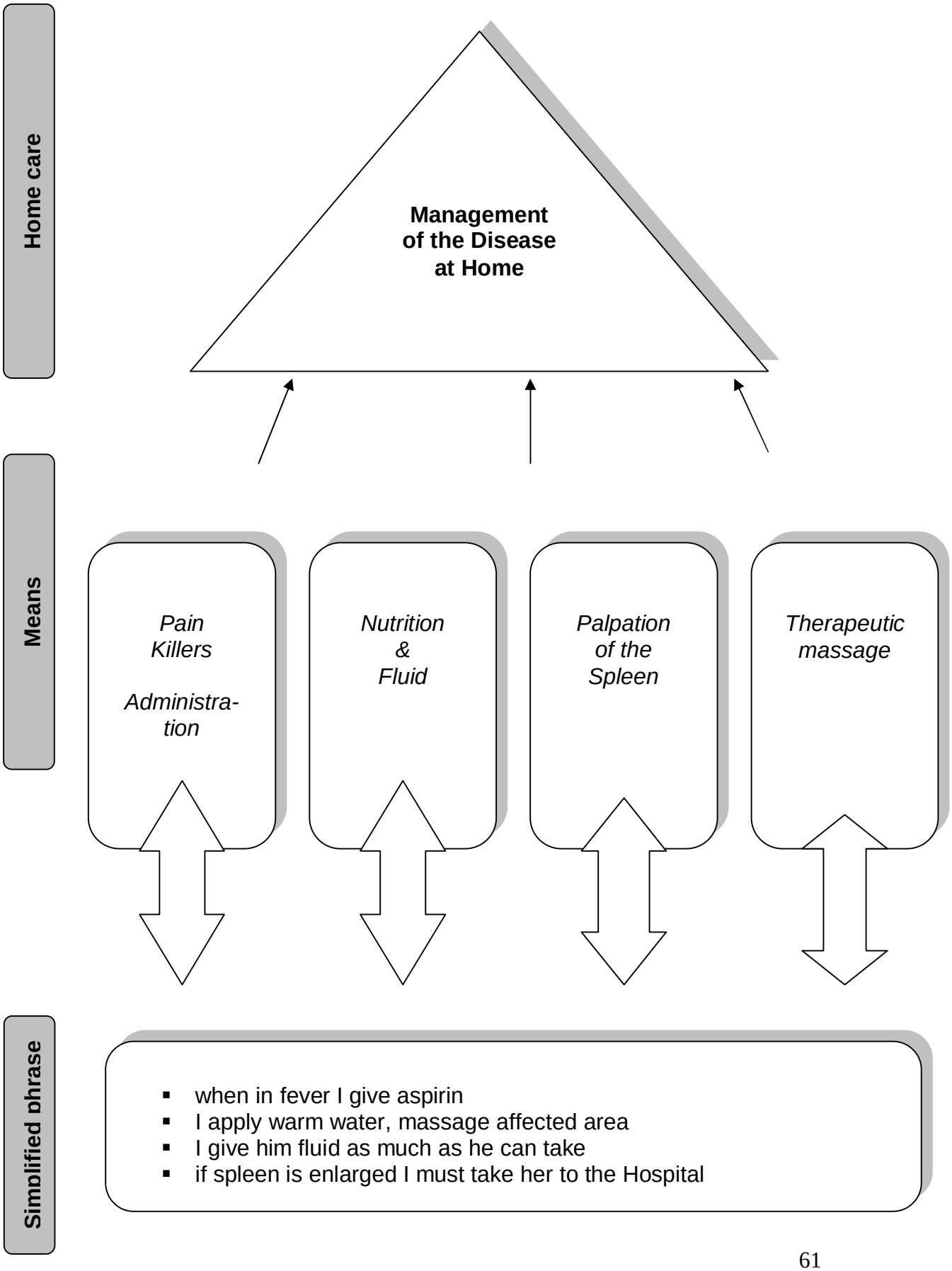
**Appendix 5:**

**15.5 Themes**

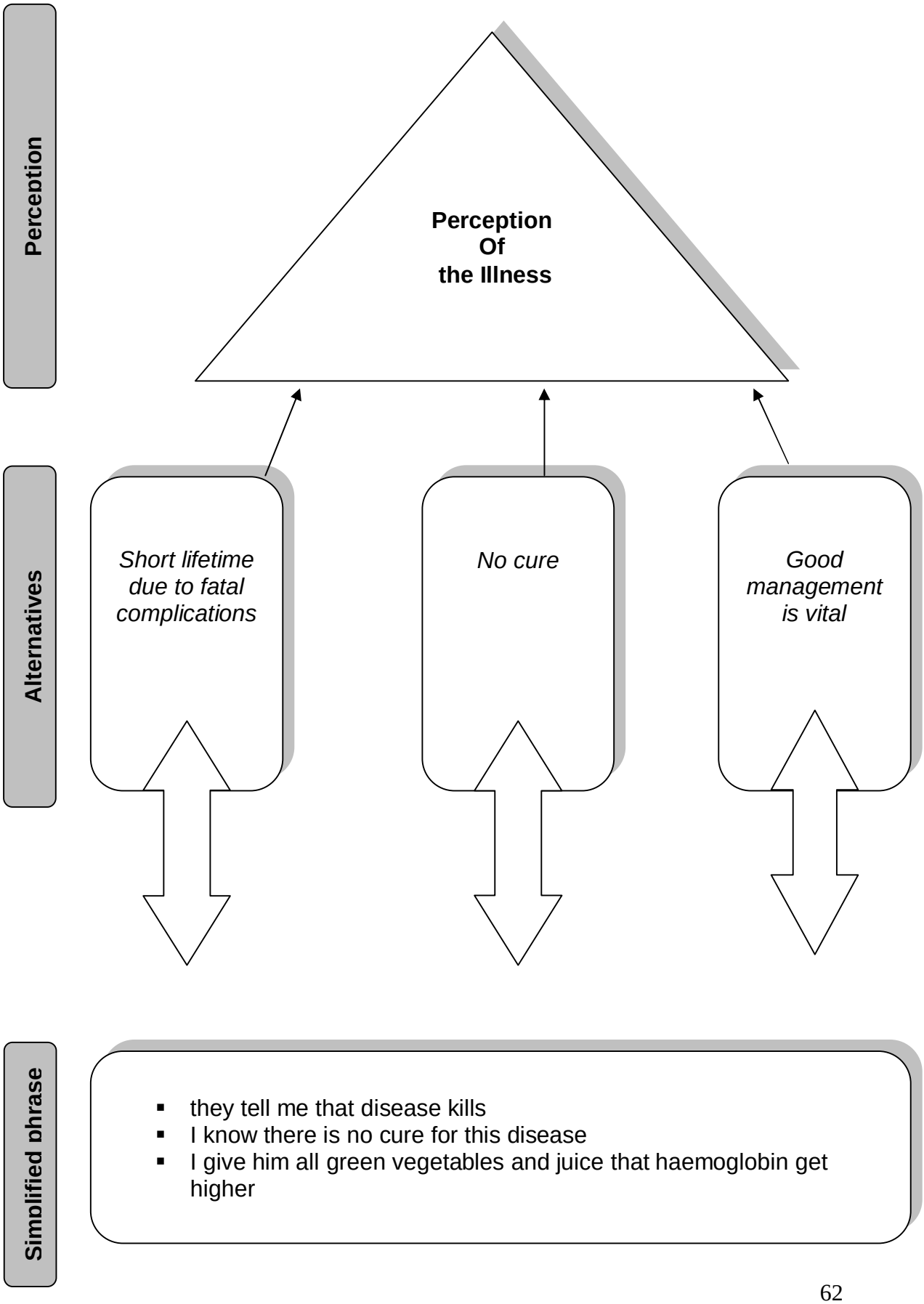
**Theme 1:** **KNOWLEDGE OF THE ILLNESS**



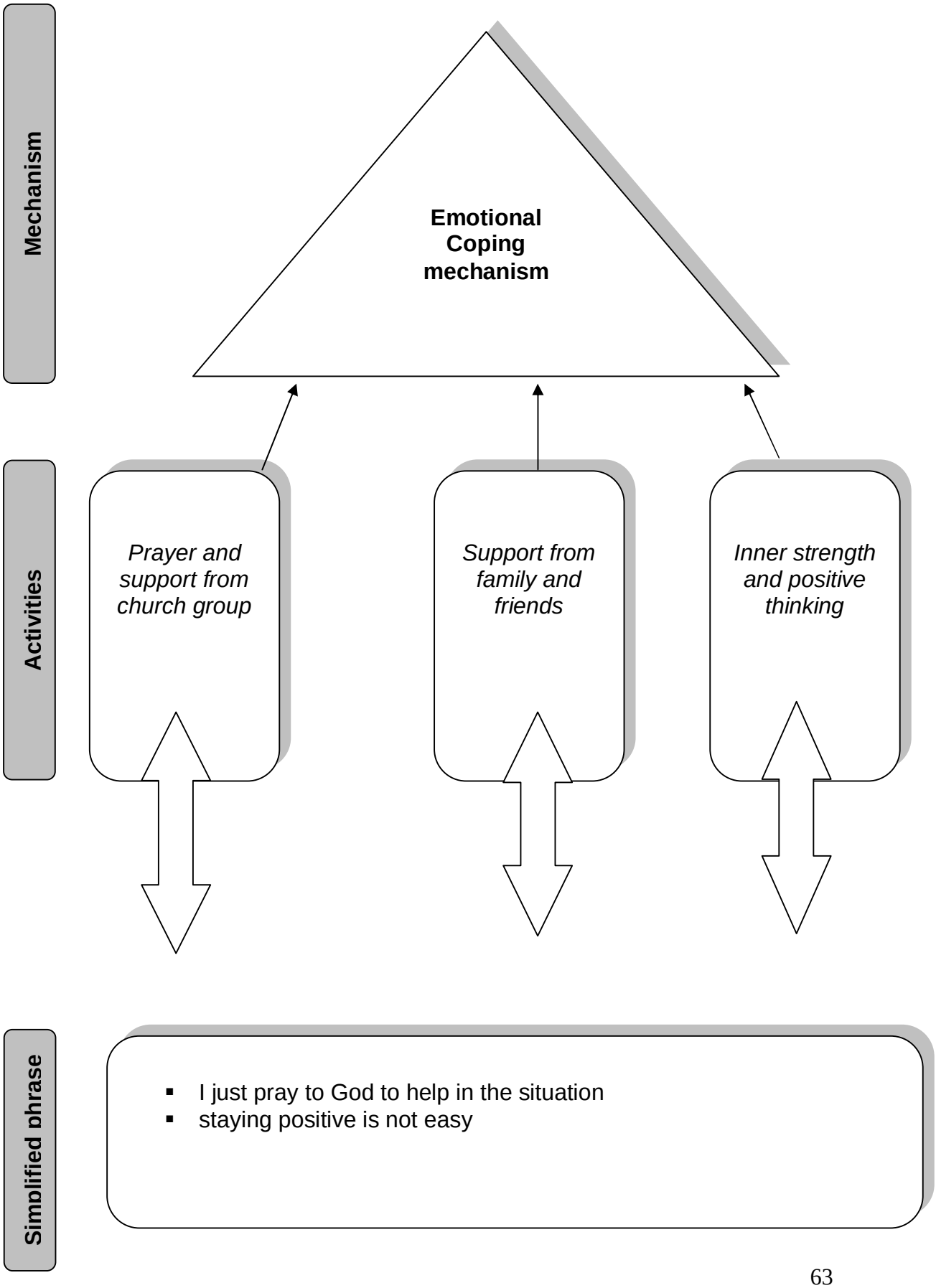
**Theme 2: HOME CARE**



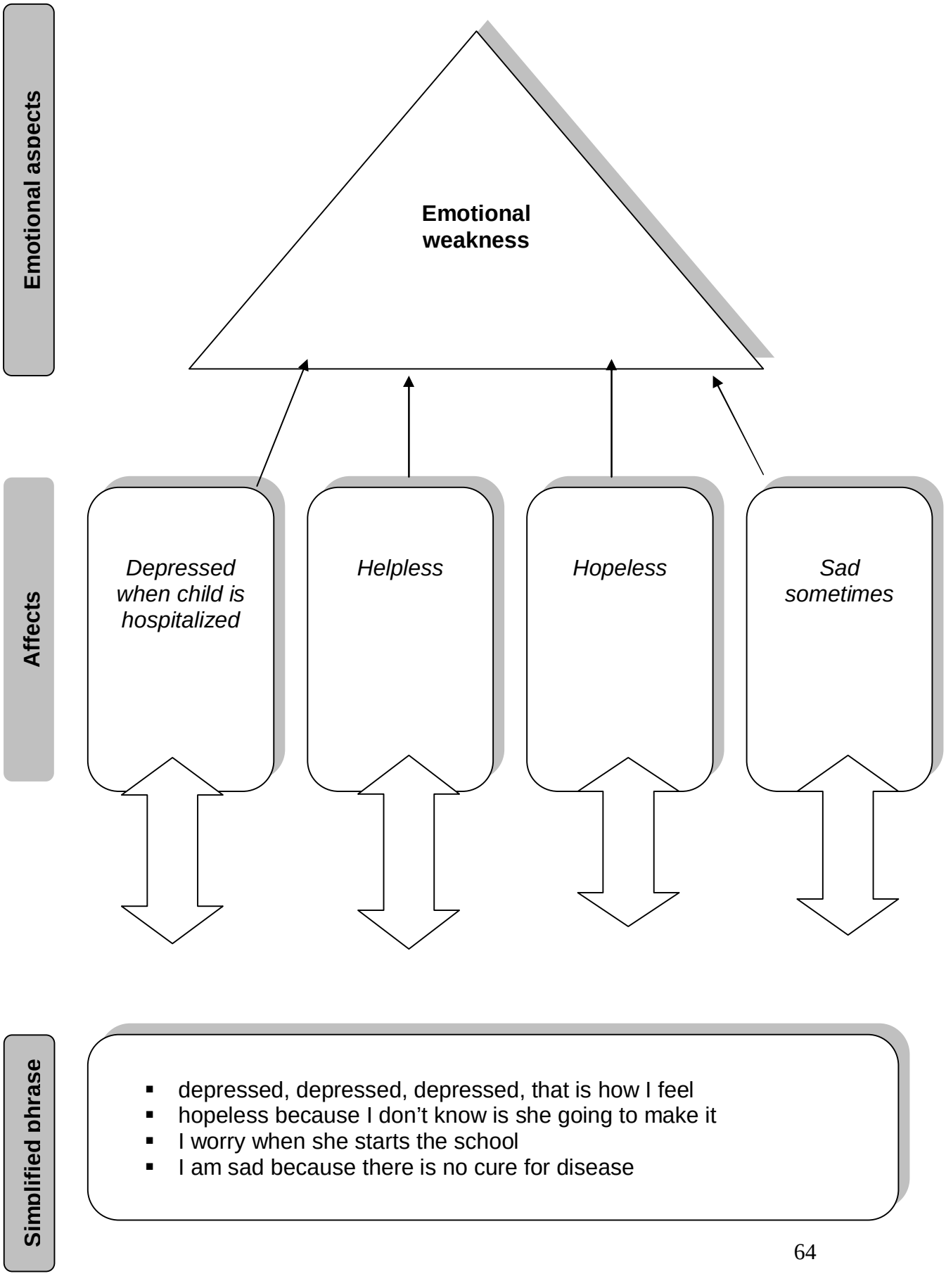
**Theme 3: PERCEPTION OF THE ILLNESS**



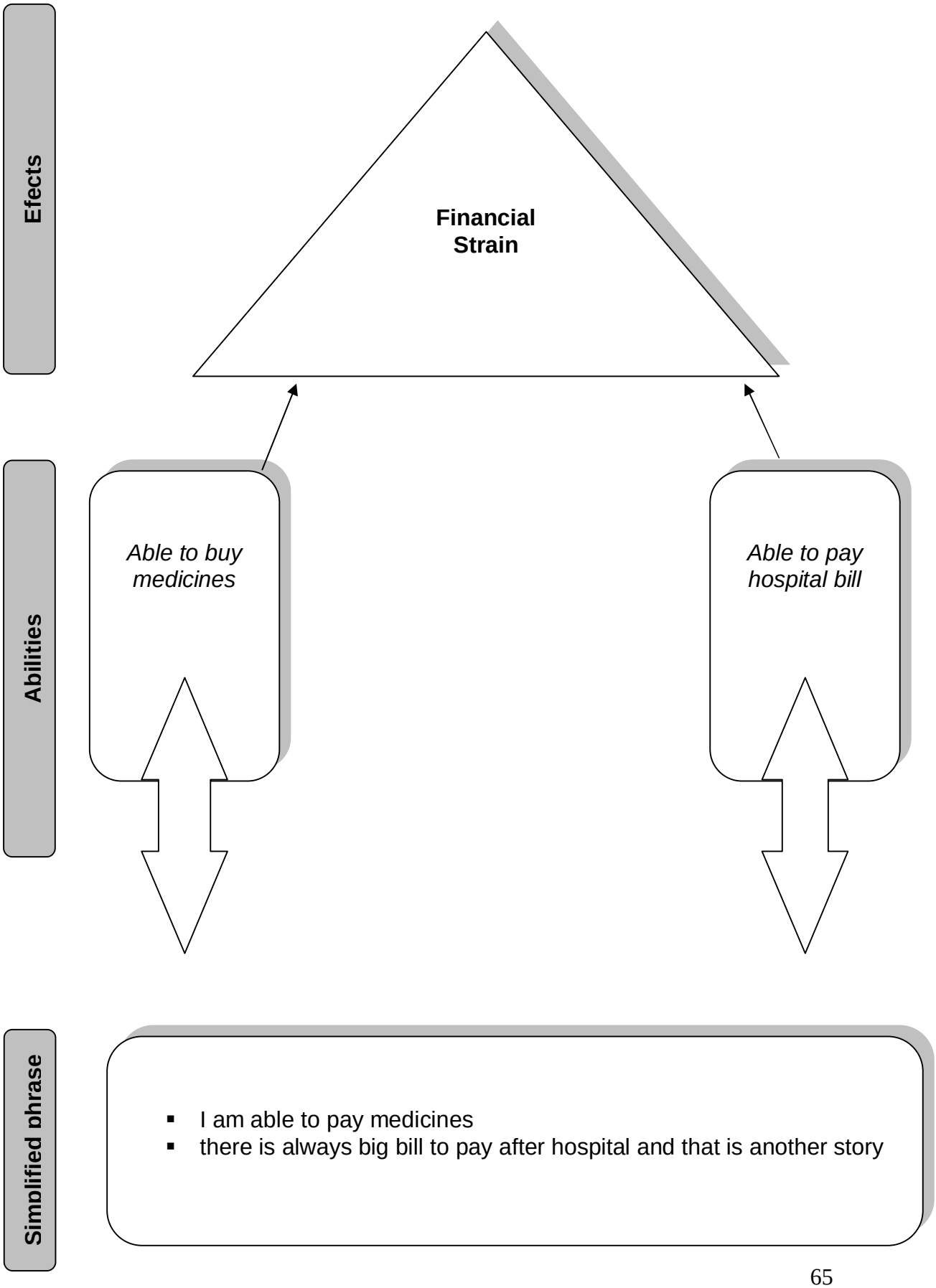
**Theme 4: EMOTIONAL COPING MECHANISM**



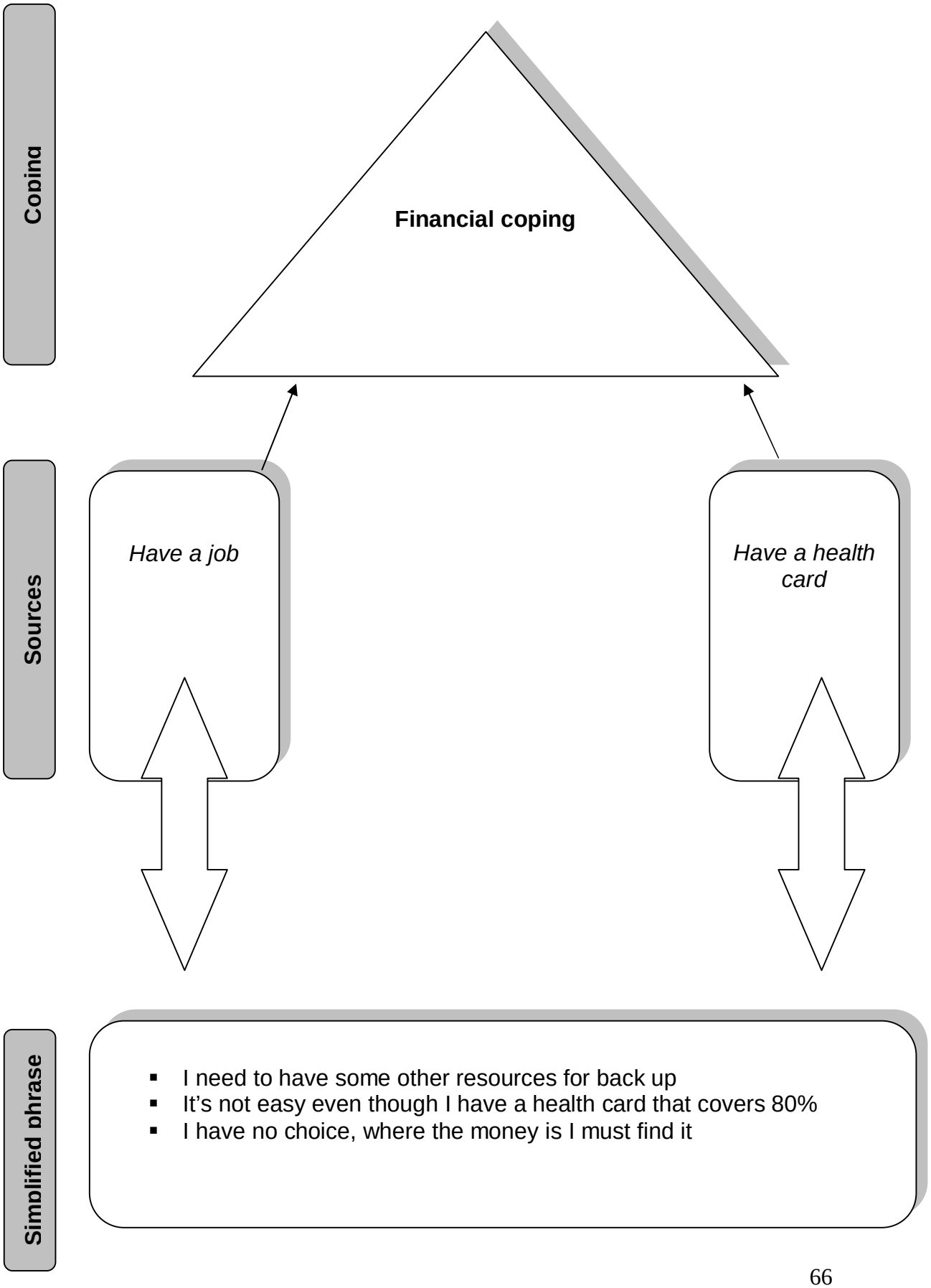
**Theme 5: EMOTIONAL WEAKNESS**



**Theme 6: FINANCIAL ASPECT**



**Theme 7: FINANCIAL COPING**



**Theme 8: FUTURE ASPECT**