

# The Cancerous Syndemic

Therapy management strategies among families affected by Burkitt's lymphoma in the North-West and West Region of Cameroon

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## Abstract

In spite of the the disproportionate occurrence of cancers between the wealthier and poorer nations in the world, modern literature and scientific research have rather unproblematic described cancer as a disease of development rather than underdevelopment. Paradoxically, more than 80 per cent of the reported childhood cases of cancer are in developing countries.

Burkitt's lymphoma is the most common childhood cancer on the African continent, with tumors growing most rapidly. Yet, if chemotherapy treatment starts as early as possible, the treatment has good chances of being successful. The high mortality among children with Burkitt's lymphoma, therefore, may indicate that caretakers, despite their uttered preferences for hospital treatment in the event of considered serious illness, delay hospital treatment.

In my anthropological research, I set out to investigate *why* families affected by Burkitt's lymphoma in the North-West and West Region of Cameroon delay hospital treatment. My research is based on a seven-month fieldwork at the Burkitt's lymphoma treatment ward at Banso Baptist Hospital, in the North-West Region of Cameroon.

I address the affected families' therapy management strategies of Burkitt's lymphoma in light of culturally meaningful disease explanations, as well as the socio-economic context of the disease. Economy, culture, climate dependent consequences and transportation problems are factors to be focused. On the basis of empirical findings from participant observation and interviews in- and outside the Burkitt's lymphoma treatment ward, I illuminate a symptomatic 'pattern of resort', potentially increasing health risk and poor outcomes among the affected children.

My ultimate aim is to make it clear that the dissemination, as well as the medical outcome of Burkitt's lymphoma are far more than narrow biomedical phenomena. The problems of late hospital arrivals and abandonment of treatment call for further social research.



## Acknowledgements

I dedicate my work to all children who have fought, are fighting, or will have to fight cancer. Your brave tears and smiles are my reasons and inspiration for writing this thesis. To the 'pekin them' of the Burkitt's ward at Bansa Baptist Hospital: Ashiah ya! Thank you for being enthusiastic about my presence, for sharing your stories and favorite songs about 'Njama Njama cows'. You all remain in my fondest memories.

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## **The Two Outcomes<sup>1</sup>**

*The pekin<sup>2</sup> be hot for skin and the belly bite  
He is in pain, suffers and has sleepless nights  
Displaced, over think and over cry*

*The pekin be troubled and depressed  
She feels unhappy, discouraged and confused  
Cold, distressed and only bearing*

*I am patient, committed and determined  
My pekin is managing and has peace in mind  
I am amazed, encouraged and relieved  
He feels free and has peace in heart  
My pekin is rewarded and alive*

*I am afraid, angry, stirred up and in conflict  
My pekin is weakened, broken down and handicapped  
I pray, struggle and trust  
She is sad and scared  
My pekin is dead and deprived*

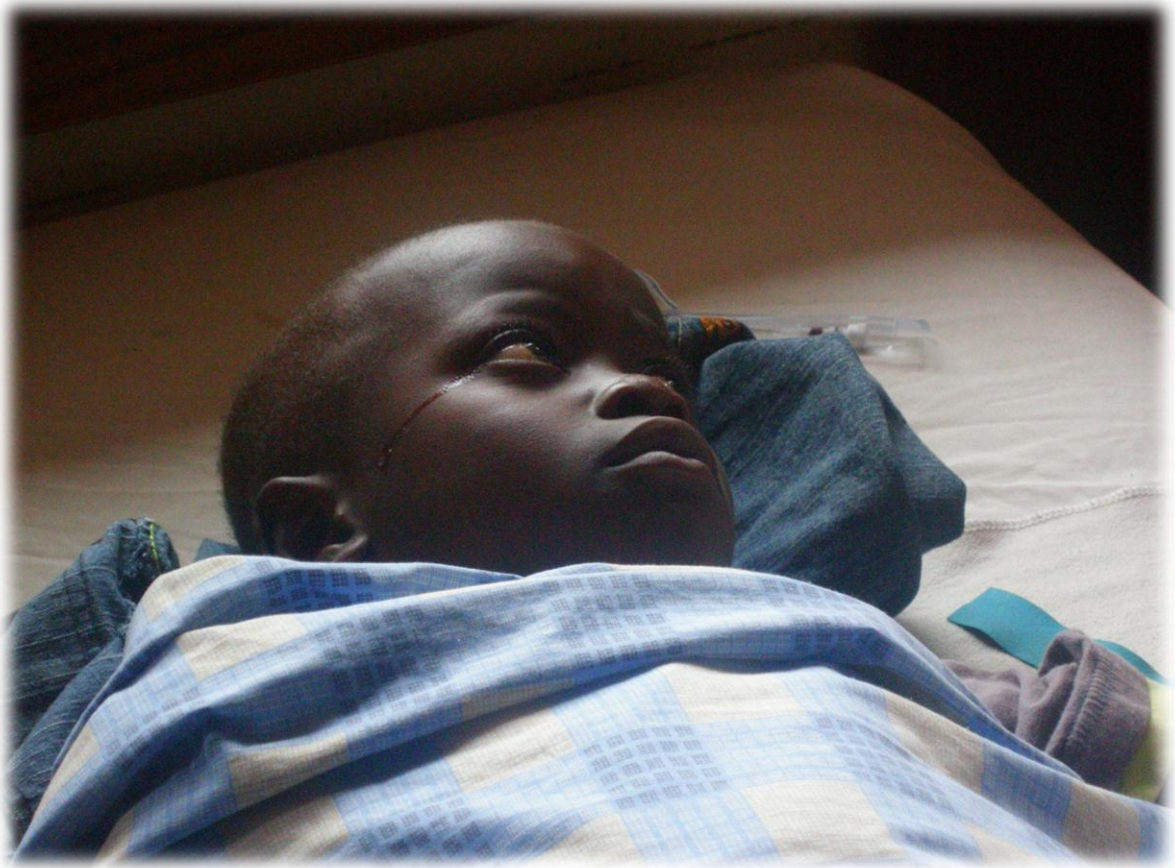
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<sup>1</sup> The 'two outcomes' of Burkitt's lymphoma described by caregivers at Bansa Baptist Hospital, 2009.

<sup>2</sup> Pekin is the Pidgin-English term for 'child'.









# Table of Contents

Abstract ..... iii

Acknowledgements ..... v

The Two Outcomes ..... vii

Prologue ..... xiii

**Chapter 1: Introduction ..... 1**

    Theoretical Perspectives..... 4

    Approaching Therapy Management..... 8

    Structure of the Thesis ..... 13

**Chapter 2: Context and Methodology..... 15**

    Interviews ..... 19

    Participant Observation..... 21

    Language and Communication ..... 23

**Chapter 3: The Last Resort..... 25**

    Yara’s Story ..... 26

    Peter’s Story ..... 36

    Patterns of Resort ..... 39

**Chapter 4: Behind Home Remedies and Delay of Treatment ..... 43**

    Home visits..... 44

    Cultural Understandings of Disease..... 51

    Natural and Unnatural Illnesses ..... 58

**Chapter 5: The Informal Sector of Pharmaceuticals ..... 65**

Health Talks .....	66
The Context of Distribution .....	68
Drug Sellers of Kumbo Town .....	71
The Customer .....	75
<b>Chapter 6: Traditional Healers and Health Clinics.....</b>	<b>79</b>
Culture as Barrier .....	80
Adjusted Medical Concepts .....	83
<b>Chapter 7: Conclusion .....</b>	<b>89</b>
<b>Bibliography .....</b>	<b>93</b>
<i>Appendix 1</i> .....	103
<i>Appendix 2</i> .....	109

## Prologue

*Dr. Evaristus Njume had just finished ward rounds when I met him on his way out of the Burkitt's lymphoma treatment ward. Unaware of what had happened I greeted him in the usual manner of a big smile and a handshake. "How did you sleep doctor?" Dr. Njume looked gloomy, - a rare sight as he always came to work cheerful and enthusiastic. The doctor shook my hand and took a deep breath before he replied, "Oh, Benedicte, I did not sleep fine. It is a very sad day..."*

*This morning, stillness had replaced the lively noise that normally filled the Burkitt's ward. Parents were sitting on stools by the bedsides, speaking in low tones while serving their children Cameroonian 'pap' breakfast. I greeted the children and their parents before I looked over to the pile of white and blue bed linens lying in the middle of Yara's empty bed. Drinking containers and toilet tissue had been removed from the bedside table; two necessities for parental care of the patient. The squeaking sound from the door shifted the parents' attention from breakfast feeding to the firm steps of Yara's father, Muhafiz, who entered the ward. In his hands, he held a green shopping bag that displayed wild animals and read 'AFRICA' in bright letters. Muhafiz faced the floor as he passed two patients and sat down on Yara's bed.*

*In spite of being well known with the appropriate pidgin words of paying respect and condolences, I felt a rush of unease as I struggled to solace the father who had just lost his nine-year-old daughter. I was relieved to hear the strong voice of Nurse Elizabeth Holike greeting me "good morning sistah". The nurse moved to Yara's bed and gave condolences in the way that I did not dare, by placing a comforting hand on Muhafiz' shoulder while saying "we ashiah, ashiah ya".*

*On my way into the office, I heard the nurse tell Muhafiz that the gates to the mortuary were open. Muhafiz immediately picked up the green shopping bag and left the ward accompanied by Zaron, - the father of five-year-old Sa'dan who had arrived the previous evening for the child's six-month follow-up. My first meeting with Sa'dan six months earlier was my initial*

*introduction to the field. Three children were going to receive their second chemotherapy and the nurse had asked me to follow her to the treatment room to observe the procedure. I had witnessed Sa'dan's gradual recovery and this morning he was running happily around the ward. At his check-up, Dr. Njume had cleared him from any signs of relapse, which meant no more hospital-visits until his final one-year follow-up.*

*"Hurry up sistah, before it is too late!" Having worked side by side for several months Nurse Holike knew that fieldwork did not mean sitting in the office. I grabbed my notebook and ran after Sa'dan who was moving in his usual playful manner behind Muhafiz and Zaroon. We reached the end of the path that stretched around the hospital; in front of us was the mortuary. I had watched families grieve and say goodbye to their loved ones at this spot, but never had I followed a father to assemble his late child.*

*There were three benches in the mortuary; Yara was laying on one, a young man on another. The chilly temperature of the rainy season had cooled down the room, which I assumed stalled unpleasant smells. Muhafiz did not attempt to look at his daughter who was covered by a white sheet. The two men instead unzipped the shopping bag and emptied it by pulling out a piece of cardboard, kitchen utensils, a teakettle and an off-white sheet. I observed their determined movements, not able to reason with what to them looked like a daily routine. Muhafiz and Zaroon carefully measured the bag and placed the cardboard at the bottom. The two men had just turned over to Yara's body when a young man entered the room. Muhafiz grabbed the bag and pulled it open while Zaroon and 'the newly arrived' lifted Yara from the bench. At that moment, I realized that the logistics going on in front of me were concerned with how to fit Yara into the shopping bag. Her head faced first, the rest of the body followed as the limbs, which already had become stiff, were forcefully manipulated. Muhafiz placed the sheet and kitchen utensils on top of Yara's body and with the strength of three men; they managed to zip the bag.*

*Muhafiz and Zaroon each held a bag handle, as they moved up the pathway that led to the run-down taxi. The two fathers dropped the bag with Yara's body in the trunk and sat down in the back seat. Sa'dan slid in next to his father, eager to go home. The taxi driver got out of the car and slammed the trunk before they quickly took off.*

# Chapter 1: Introduction

**That one, with his swollen belly,  
is pregnant with his own death.  
St. Jerome, c. 347 - 419 C.E.**

Cancer is an illness that is global in scope, but it affects people in very diverse ways. The childhood cancer *Burkitt's lymphoma* is endemic<sup>3</sup> in Central-Africa and Papua New Guinea but only occurs sporadically in other parts of the world. In Central-Africa, the disease is accountable for more than 70 per cent of the reported childhood cancer cases in the region. St. Jerome could very well have described the disfigurative illness, where firm swellings, sometimes of huge size, occur in the bowel, jaws, kidneys or central nervous system. The tumours are eligible to double in size within twenty-four hours and the symptoms may appear as soon as four to six weeks after the lymphoma begins to grow. If treatment is initiated before the central nervous system is involved, the child is thought to have about 50 per cent chance of surviving four years and most likely indefinitely. Without treatment, the disease is invariably fatal within weeks or a few months.

The discussion of this thesis is concerned with the close relation between the *social aspects* of Burkitt's lymphoma and the medical outcomes of the treatment. During the period January - August 2009, I conducted an ethnographic research at the Burkitt's lymphoma treatment ward at Bansa Baptist Hospital in the North-West Region of Cameroon. I chose the hospital as my primary field site based on the extraordinary high incidence of Burkitt's lymphoma in the North-West Region and for its high standard Burkitt's lymphoma treatment protocol. I also found valid reason to include the West Region in my research, as the dominant group of patients admitted to the Burkitt's ward during my fieldwork was from this area.

With a 60 per cent cure rate among the patients, the Burkitt's lymphoma treatment protocol at Bansa Baptist Hospital holds impressive figures compared to the overall rates in the region.

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<sup>3</sup> A disease that is very common or strongly established within a geographical area, such as in a country or region.

On the condition of paying a 30.000 CFA<sup>4</sup> hospital fee (about 45€), the full course of treatment and supportive care was at the time of my research provided free of charge. An inexpensive treatment alternative compared to most hospitals in areas affected by Burkitt's lymphoma. In neighboring country Nigeria, a physician informed me that his patients had no option but to pay 190 € for a single course of chemotherapy, which was impossible for most patients. In spite of the outward availability of treatment at Bansa Baptist Hospital, health personnel expressed concern about deaths that were out of proportion to what they should be. The health workers commonly related the loss of a patient to pure biological factors, but also to the occurrence of co-infections, as well as the social context of the disease; characterized by *late hospital arrivals* and *abandonment of treatment*.

Attention to the social aspects of cancers in resource poor settings has until recent years been neglected in the fields of medical and social research. The main argument for this thesis is that in order to improve cancer treatment in developing countries, one has to pay more attention to these aspects of the disease. The original aim of my research was to address the high incidence of Burkitt's lymphoma in Central Africa, with attention to the harm it causes to an individual- and to the society as a whole. Based on experiences acquired in the field, I have found it tangible to explore this query through the lens of 'therapy management' (Janzen 1978), which highlights the treatment resorts that people turn to in the event of illness, as well as the motivational factors behind their choice of medical care. With the research question of my ethnographic research, I set out to investigate:

*What are the therapy management strategies of families affected by Burkitt's lymphoma in the North-West and West Region of Cameroon?*

I investigated the structuring factors behind the families' decisions on medical care and elaborate upon what I experienced as a divergence in the caregivers<sup>5</sup>, *uttered* partiality to hospital treatment, and their *actual* therapy management of Burkitt's lymphoma. During

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<sup>4</sup> Cameroonian Francs.

<sup>5</sup> The caregiver is the person responsible for the patient during the time of hospitalization.



interviews, more than 90 per cent of the caregivers at the Burkitt's ward claimed predilection to hospital treatment in the case of a serious ailment. Yet, 77 per cent of these caregivers did not bring the child for admission until a month or more had passed from the first symptoms appeared; some delayed as long as six months. This deviation caught my interest for acquiring more knowledge about the time prior to hospitalization; including the treatment resorts that the families had turned to, therapy received at the various consultations, and time spent at each locality. On the basis of empirical findings from participant observation and interviews in- and outside the Burkitt's ward, I illuminate a symptomatic 'pattern of resort', potentially increasing health risk and poor outcomes among the affected children.

Following the footsteps of anthropologists who have studied- and reviewed the therapy management of people in various localities (Janzen 1978, 1983, 1992, Fabrega 1979, Pool 1994), I hope to convince the reader that in order to gain an understanding of the management of Burkitt's lymphoma in Cameroon, we must investigate individual- and collective understandings of illness, as well as the social context for people's choice of medical care. I examined the families' decision-making process in light of culturally meaningful disease explanations. These disease explanations are far from fixed; on the contrary, I argue that they are constantly negotiated to fit the socio-economic context of the disease. The families' therapy management strategies may thereby become less a matter of *preference* for treatment, than a *lack of access* to existing effective therapy.

Taking on the challenge of communicating the structuring factors behind families' choice of medical care for Burkitt's lymphoma in the North-West and West Region of Cameroon, I hope to offer a valuable contribution to a more holistic understanding of reasons for delay- and abandonment of treatment among my informants. My findings may have transferrable value, in which it can be of use to health personnel working at other Cameroonian hospitals, as well as in neighbouring countries. An increasing number of reports by medical practitioners dealing with cancer in impoverished nations indicate similar problems to those addressed in this thesis (Farmer 2010, et. al. Israels 2008 et. al. Arora et. al. 2007). Israels (2008) calls for research that offers insight to the affected families' point of view regarding delay and abandonment of treatment. Personal accounts on these topics are at the centre of analysis in this research. A thorough examination of the therapy management strategies

among families at the Burkitt's ward may also offer some insights to a better understanding of why the thousands of children who every year are affected by Burkitt's lymphoma are not brought to a hospital for treatment.

## **Theoretical Perspectives**

Biomedicine has historically conceptualized disease according to 'germ theory', or in terms of various chemical imbalances within our bodies (Smith 2009:7). In this tradition, disease is treated as "a distinct, discrete, and disjunctive entity, which exists separate from other diseases and from the social groups and social contexts in which it is found" (Singer and Baer 2007:204). Different types of cancer have ordinarily been related to pure biological factors, such as aging, hormonal disturbances and hereditary factors. Recent cancer research has increasingly focused on the array of environmental factors, lifestyle and stress that may contribute to the aetiology of the disease. Up to this date, only few researchers have emphasized the role of socio-economic factors to the dissemination of cancer (Epstein 1978, Michaels 1988).

Merrill Singer (2009) is one of the critical medical anthropologists who have argued that the medical sphere of life cannot be broken off from other areas of people's existence. He stresses that increased attention must be brought to the social and biological interconnections in health. He contends that one cannot understand a population's health without an investigation of its social context, such as access to food, shelter and availability of medical treatment. In line with Singer's argument, Partners in health (PIH) Physician, Gene Bukhman, emphasizes that the cancers which afflict people living on less than a dollar a day, often have very different causes from those affecting the financially sturdy (PIH 2011: February e-bulletin). For this 'bottom billion' he argues, "non-communicable diseases – like rheumatic heart disease, type 1 diabetes, mental illnesses, epilepsy, and cervical cancer – are often the result of lack of access to food, shelter, education, and health care interventions readily available in developed countries" (PIH 2011: February e-bulletin). In other words, we must go beyond pure biological factors to understand the aetiology, dissemination and medical outcomes of disease.

In spite of the the disproportionate occurrence of cancers between the wealthier and poorer nations in the world, modern literature and scientific research have rather unproblematic described cancer as a disease of development rather than underdevelopment. Paradoxically, more than 80 per cent of the reported childhood cases of cancer are in developing countries, in which only 10 per cent receives treatment (International Union against Cancer 2010). The 'Burkitt's zone' stretches between latitude 10° north and south of the equator, with a tail down the coastal region of Mozambique. The zone is coincident with that of holo-endemic or hyper-endemic malaria and the occurrence of the tumor is most frequent within hot and humid areas, where there is a low altitude and more than 50cm of annual rainfall; such as in river valleys, lakeshores and regions near the sea coast (Wright 2009). It is the first malignant tumor that has been related to ambient temperature, annual rainfall, altitude above sea level, to malaria and its vector.

In the period 2003-2006, UNICEF estimated that only 13 per cent of children below the age of five in Cameroon slept under an impregnated mosquito net (UNICEF-Cameroon statistics 2008). Among those who had malaria fever, only 58 per cent received treatment (UNICEF-Cameroon statistics 2008). The lack of access to satisfactory malaria management, particularly in the rural areas of Cameroon has similar to the devastating consequences of the HIV/AIDS crisis, as described by Didier Fassin, contributed to “the deeply disturbing phenomenon of the collapse of immune systems among millions of our people, such that their bodies have no natural defense against attack by many viruses and bacteria” (Fassin 2007:15). Recurrent exposures to the malaria parasite over time cause those who are affected to develop a degree of immunity that limits severe disease expression, but sadly not sub-acute expressions of the disease. In the Burkitt’s zone, much of the population who are already weakened by one disease are likely to suffer from other diseases, both infectious communicable and non-communicable. This is the case of Burkitt’s lymphoma, in which repeated attacks of malaria has weakened the child’s immune system, causing it to become less resistant to infection. Together with the contagious Epstein-Barr virus and a genetic predisposition, malaria is believed to lay foundation for cancerous Burkitt’s cells to evolve.

Merrill Singer and colleagues introduced in the early 1990s the concept of a ‘Syndemic’. At its simplest level it refers to “the association between two or more epidemics that interact

synergistically with each other inside human bodies, contributing as a result of their interaction to an excess burden of disease in a population beyond what would otherwise be expected” (Singer and Baer 2007:204). The emergence of the concept of a Syndemic derived from anthropological research and improved knowledge on the relation between diseases, such as AIDS/tuberculosis (TB) and the socio-economic environment of where the diseases were found. Singer and Baer report that HIV-positive individuals infected with tuberculosis are 100 times more likely to develop active disease than those who are HIV negative with TB (Singer and Baer 2007:204). This causes the affected individuals and their families an additional load to carry, as well as it negatively affects the community as a whole.

Cancer has for a long time been regarded as a non-communicable disease. This might explain why few anthropologists have investigated cancer in light of the Syndemic concept. Medical and anthropological research alike has thus highlighted the close relation between various types of cancer and other diseases, such as Kaposi Sarcoma and HIV/AIDS (Garry et al. 1988). In the discussion of this thesis, I point to the Syndemic character of endemic Burkitt’s lymphoma. I regard it to be a Syndemic disease based on its indirect relation to malaria, which has caused Burkitt’s lymphoma to obtain an epidemic status in Central Africa. The biological interactions between the diseases will not be granted more space in this thesis. However, I elaborate upon the high occurrence of Burkitt’s lymphoma in the rainy season and the social and medical consequences this entails.

I bring further attention to the socio-economic context of the disease and adhere to Paul Farmer (1999) who highlights that “the most well demonstrated co-factors [for HIV/AIDS] are *social inequalities*, which structure not only the contours of the AIDS pandemic but also the nature of outcomes once an individual is sick with complications of HIV infection” (Farmer 1999:51-52). In line with Farmer’s argument, I contend that we must attend focus to the social forces that tie diseases together. In order to prevent the occurrence of a Syndemic, it is not enough to only prevent or control each disease. We must also come to grips with the structuring forces behind its dissemination; including their cause and consequence for human life. These factors are intimately linked to families’ therapy management of Burkitt’s lymphoma. Indeed, the empirical findings of this thesis suggest that one cannot comprehend

the delay and abandonment of treatment, resulting in poor medical outcomes, without bringing attention to the structures that influence the aetiology of the disease.

Among the 37 new admittances to the Burkitt's ward during the time of my research, 91 per cent of the families had a monthly income of less than 25.000 CFA (38€), leaving each household with less than 1.20 € per day to share between the family members. The patients could therefore be seen in light of a social group; that of the materially poorest members of the society. Dr. Evaristus Njume; head of the Burkitt's ward at Banson Baptist Hospital during the time of my research, supports these findings, in which he appoints *poverty, poor diets and sanitary conditions* as important contributing factors to the dissemination of Burkitt's lymphoma. His estimates were that more than 90 per cent of the patients he consulted came from a very low socio-economic status, living below the poverty line<sup>6</sup>. These factors are likely to also have an impact on the affected families' response to the illness. Using the Syndemic approach I try to illuminate the connectedness between the aetiology, therapy management and likely outcomes of Burkitt's lymphoma.

In the next section, I take a closer look at the theoretical approach to therapy management. I compare this theory to the notion commonly referred to as 'non-compliance' in medical circles. In line with other critical medical anthropologists (Farmer 2005, Briggs 2002), I contend that the non-compliance explanatory model presents a much too simplistic image, in which it excludes the social context of people's treatment seeking behaviors from consideration. Janzen's (1978) approach to therapy management does on the contrary recognize the processes involved in people's selection and evaluation of treatment, in which it holds promise for "contextually sensitive analyses of the relationships between cultural assumptions and values, behavioral processes and social and economic structures that influence the therapeutic process" (Janzen 1987:68).

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<sup>6</sup> US. \$ 1.25 a day (<http://Web.worldbank.org>)

## Approaching Therapy Management

Unexpected outcomes or “failures” in therapy have in biomedicine traditionally been referred to as ‘non-compliance’. The non-compliance explanatory model is frequently used by medical professionals in regards of the delay- and abandonment of hospital treatment. In evaluations of treatment programs and trails, patients have rather unproblematic been labeled as ‘compliant’ or ‘non-compliant’. Treatment failure has recurrently been blamed on cultural and psychological barriers that depart from the bio-medical treatment regime (Farmer 2004). An anthropologist would certainly agree that people do not make therapeutic decisions out of nothing, “but rather make grateful use of building materials they find lying around in their own culture” (Van Der Geest 1991:80). Studying how individuals perceive and react to ill health, we must, therefore, know something about the cultural attributes of the particular society in which they live. Unfortunately, comparable to the former ‘culture as text’ approaches in anthropology, the non-compliance explanatory model treats cultural knowledge as a more or less firm foundation for people’s selection of medical interventions.

Sjaak Van Der Geest (1991) describes how early anthropological research saw culturally meaningful disease explanations as ‘charters’ for people’s preventive and curative actions. By approaching the matter from such a standing perspective, social-science analysts of health care have sought to generate contours and structures of knowledge, in which it was believed that one could see the rationality of people’s medical actions. This has resulted in clinicians and public health authorities who have mistakenly assumed individuals and populations with little access to health care to delay hospital treatment based on cultural reasoning. Members of particular communities have been regarded as ‘less cooperative patients’, causing them to be ‘natural targets’ for morbidities in the viewpoint of government officials.

Looking at a critical time in Venezuela’s history, - at the outbreak of cholera, Charles and Clara Mantini-Briggs have illustrated that using such strategies really does not work for anyone and one will only face the same problems, of bigger or smaller scale again (Briggs and Briggs 2003: xvi). At the outbreak of cholera, Marusian Indigenas were severely hit by the disaster. Yet, information on the epidemic was unavailable to the Indigenas until after many lives were lost. Using the logic of culture, officials justified the lack information and

treatment based on the Indigenas' 'tradition' for using local healers. This led to the exclusion of Indigenas from the public health services and consequently a deprivation of constitutional rights in a democratic state (Briggs and Briggs 2003:161). The authors highlight that it is when the notion of local knowledge is connected to stereotypes of culture that people are labelled as being of a 'different time' or as 'backward' and such deprivations are blamed on the victims themselves.

Physician and anthropologist, Paul Farmer (2007), has in the same line of thought underscored that when we see the problem of treatment failure as one of non-compliance, we imply that we must change the patients, rather than the treatment programs. He argues that instead of blaming the victim through notions of cultural barriers for seeking appropriate medical attention; a more productive way of addressing the issue is to concentrate on a lack of access to medical treatment (Farmer 2007). In *Pathologies of Power*, Farmer concludes:

Certainly, patients may be non-compliant, but how relevant is the notion of compliance in rural Haiti? Doctors may instruct their patients to eat well. But the patients will 'refuse' if they have no food. They may be told to sleep in an open room and away from others, and here again they will be 'non-compliant' if they do not expand and remodel their miserable huts. They may be instructed to go to a hospital. But if hospital care must be paid for in cash, as in the case throughout Haiti, and the patients have no cash, they will be deemed 'grossly negligent' (Farmer 2007:151).

By attending focus to the affected families' social suffering, Farmer draws attention away from personality factors, attitudes and beliefs and place the responsibility on the society around the sufferer – on economic and political structures – and the serious limitations it creates for individuals to reach their personal goals (Ingstad 2007). Helman similarly argues that whatever the local culture; reduced health among people living in poverty is usually associated with a low income, since this influences the sort of food, water, clothing, sanitation, housing and medical care that people are able to afford (Helman 2007).

In accordance with Briggs and Farmer, I found that among the patients at the Burkitt's ward, culturally meaningful disease explanations were aspects of – but not determinants for – the

choice of medical care. Ultimately, it appeared that socio-economic factors had the greatest influence on people's treatment strategies. In this case, labelling patients as 'compliant' or 'non-compliant' would be a gross failure, as it relinquishes to acknowledge the social context of where knowledge is used, as well as the manner in which social relationships and power interests manipulate it (Janzen 1978). Farmer concludes that it is only by removing the barriers to "compliance", when coupled with financial aid that we may dramatically improve medical outcomes.

Medical anthropologists continue to be concerned with the determinants of choice in the therapeutic process, with the relationship between alternative medical traditions and pathways available, and with the control and application of medical knowledge (Janzen 1978:82). Modern anthropological views of cultural knowledge stress the importance of seeing it within its particular context; a context made up of historical, economic, social, political and geographical elements (Helman 2007).

Challenging the static line of attack in the non-compliance explanatory model, John M. Janzen (1978) views knowledge as a *process*. He argues that people's medical knowledge is fragmentary and continuously adjusted to the changing circumstances of where people find themselves. A person re-evaluates disease explanations along with new interpretations that he or she makes during the course of the illness. This leads to new choices of treatment until the patient receives cure – or dies. Choice and decision on medical care does according to Janzen "occur within a range of latitude and at several levels, demonstrating in statistically verifiable interactions the existence of roles and structural arrangements, on the one hand, and the categories and values of an ideational system on the other" (Janzen 1978:74). In this sense, medical knowledge is processual and most likely to both precede and follow therapeutic decisions.

Barth (1966) was among the first to lay ground for this new approach. He conceived actors to rationally engage in transactions in which they attempted to ensure that the value gained was greater than, or equal to, the value lost. Transactions, as Barth understands them, can be applied to the therapeutic context by examining how choices are confronted and managed by healer, patients, family, or kin (Janzen 1978:74). Janzen highlights that seeing the therapeutic choices in this manner yields understanding for the cumulative impact of successive choices,



and the mutual effect that actors have on one another (Janzen 1978:74). By attending focus to the actor, Barth underscored how changes in values and forms of organization were generated (Garbett 1970:176-177). Inspired by Barth (1966) and Janzen (1978), I examine individual processes of negotiation between cultural values, social roles and the context of therapeutic decision in light of therapy management. It is in this symbiosis, I argue, that decisions and strategies towards the symptoms of Burkitt's lymphoma are made.

The concept of therapy management was developed in medical anthropological research in Central Africa and was first established as a theoretical approach by Janzen in 1978. He found that a focus on therapy management as an ongoing process was a useful analytical tool to illuminate the logic of patient behavior. Genest identifies the concept of therapy management in a review of Janzen's book as "the set of actions whose aim is to formulate a diagnosis, to select and evaluate the treatments at the time of a sickness" (Genest 1985:348). Janzen contends that in spite of most people not operating with a term for this process, they very much recognize its reality (Janzen 1987:69). The therapy management strategies of families admitted to the Burkitt's lymphoma during my fieldwork reflected a wide variety of treatment modalities tried along the course of the disease. There was a high frequency of 'doctor shopping', in which seemingly contrasting treatment alternatives, such as Western-based hospital treatment and traditional medicine, were used in sequence, or simultaneously. In interviews with the caregivers it appeared that the hospital was regarded the best medical care in the event of serious illness. Yet, it was evident that in reality it became the last resort.

Just like it was important for Barth (1966) to develop a process model that considered choice and decision, studies of therapy management investigate the consequences of consensus and dissent among parties involved in a given therapeutic process (Janzen 1987). It is important to question *who* takes charge of the decisions regarding medical treatment. The patients whom I am concerned with are minors who cannot make therapeutic decisions on their own. They rely on the advice and decisions of the people whom Janzen refers to as the 'therapy management group'. By 'group' Janzen implies a set of individuals involved at the moment in which the therapy management decisions are at hand. This may be family members who act as intermediates and advocates between the sufferer and the specialists of the treatment resorts, but also relatives and friends giving advice or lending money for treatment. The group usually coalesces when a person presents with the first symptoms of illness, - a time in which they

rally for the purpose of sifting information, lending moral support, making decisions, and arranging details of therapeutic consultation.

Among the patients at the Burkitt's ward, the therapy management group was commonly headed by one, occasionally two, caregivers. The caregiver was usually a parent, but in some instances maternal/paternal relatives, such as grandparents, uncles and aunts. The other members of the therapy management group were seldom present at the hospital. These members were rendered visible to me during interviews with the caregivers, in which their particular role in the therapy management of the illness was narrated. These members were relatives, neighbours and friends who provided support and advice based on their personal knowledge- and interpretation of the visible symptoms of disease. The members of the therapy management group and the ways in which they negotiate decisions on medical care within the socio-economic context of the disease are at the center of analysis in this thesis.

## Structure of the Thesis

This thesis is presented in seven chapters, including the introduction and concluding remarks. In chapter two, the methodological approach to the field is discussed. I deliberate on the implications the methods used during the research holds for the following discussions and conclusions of the thesis.

In chapter three, the therapy management strategies of families affected by Burkitt's lymphoma are considered. The empirical examples of the stories of Peter and Yara tell us about cultural and socio-economic concerns and how they influence and often the families' chances to obtain cure for the sick child. These concerns, I argue, contribute to a symptomatic 'Burkitt's pattern of resort' and cause delay of the hospital treatment.

In chapter four, I investigate why home based treatments usually constitute the first treatment resort among families affected by Burkitt's lymphoma. I also highlight that the therapy management strategies are reflections of the caregivers' explanatory models of the disease, in which the therapy management group plays an important role in defining the ailment and determining the appropriate cure.

In chapter five, I take a closer look at how access and availability of treatment may result in therapeutic options of possibly inferior quality and the consequences this might entail for the affected child.

In chapter six, I discuss therapy management strategies in the advanced stages of Burkitt's lymphoma. I suggest that traditional healers and health clinics are used in complementary ways to maximize the chances of cure.

In chapter seven, I take a final look at the many burdens associated with the dissemination of Burkitt's lymphoma and draw some concluding remarks.



## Chapter 2: Context and Methodology

*Sitting next to 'the Burkitt's nurse', Edith Ngang on the hospital bed in the maternity ward, I gently rubbed her back to ease the pain of her second day in labor. The previous morning, Edith had come to the Burkitt's office to tell me that her labor had started. This was a secret that few had been trusted and I found myself surprised when she asked if I could stay with her. At the time, I had only spent three months in Cameroon and this felt like a personal break-through. Having spent several hours at the maternity ward, her husband Isaac suddenly asked: "Benedicte, are you here as an anthropologist or as a friend?" Not quite sure whether I could leave the anthropologist aside, a nervous laugh preceded my reply: "I am here as a friend". Edith who was in the middle of labor, interrupted our conversation and said: "No, she is more than both".*

Conklin (1968) describes:

"An ethnographer is an anthropologist who attempts – at least in part of his professional work – to record and describe the culturally significant behaviors of a particular society. Ideally this description, an ethnography, requires a long period of intimate study and residence in a small, well-defined community, knowledge of the spoken language, and the employment of a wide range of observational techniques including prolonged face-to-face contacts with members of the local groups, direct participation in some of that group's activities, and a greater emphasis on intensive work with informants than on the use of documentary or survey data" (Conklin in Mintz 1979:19).

Following Conklin's characteristics of an ethnographer, I find my research to have obvious shortcomings. Nevertheless, there are also strengths in my ethnographic approach to the field that I will discuss in this chapter.

To examine therapy management, the researcher has to make sure, as far as possible, that she understands all aspects of the situation being studied (Helman 2007). To achieve this, one

should ideally aim to examine and integrate four different types or levels of data, each one collected and analyzed in a very different way (Helman 2007).

- First, one should pay attention to what people say they believe, think or do
- Second, what people actually do
- Third, what people really think or believe
- Fourth, the context of the above three points

The research method of this thesis is qualitative, based on a ‘mixed method approach’, where I rely on data produced from participant observations and detailed recordings of behaviors and events witnessed in the field. I have also conducted in-depth interviews at the hospital with patients, caregivers and health personnel involved in the treatment of Burkitt’s lymphoma. This, along with document analysis of forms filled out by the caregiver at admission gave valuable insights to the lived experience and therapy management of the illness. I also found it important to investigate the social life of Burkitt’s lymphoma outside of the hospital premises. This has resulted in a multi-sited fieldwork in which both the topics, as well as the affected people, have been followed in a wide variety of settings (Marcus 1995). I will start off this chapter with a brief introduction to the field site before moving on to the methodological discussion.

The majority of children, who have been recorded with Burkitt’s lymphoma in Central-Africa, live in the North-West region of Cameroon (Wright 2009). The region is 5-7° north of the equator and has a temperature of 18-29° C. There is an annual rainfall of 101.6 cm and an altitude ranging from 2500-3000 m in the mountains to 1100-1300 m in the Ndop plains (Wright 2009). The confirmed incidence of Burkitt’s lymphoma in the region is 5.9/100 000 children under 15 years of age, with a potential incidence of 7.5/100,000 (Wright 2009). This is the second highest incidence documented to date (Wright 2009). In spite of its high occurrence, researchers believe that we are only seeing the tip of the iceberg, as most children affected by the illness are most likely never brought to a hospital for treatment.

The high incidence of Burkitt's lymphoma has alerted physicians to establish affordable treatment programs in Cameroon. Currently, five hospitals offer treatment of Burkitt's lymphoma. Two of these hospitals are governmental, while the remaining three are run by the Cameroon Baptist Convention Health Board (CBCHB). The CBCHB hospitals' treatment regime is based on the *Burkitt's lymphoma Treatment Protocol*, founded by Professor Peter Hesselting at Stellenbosch University, Cape Town and Dr. Peter McCormick, initiator of 'The Beryl Thyer Memorial Africa Trust'. The physicians first implemented the protocol at hospitals in Malawi and Namibia, with the aim of providing efficient cancer treatment at low cost. Funding from pharmaceutical companies and various donations has made it possible to offer treatment free of charge. Other hospital expenses, such as electricity, water and laundry require that patients must pay a hospital fee.

Out of the CBCH hospitals, Bango Baptist Hospital (BBH) hosts the largest Burkitt's lymphoma treatment ward. The hospital is beautifully located in Kumbo, a market town in the Bui Division of the North-West region of Cameroon. The Bui division is situated north of the Ndop plains that stretch between the town of Jaikiri and the regional capital Bamenda. BBH started out in 1949 as a missionary hospital of four small buildings and twenty beds. Today it has a bed capacity of 250 and reputedly offers some of the finest treatment in the country. Annually there is an average of 60 children admitted to the Burkitt's ward.

The territorial context where I conducted my fieldwork frames my findings to a certain degree. It situates it geographically and limits it in place. My fieldwork is fixed in place and at the same time my fieldwork is fixed in time, and time as a limitation is something worth thinking twice about. I did my fieldwork from January 2009 – August 2009, which could be considered, by some professional anthropologist, a bit of a short period for a fieldwork. I see this point myself and can imagine the value in participating in the field for a longer time and through all the climatic changes, but at the same time I know that I have seen the hardest part of Kumbo, climatically speaking. It is in this period, the rainy season, when most children are affected by Burkitt's lymphoma and since it is the surroundings concerning this cancer, I am confident that I participated at the right time.

The initial focus of my research was based on a desire to gain knowledge about the lived experience of Burkitt's lymphoma through the eyes of the affected child. The mean age of children recorded with Burkitt's lymphoma in the North-west Region between 2003 and 2006 was 7.9 years (Wright 2009). The mean age of the 37 new admissions to the ward during my research was correspondingly 7.7 years. I found the young age of my study subjects, as well as the severity of the child's condition during admission, to have serious implications for the research. With the young age followed language barriers, where I found myself to be dependent on two interpreters; one for translation between my English to French or Pidgin-English, another from these languages to the child's local dialect. During interviews with children, the second interpreter was commonly the child's caregiver. The interview setting could then be described as one of three adults asking a child questions that were ultimately not communicated properly. I found these issues to set serious limitations for a fruitful research. Nevertheless, there were some older children, ages ten and twelve, who were admitted to the ward in which fruitful interviews were conducted. Another, perhaps equally important arena for gaining an understanding of the patient's experiences of the disease was my participant observation at the hospital.

The restrictions of interviewing children at the ward prompted a shift, in which I decided to attend focus to the caregivers' experiences of the illness. I found their experiences to be of great relevance, as they were the ones who made therapy management decisions concerning the child. In this shift, I still hope to render visible some of the realities that the children affected by Burkitt's lymphoma are faced with. In addition to the new admissions, I have included patients who were re-admitted to the ward with relapse. Patients who came for their six month- and one-year follow-up also became an important source of knowledge, enabling insight to the various stages – and outcomes – of the disease.



## Interviews

The first level of analysis of therapy management should include what people say they believe, think and do (Helman 2007). Such data is commonly produced during interviews and conversations between the informant and the researcher. In order to approach the caregivers' therapy management strategies of Burkitt's lymphoma I found in-depth interviews to be of great importance.

I conducted 33 interviews with caregivers at the ward, most of these were held in the Burkitt's registration office where the patients are registered and admitted to the ward. This is a room loaded with meaning and associations. It is where the nurse counsels the caregivers about the illness. The context of where the interviews were held, who was present and how far the child had come in the treatment were all factors that had to be taken into consideration in an analysis of the results.

One of the challenges I faced during interviews was that the caregivers expressed different views at different times, situations and health conditions. I conducted interviews *after* the first round of chemotherapy, a stage in which most families had seen a positive change in the child's condition. This could clearly influence their answer in a different way than if the question was asked *before* treatment was initiated. I also experienced that for some of the caregivers, the interview situation was experienced as one of high psychological pressure. Reasons for this could, according to Van Der Geest, be influenced by inequality between interviewer and informant and the latter's wish to avoid making an ignorant impression on the interviewer (Van Der Geest 1991:69). In some instances I suspected that the caregiver was more concerned about not losing face, than about giving accurate and honest answers.

One interview that alerted me on this issue was with a young mother who only understood Pidgin-English. I was dependent on an interpreter who could translate during the interview. Starting with the first question, I could tell that the woman was worried and anxious. I asked my interpreter on numerous occasions to ensure her about the purpose of the interview, in which there would be no right or wrong answers, nor any consequences for the medical care

received at the hospital. Nevertheless, we found ourselves forced to end the interview before all the questions were asked. I suspected that the woman struggled to comprehend the questions, which was an important observation in order to improve the interview guide. At the end of the interview, my interpreter made an interesting comment about the mother's twitching eye. He asked her whether she had consulted a doctor for the disorder, in which she nervously laughed and replied no. At this point in time, Dr. Njume, had entered the office and he was working on a computer. My interpreter asked the doctor whether he would have a look at the woman's eye. The doctor examined the woman and asked her about the duration of the problem. The woman replied that she had never had the problem until the interview. This experience alerted me on the context of the interview situation and reminded me how no situation can be understood out of context.

My research was enabled by the hospital's Institutional Review Board by agreeing to follow a 'best practice' in medical research. I was asked to create an interview guide as well as an informed consent form. This structured the interviews to a certain degree, in which they were formalized. Fairhead and Leach highlight that for researchers conducting studies in biomedical institutions,

Connectivity ... [With informants] is structured by the globalized institutions and practices of biomedical ethics. Connectivity turns on internationally recognized 'best practices' in communication aims and procedures for trials and research to the community and to potential research subjects. This is usually conducted through information sheets and 'informed consent'. The assumption is that subjects' interpretations of what researchers are up to can be strongly determined by such trial-by-trial communication (Fairhead and Leach 2006:1110)

My work ethics was to have an open dialogue with the people I met and who handed me their trust. Together with my interpreter, I explained the content of the voluntary participation sheet. The informants were asked to give their informed consent on their participation in the research and to use the material from interviews. The caregivers did, in addition to the child who was interviewed, give their consent for their child to be part of the research. The informants were informed that there would be no consequences if one chose to not participate

or withdraw ones participation from the research. They were informed that the benefits of participating would be their contribution to a broader knowledge about the lived experience of Burkitt's lymphoma and to have their stories heard by a wider audience. The interviews were held in the registration office, which made it possible to record detailed descriptions made by the interviewed on the computer. This also allowed caretakers to be in close reach of their children while doing the interviews. I formed an interview guide prior to the fieldwork, which I continuously improved and adjusted in accordance to my experiences in the field. This may be considered both a strength and weakness, as the research questions were improved, but everyone did not receive the same questions. The interview guide used with the caregivers, as well as the informed consent and study withdrawal letter is attached in the appendix.

## **Participant Observation**

Janzen describes anthropology's distinctive approach as one in which we "go out and see what is actually occurring and talk to people themselves" (Janzen 2001:18). Adhering to the goals on Kathrine Fangen, my ideal of doing ethnographic research was not to be a spectator, but a subject who was "present in the action" (Fangen 2007). I found it crucial to participate in the daily life at the hospital, as well as the various treatments that the children were going through while in the hospital. Doing participant observation, it was with knowledge in mind that my presence changed the situation. In the following section, I present four arenas for participation at the hospital, which I have found to be of significance for my understanding for the people and the place in which I conducted ethnographic research.

One important arena for participant observation was the ward. This was a site in which I could take part in the daily life of the patients and caregivers. To establish trust between the families and myself I found interaction on a daily basis to be important. I spent time with the children making bead necklaces and drawing, while observing how the caregivers, children and health personnel interacted together. Participation during ward rounds was a time where I observed the interaction between newly arrived patients and the doctor. I observed his inquiries about the child's condition and the caregiver's response. This was also a time when I could pose questions to the doctor and nurse about the caregiver's treatment seeking actions and about

the child's physical state. It was also an important arena for my social contact with the patients and the caregivers were informed about the purpose of my presence.

A second arena for participant observations was during medical procedures, such as during the administration of chemotherapy in the Intensive Care Unit (ICU) and the operating theatre. This was the field site was experienced as personally challenging, but also a time in which I experienced strong resonance for the child's experiences during hospitalization. Participation during the first administration of chemotherapies resulted in fainting several times. This embodied experience of doing fieldwork was unquestionably a result of my resonance for the children and what they were going through. Wikan suggests that resonance is the crucial – and charitable – orientation that allows us to go beyond the words to engage people's compelling concerns (Wikan 1992:460). She further explains how it is a reflection of empathy and compassion. This requires that the ethnographer includes feelings as well as thought (Wikan 1992:463). I now find this experience to be a strength in my research, whereas during the fieldwork it was a source of great frustration.

A third arena in which I participated was the nurse and hospital chaplains' counseling of the caregivers. During counseling with the nurse, one day after admission, most caregivers were told that their child suffered from cancer. I found it pertinent to observe their initial reaction, as well as the terminology the nurse would use to explain the nature of the illness. It was also a situation where I was made aware of several problems and worries that the caregivers had encountered before and after hospital admission. During counseling, the caregivers were enquired about their social and economic background, which allowed me to get a fuller picture of factors that might influence the caregivers' therapy management strategies.

Observation of the chaplains' religious counseling of the patient and caregiver was also of great interest, as it revolved around the individual caregiver's handling of the illness. The chaplains were not only concerned with providing spiritual care, but also to assess an image of the caregiver's personal struggles, of emotional and economical scale.

## Language and Communication

The formal languages of Cameroon are French; practiced in eight of the ten regions, and English; spoken in the North-West and the South-West region. In addition to the formal languages, there exists between 250 and 280 ethnic groups and languages in Cameroon (Gullestad 2008). A great amount of the population interacts in Pidgin-English, predominantly in the English-speaking parts of the country. The multitude of languages spoken in Cameroon posed a challenge to my communication with informants, both in- and outside the hospital. The official language of Bango Baptist Hospital is English, but due to the high number of patients coming from the West Region there were many Bamoun- and French-speaking families.

After one month in the field I hired Mr. Alex Tsemi as my interpreter. He was a hospital worker in outpatients department, as well as being an auxiliary ward attendant. He had great knowledge of a wide variety of local languages, as well as being fluent in English, French and Pidgin-English and was therefore a valuable resource in my communication with the patients and caregivers. Wikan (1996) argues that the interpreter should, as much as possible, associate with the informants. In addition to his language skills, Mr. Tsemi had extensive experience from working with patients, which I experienced to be very important. He was also a gatekeeper who introduced me to many families and healers in the Kumbo area.

It is never ideal to make an interview with total dependency on the interpreter, as you might not catch linguistic nuances and metaphorical meanings. The interviews were thus crucial to be held in order to understand the mechanisms of how, when and why people choose medical care. I attempted to learn Pidgin while in the field and towards the end of my stay I could, with support from my interpreter, capture most of the details presented in interviews. Nonetheless, I am much aware of the possibilities of something being lost in the translations and that this is a limitation in my fieldwork.

A common mistake made by social researchers is to be mostly concerned about their findings fitting into one's own models, rather than actually understanding a situation on its own

premises. The perspective I brought with me to the field has indisputably influenced the way I approached the field of inquiry, such as the questions that were asked during interviews. The answers that I have deemed 'sufficient' and 'adequate' are inescapably a result of my own positioning as an engaged student with dedication to the works of critical medical anthropology. This requires some ethical consideration. Good (1994) emphasizes that we understand the experiences of others in some measure by the experiences provoked in us when we hear such stories, experiences which are affective, sensual and embodied (Good 1994:141). In this sense there is a translation going on between the informant and the anthropologist.

I believe that it was positive that I was a young woman when interacting with mothers and children. The fact that I have worked at a hospital as an activity leader for children affected by cancer was perhaps a strength, as communication with the children was largely through mutual play and activities. The fact that there were language barriers made this form of communication important.

## Chapter 3: The Last Resort

*Dr. Njume came into the Burkitt's registration office, clearly bothered after a long day in outpatient department. The doctor, whom I at this point knew as a good friend, sat down and shared his frustrations. Earlier that day, a five-year-old boy named Peter had limped into the consultation room. He was accompanied by his eighty-year-old grandmother, Marie. The doctor immediately ordered an ultrasound of Peter's stomach, as it was distended and he had severe pain in his joints. When the results came back, Dr.Njume had sufficient evidence to start treatment of Burkitt's lymphoma and he asked Marie to take the child to the Burkitt's ward for admission. Peter's grandmother insisted that the doctor should rather prescribe some tablets that they could take home. Confident that the disease could only be treated in a hospital, Dr.Njume underscored the importance of admission. Sitting in the Burkitt's office that afternoon, he was disappointed to find that the patient had abandoned treatment.*

Dr. Wright who has worked with Burkitt's lymphoma in the North-West region of Cameroon argues that the belligerent nature of the disease drives most cases to a health facility (Wright 2009:228). In my experience, this does not mean that the caregiver will first take the child to a well-equipped health facility; on the contrary, in a materially poor setting going to the hospital is often considered the last option, even when regarded as the best medical care. In the discussion of this chapter, I investigate: *Why does the hospital usually become the last – among many treatment modalities – in the Burkitt's pattern of resort?*

The reader is familiarized with the story of Yara, introduced in the prologue, and will be introduced to the story of Peter who absconds from treatment, but later returns to the ward. These stories highlight the many pressing concerns that families are faced with trying to find remedy for Burkitt's lymphoma. It also illustrates how treatment provided free of charge may in actual practice become very expensive for a family. I introduce the reader to what I suggest is a typical 'Burkitt's pattern of resort', structured by availability and access to treatment.

## Yara's Story

It was a chilly morning during the rainy season. Health personnel at Bansa Baptist Hospital were no longer brushing red dust from the Harmattan<sup>7</sup> off their white coats, nor did they worry about jiggers<sup>8</sup> in the sand. At this time of year, there were other pressing concerns, such as the sand that transformed into mud and made the roads leading to the hospital barely passable. This morning, the rains that had ravaged in the night forced people to balance their step, avoiding the mud holes, as they struggled to get to the entrance of Bansa Baptist Hospital. Notwithstanding the slippery road conditions, motor bikes and run-down yellow taxis were rolling in and out of the crowded parking lot. Bike riders usually offered the cheapest rides, but as the bumpy roads took their toll on the machines in the rainy season, fees tended to double. The result of passengers not being able to pay for private rides were bikes and taxis filled to the breaking point, sometimes with four passengers in the front- and five in the back seat. A financially beneficial practice for both the driver and passengers, but sadly one that added greatly to the number of patients admitted to the hospital with serious traffic injuries. In spite of poor road conditions from the start of April until the end of September, the number of patients admitted to the Burkitt's ward *doubled* in the rainy season. At this time of year, approximately two children were admitted to the ward every week.

The time had reached 07.30 a.m. when I entered the Burkitt's ward. This morning in July, four boys and two girls occupied six of the eleven beds. Dr. Njume and Nurse Holike were already busy conducting ward rounds. The doctor was writing in a patient's journal, with the occasional pause of doing a medical examination of the child's distended stomach. Before he moved on to the next patient, Dr. Njume lightly pulled the hospital shirt to cover the child's abdomen. Nurse Holike, standing next to him, poured a small amount of sanitizer to the doctor's hands. There had been a shortage of water for several days and the nurse was careful not to squander such a valuable resource.

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<sup>7</sup> The Harmattan is a dry and dusty West African trade wind. It blows south from Sahara into the Gulf of Guinea between the end of November and the middle of March.

<sup>8</sup> A Jigger is a small insect larva common in warm parts of the world, such as Central-Africa and Latin-America. The larva has a bite, which causes painful lumps on your skin.



Elizabeth Holike had been the head nurse of the Burkitt's ward since the early months of my field work, when Nurse Ngang went on her maternity leave. The ward had been in dire need of a replacement, but approaching retirement, Holike spent much time worrying about "not being in her prime years to acquire new medical knowledge". Her initial nerves were replaced by self-confidence, as she successively managed the demanding responsibilities at the Burkitt's ward. Aware of the nurse's busy morning schedule, I offered to assist the doctor at the morning rounds. The doctor's frame of mind noticeably changed, as I handed him nine-year-old Yara's chart. Yara had been re-admitted to the ward, suffering from a relapse of Burkitt's lymphoma. The tumors that were re-emerging, causing gross swellings in her gums and jaw had led to a displacement of the teeth. Unable to close her mouth and to ingest food, her body was left in knuckles and bones. The rapid dispersion of the tumors was causing paraplegia from the waist through her legs; rendered clear to me as a strong smell of human waste forced its way through my nostrils.

I knew that the doctor's mind was working hectically, as he observed Yara's critically malnourished body. Looking at Yara's father, Dr. Njume asked "has she podged?" Muhafiz hectically moved his hands, trying to keep flies away from his daughter's bed, before he replied "yes, two times in the night". With little room for privacy, both patients and caregivers intently observed each of the doctor's medical assessments. The attention towards rounds quickly changed as Nurse Holike gave a health talk to the newly arrived families. The nurse moved from bed to bed, teaching caregivers on hygiene and nutrition. The mother of seven-year-old Arami politely nodded and left the ward as she had been told to go to the hospital market and buy eggs for her son. Four-year-old Sudicatou was sitting on her father's lap, resting her head on his chin. She had received her first course of chemotherapy the previous morning and Nurse Holike was telling her father how to avoid unpleasant side effects, by drinking three liters of water every day.

Unable to administer chemotherapy until Yara's condition had been stabilized, Dr. Njume called for the nurse and asked her to remind the pharmacists about his pending order on the F100 formula. Being unfamiliar with the term, Dr. Njume took the time to enlighten me that it was a therapeutic milk product developed by the WHO, designed to treat severe malnutrition. In addition to the regular diet, the formula was to be administered every six hours. The

formula had delayed for more than one week, a time in which Yara's condition had unremittingly deteriorated. Dr. Njume was becoming increasingly agitated, as odds were against his attempt to cure the child. Being in charge of the maternity, women's and Burkitt's ward, Dr. Njume carried a tremendous responsibility. The one that weighed heaviest on his chest was the Burkitt's ward. Yet, there was a sigh that always accompanied his exit from the ward, which rendered visible the dedication he felt towards his job.

Twenty minutes after her departure, Holike returned to the ward. This time, equipped with a plastic bag containing the much-needed formula. Brusquely, Dr. Njume inquired what had delayed the pharmacists. His initial agitation was replaced by anger as the nurse replied: "there was no sugar in the pharmacy". I was instantly reminded on the constant pressure the health personnel were working under, in which the lack of resources limited their ability to deal with the tasks at hand.

With the help of a nursing student who held Yara with a firm grip to the mattress, Holike inserted the tube leading into the child's nose. Certain that the tube was in place, the doctor gave signal to run the formula. Yara's weak cries of discomfort were followed by waves of vomitus from mouth and nostrils. Dr. Njume's worst fear had come true; Yara's body was no longer susceptible to the high amounts of nutrients in the formula, such as energy, fat, and protein. The child was in dire need of nutrition, but incapable of holding food. Muhafiz instantly got up from the stool to remove the bed linens that were covered by body fluids, but was halted to a stop by Holike's sharp voice, ordering him to wash his hands and let the health personnel do their jobs. As a result of the water shortage, Muhafiz left the ward to rinse his hands. The tube leading through Yara's nose was disconnected, a time in which the doctor respectfully whispered: "She is a stage IV now. All left to offer is palliative care".

Few minutes later, Muhafiz rushed back into the ward. Behind him were two nursing students whose task was to remove the bed linens. Muhafiz could not have been more than 1.60 meters, but somehow he stood taller than anyone in the ward did, as he gently picked up Yara's fragile body and carried her to the far end of the bed. He softly undressed the girl's tainted hospital shirt and wrapped his arms around her shaking body while the nurses stripped the bed and found a clean shirt. I observed the unmistakable affection and love that a parent showed towards his child, but I was like Dr. Njume puzzled about why Muhafiz had not

brought the child for treatment at an earlier stage. Suffering from a relapse, Muhafiz was expected to bring the child to the hospital immediately after the symptoms re-emerged. Yet, he had waited for more than three weeks, causing the child to be severely malnourished. In order to better understand what caused Muhafiz to delay hospital treatment, my interpreter and I sat down with Muhafiz later that day and asked him about the family's therapy management of the illness. I encouraged him to start with the first time the child fell ill and moving towards the child's present condition:

In our tradition, we call a swelling like that 'Yutaamou'. The country doctor treats it, so the first thing I did was to seek traditional medicine. A country doctor came to my house to look at the child and he said it was a common disease in the area. He made razor cuts on the child's jaw and rubbed herbs inside the cuts. I was told that Yara had to stay home for one week and the concoction would cure it. After one week, the healer came back to check up on the child but all this was no help. I decided to go to the health center where they told me what I suspected; when the jaw swells like that, one must treat with injections. We stayed two days in the health center. The first day I did not think much about what had caused the disease. When the treatment did not work, it started to turn my head and I ran into confusion about the disease. I started to think whether this was a disease caused by God or by a sorcerer. The doctor told us that the child suffered from cancer and that they could not treat this kind of sick, so we went back to the house.

On the third week, I decided to go to the hospital. Yara's was feeling pains in her belly and it became high. The doctor told me to go to a large hospital, like Bafoussam. I thought that these hospitals are the same, so I changed direction and went to Banson Baptist Hospital because I had heard that it is a big hospital. Yara and I left the house early in the morning. I arranged for a bike to take us from our house to the Fouban car park for 2000 CFA. I found a taxi that would take us to the Kumbo car park for 3000 CFA, but it delayed and we did not reach Kumbo until 4.00 p.m. There we got on a motorbike that brought us to the hospital for 350 CFA.

The *second* time the child fell ill was about 3 weeks, or one month ago. I left home and went to work on our farm, which covers about 20Km. When I came back to the house, I saw that the child was not really feeling fine. She sat very quietly and looked lonely. I could tell that she was trying to play with the other children, but she kept falling out. It was not until later, I realized that it was serious and that it might be the same disease. Then I had it confirmed: the sickness had come back. I saw a swelling in the same place but did not do anything about this on the first day. I did not want to go to a traditional healer again, since I only wasted time there the first time. I started to look for money to take the child to the hospital, but it delayed for two weeks because the person who was going to lend me money told me to look elsewhere.

Illness narratives have been interpreted by medical anthropologists and others in several different ways, including seeing them as a common way “by which people organize, display and work through experiences” (Singer and Baer 2007:74). Byron Good (1994) describes a narrative as a form, in which experience is represented and recounted, in which events are presented as having meaningful and coherent order, in which activities and events are described along with the experiences associated with them and the significance that lends them their sense for the persons involved.

In the case of illness narratives, expressing feelings and recalling actions around a particular illness form the core elements (Singer and Baer 2007). Kleinman (1980) suggests that a way of looking at the process, in which illness is patterned, interpreted and treated, is through the *explanatory model*.

The explanatory model is defined as: “the notions about an episode of sickness and its treatment that are employed by all those engaged in the clinical process” (Helman 2007:128). Explanatory models for the course and symptoms of a disease are held by patients and physicians alike, but tend to be very different. The model is a reflection of how, at that particular moment in time, a person explains what has happened to him or her, and how they regard that it should be dealt with (Helman 2007:130). Kleinman regards the explanatory models to be partly conscious and partly outside of awareness. Conducting analysis of explanatory models and the way they are narrated, one finds that they are characterized by

vagueness and multiplicity of meanings. What I find particularly interesting about Kleinman's model is his emphasis on the sorts of questions that people may ask themselves when they, or someone else becomes ill. He highlights the ways in which the answers to these questions are weaved into the story or narrative of their ill health (Helman 2007). Reflecting on the *What, Why, How, and Who* questions that people ask themselves, opens up for analysis of what guides people's choices among available therapies and therapists.

Using the explanatory model approach to Muhafiz's narrative, I attend focus to the queries in which he sought answers during the course of Yara's ailment. These questions, I argue, illuminate the many factors that influenced therapy management decisions, as well as the processual change in his interpretation of the illness symptoms. Because explanatory models are strongly influenced by context; explanations may vary, depending on when and where they are given, by whom, and to whom they are told (Helman 2007:130). Muhafiz's explanatory model is a reflection of the questions of the interview guide, the place that the questions were asked, the stage of the treatment and my own presence in the field. His explanatory model must therefore be seen as a result of the interaction between the researcher and the informant, a point that I will elaborate further upon in the next chapter.

Muhafiz starts the interview by providing a 'country name' for the illness, which indicates that he on the basis of the symptoms was familiar with the disease. My impression is that Muhafiz did not acquire this knowledge until consulting a traditional healer. When Muhafiz decided to consult the traditional healer, he was likely to have made an evaluation of the first symptoms of the disease. This, I argue, because most families affected by Burkitt's lymphoma in Cameroon spend considerable time observing the illness, hoping to find the appropriate cure. When the disease did not pass, Muhafiz started to question *what* had happened to the child. Being unable to identify the symptoms, he invited a healer who came to his house. The healer indicated that the child was suffering from 'Yutaamou'<sup>9</sup>, a common illness among children in the area. Muhafiz did consequently not spend much time thinking about other plausible causes. The healer made razor cuts on the child's jaw and mixed medical herbs

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<sup>9</sup> Yutaamou is a local name in the Fouban area for a swelling that occurs in any part of the body.

inside the cuts, but the child's condition only continued to deteriorate. Muhafiz saw himself forced to try a different mode of treatment and brought Yara to a health center. He was told that the ailment had to be treated with injections; indicating 'Western' medical treatment. As the traditional treatment had failed, Muhafiz suspected that this might be the case and he agreed to admit the child to the health center.

Two days into admission, the health personnel informed Muhafiz that they could not treat the disease. He was instructed to bring the child to Bafoussam Hospital, where they would have the equipment to treat the child's condition. At this point, the health personnel referred to Yara's condition as cancer. The second failed attempt to treat the child forced Muhafiz to once again re-evaluate what had caused the child to fall ill. He started to question whether the ailment was caused by God or a sorcerer. His unfamiliarity with childhood cancer caused him to question *why* it had happened to *his* child at that *particular* time. Drawing on popular medical knowledge on health, he suspected that it might be a supernatural cause to the ailment. Having tried several treatment alternatives without results and unsure of what was causing the disease, Muhafiz decided to bring the child home where the family could observe the illness and make further decisions.

Three weeks after the first symptoms, Yara's condition seriously deteriorated. Her stomach was distended and the cuts made by the traditional healer had not healed. Muhafiz started to worry about what would happen to the child if nothing was done. Being head of a household, with five children and a wife, he was obliged to evaluate the likely effects the choice of medical care would have on other family members. Going to the hospital would require that he abandoned his household- and farming activities. These were additional concerns to that of paying for transportation, medical treatment and food at the hospital. These pressing concerns forced Muhafiz and his wife to make a serious undertaking of the best practice regarding Yara's ailment. Seeing the hospital as the last option for cure, Muhafiz started to look for money to borrow. To Muhafiz' relief, a neighbor agreed to lend him 40.000 CFA. On departure, Muhafiz considered going to Bafoussam<sup>10</sup>, which was the nearest hospital. Yet, he

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<sup>10</sup> This hospital did at the time of the research not offer treatment of Burkitt's lymphoma.

changed direction and headed towards Bansa, as he had heard that it was a big hospital. The choice of taking Yara to a remote hospital in hopes of cure was risky and could be followed by a series of negative consequences.

When the first course of treatment was completed, Muhafiz felt encouraged about the child's rapid improvement. He settled with the disease explanation provided by the nurse; in which she told him that the child was suffering from a childhood cancer caused by malaria. Muhafiz decided to stay at the hospital in between the three chemotherapies, as he could not afford going back and forth with Yara to the village. This decision caused him to be away from home for one month. Muhafiz received his compensation, as the child was in good health and the tumors had completely regressed.

In spite of the financial consequences of hospital treatment, there were no disagreements in the family about the choice of medical care when the child fell sick with a relapse of Burkitt's lymphoma. According to Muhafiz, "even the child's grandparents agreed that she should be taken to the hospital". Having "wasted time with the traditional healer", the therapy management group agreed that Muhafiz should bring the child back to the hospital. Yet, there were a series of challenges to overcome. All of their money had been spent on the first admission, and the few coffee bags that they owned had been given to the person who lent them the money. At the same time an additional concern troubled the family. Yara became ill during the rainy season; a time in which the crops needed to be taken care of. Leaving the farming activities at this time of year could place the household in a devastating position of damaged crops; not only their primary source of food, but also their source of income. His absence would be an additional burden to the costs of bringing the child to a hospital as Muhafiz characterized himself as "a person who bends down", a farmer heavily dependent on subsistence farming.

A third concern, which troubled most of my informants, was the deteriorated road conditions during the rainy season. Travelling from a remote village would only be possible by motorbike. On the worst stretches, Yara and Muhafiz would most likely have to get off the bike and walk, in order for the bike rider to get past the mud holes filled with water. These factors, along with the person who was going to lend him the money, but withdrew, were all

contributive factors to the three weeks of delay of treatment. Asking Muhafiz how he was feeling towards the situation, Muhafiz replied with a low tone, as if the strength of his voice was gone:

She is so weak and tired; it is like there are no bones in her system. She is worried because she is no longer in control of her body. I have to argue with her to make her eat. It is as if I myself have the illness. My blood is not strong and my mind is no longer with me. I am tense and my heart is weakened. I feel like I am missing out of being other places, but I will be rewarded the day the child recovers.

Tragically, the following day it became clear that Muhafiz would not receive his reward. Instead, in the grim realities of life and death, the father saw himself forced to transport his daughter home in a shopping bag. These horrible circumstances led me to expect that Muhafiz would be devastated. Yet, I found Muhafiz to be calm and unattached while managing the tasks before his and Yara's departure. Trying to understand the contrast between Muhafiz' personal account and his seemingly unattached behavior in the mortuary, I find support in Nancy Sheper-Hughes' description of "Death without Weeping: The Violence of Everyday Life in Brazil".

In her book, Scheper-Hughes (1992) presents the story of mothers in Bom Jesus, a shantytown in northeastern Brazil whom she experiences to show indifference towards the weakest of their children. In the initial stages of the fieldwork, Scheper-Hughes is unable to resonate with the mothers' lack of mourning over the death of a child. Similar to Scheper-Hughes, I was long troubled by Muhafiz' lack of mourning after the child's death. It was not until later, during a conversation with my interpreter, Mr. Tsemi, that I managed to contextualize Muhafiz' actions. Mr. Tsemi told me: "If you already know what you are going to face, then you prepare your mind for it". He was talking out of personal experience, but he highlighted an imperative point about the reality of most of my informants. Mr. Tsemi altered my understanding by bringing attention towards what at first glance had not been visible to the eye.



In Cameroon, a corpse is usually transported from the mortuary in a taxi or a private vehicle. I did also on occasion observe coffins transported on motor bikes in Kumbo town, most likely empty. Never did I see a hearse come by to collect a casket at the hospital, which gave me the impression that it was the privilege of the very few. For those who had travelled a long distance and experienced a poor treatment outcome, the close relatives had the opportunity to bury their beloved one at the hospital burial site. This option was expensive and the people whom I talked to indicated the importance of burying their relatives in close proximity to their home. Passing houses while travelling by road in Cameroon, I had this confirmed, in which a cross or a tomb stone was commonly situated in people's yards.

Muhafiz had made up his mind to bring Yara home for her burial. With no money to pay for a hearse, the only way to transport her body was by taxi. For most taxi drivers, a dead body is unpopular cargo. One can imagine several reasons for this, one being that a coffin takes up much space that could have been replaced by paying customers. Usually, this causes a taxi driver to double the price of transportation. Unable to buy a coffin or to pay double the price, Muhafiz had to find a different alternative. Mr. Tsemi enlightened me that Muhafiz' decision of hiding the body inside a shopping bag, under kitchen utensils, was most likely the only way that he was able to get his child home. If Yara's body was to be discovered, Muhafiz would be at risk of being kicked out of the taxi, as he did not have the money to pay for Yara's transportation. He was, therefore, forced to keep the body away from the taxi driver's attention. Under such conditions, there was little time for grief or sorrow. What had been important was to get Yara home. I see this in light on Scheper-Hughes's argument, in which she argues that poor Brazilians work on their self and emotions in a very different way than what is regarded as the norm in Euro-American milieus.

Instead of the mandate to mourn, Scheper-Hughes argues that: "The Alto mother is coached by those around her, men as well as women, in the art of resignation and 'holy indifference' to the vagaries of one's fate on earth and a hopefulness of a better life beyond" (Scheper-Hughes 1992:429). I did not experience an indifference towards the child's health, but I found that Muhafiz could not let himself be run over by emotions when dealing with the child's death. Like Scheper-Hughes illustrates with the mothers, Muhafiz indicated that he felt an inability to influence the situation at hand: "I put everything in God's house. It is only God who knows whether a disease comes to pass, or to put everything to an end". I interpret this statement as a

belief that “God is ultimately in control” and that he was prepared to accept whatever came to him. I also find this statement to illustrate the realities that the family members were faced with, colored by social inequality and poverty. Muhafiz seemed to act out of the little resources that were available to him and accepted those that were not.

The desperate struggle to survive does, according to Scheper-Hughes, create a distance between the mothers and their children, which has transferrable value to this family’s therapy management of Burkitt’s lymphoma. A life shaped by scarcity and deprivation is the context for the families’ experience and actions towards death. What we then find is that what may appear to be a cultural expression of sorrow is in reality a reflection of the socio-economic context of the disease. My story of Yara ends here, but her family members go on with their lives, dealing with the devastating consequences of the cancerous syndemic. The disease affected them in a multiple of ways; experiencing the loss of a child, being forced into debt, seeing their crops go to waste, while being forced to give away the little ‘food stuff’ they had to people who had lent them support. This tragic outcome is perhaps best described by Mr Tsemi who concludes: “When something comes into your family here in Africa and drain all you were relying on it will be a very big problem, because that was all you had”...

## **Peter’s Story**

It was the last day of July and I was surprised to find that three days after eighty-year-old Marie and her grandson Peter had abandoned hospital treatment, they had returned to the Burkitt’s ward. We assumed that the patient’s grandmother had decided on a different form of cure and feared we would not see them return. In order to gain an understanding of the mechanisms behind Marie’s therapy management of the illness, Mr. Tsemi and I sat down to talk with her in the registration office at the Burkitt’s ward. The following story unfolded:

Marie grew up in Kumbo town where her father was an influential man among the Jujus<sup>11</sup>. The Jujus would often come to their compound to congregate and Marie grew up with their practices. One Sunday, during the ‘Juju season’, there was an issue in which a Juju trespassed into the church. The Jujus were only allowed to follow the main road, so people questioned why he would go through the church where there were both men and women. The Christians became very angry and attacked the Juju who then ran off. The case was taken to a traditional court at the palace, where Marie’s father judged the case. He did not vote in favor of the trespassing and the Jujus were consequently dissatisfied with him. Marie’s father was angry about the way the Jujus were handling things, - not obeying the rules. As his hands were not tied with the traditional practices, he decided to hand back the Juju-things and to follow the Christians to church. He became a devoted Baptist-Christian and Marie was baptized at a very young age. She was taught to live in accordance to God’s will and when a family member became sick with an ailment she was told to always bring the person to a Christian hospital.

At the age of thirty, Marie got engaged and later married a young farmer. In the following years, she gave birth to ten children. The children grew up working at the family farm, selling whatever extra they had from the rice- and palm tree plantations at the market. They moved out and established families on their own, but to Marie’s despair, seven of her children passed away in their adulthood. The youngest of her children, Blessing, married a man with whom she had four children. She was later divorced from her husband and met a new man whom she decided to move in with. Her new fiancé did not allow her three oldest children to move into their compound (amongst them Peter), and Blessing saw herself forced to re-allocate them to her parents. Marie and her husband became Peter’s primary caregivers.

Two and a half months prior to the hospitalization, Marie discovered that Peter was looking pale and rapidly losing weight. She had no idea what had caused the ailment

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<sup>11</sup> “Juju” is Pigin-English and transfers to ‘black magic’. The Juju practices are manifested in animism, in which people dress up wearing masks and outfits while acting as supernatural beings.

and decided to wait and see if the symptoms would pass on its own. It was not until two months after the first symptoms of disease that Marie brought the child to Bangolan health clinic. The child's condition had not improved and his abdomen rapidly distended. The health personnel at the clinic examined Peter and referred them to Bansa Baptist Hospital, but Marie did not have any money at her disposal and decided to bring the child back home to Mambin.

The next couple of days, the family looked for money to take the child to the hospital. Several people came to her house and advised her to take the child to a nearby hospital or health center. Convinced that Bansa Baptist Hospital provided the best care, she had her mind set. She told them that "If the child survives at Bansa; fine, if the child dies at Bansa; fine". Peter's grandparents managed to borrow 10.000 CFA from a neighbour. Marie paid a bike rider to take her and Peter to Babessi where they got on a bus that took them to Kumbo. On arrival at the hospital, Peter was examined by Dr. Njume in Outpatient Department (OPD). The doctor told Marie that the child was suffering from cancer, a disease affecting the abdomen and legs, and in her own words, "causing the child not to be walking strong". Dr. Njume completed the consultation and instructed Marie to have the child registered at the Burkitt's ward, where she had to pay a hospital fee of 30.000 CFA; a vast problem for Marie who only had 8000 CFA at her disposal. Thinking she had no other option, Marie brought the child back to the village to look for money. Back in the compound, she asked her husband to beg for money from neighbours and friends. She was very worried about how to finance the hospital treatment and had sleepless nights because of it. Having a lot of trouble getting the money, they went to three different people. Marie's husband was "just up and down looking for money" and finally managed to borrow 20.000 CFA from a friend. In hopes of that the hospital would receive the child; Marie brought Peter back to the hospital, well aware that she did not have enough money to pay for the treatment.

At the time of the interview, Peter had received his first chemotherapy, but Marie was still contemplating on how to find the remaining 10.000 CFA to pay for the treatment. What to us seemed like negligent behavior and abandonment of hospital treatment had in reality been a

grandmother's desperate – but in fact remarkable ability – to find the means to pay for the child's cure. When I asked Marie about why she preferred hospital treatment, she answered: “When you go to the hospital and take medicine the sickness will pass. I was very determined to come, even though I was facing financial difficulties”. Marie indicated that she considered the hospital the only appropriate resort. Yet, there were important deviations in her actions, compared to these statements. During the interview it became clear that Marie had a ‘home pharmacy’, consisting of numerous pharmaceuticals. These drugs were bought from local drug sellers. In the event of illness, Marie observed the symptoms and made an evaluation whether the disease would pass on its own, or could be treated with simple pharmaceutical drugs available in the household. Before taking Peter to the hospital, Marie had tried various pharmaceutical drugs, as well as prayers for cure, but without result. The example illustrates how preference of treatment does not necessarily apply to all symptoms, neither does it always become the first choice when regarded the appropriate resort.

## **Patterns of Resort**

In the previous section I pointed to the despair that patient, caregivers and health personnel experience in their meeting with Burkitt's lymphoma. The examples indicate that various types of treatment are explored in search of cure. Paul Brodwin (1996) argues that people who fall ill in a *pluralistic medical setting* must choose between a multitude of treatment alternatives. This is true both in small-scale communities and in the urban centers of post-industrialized societies. The Cameroonian health care system is characterized by medical pluralism, in which a wide variety of health care options are working side by side in the ‘formal’ and ‘informal’ sector of medical care (Van Der Geest 1991). The main treatment resorts of the formal sector are hospitals and health clinics run by the government and religious missions, as well as private health clinics and pharmacies. The informal sector generally constitutes home-based treatments, as well as religious healing activities. Other main resorts of the informal sector are unauthorized drug vendors who sell pharmaceuticals, as well as various forms of ‘traditional’ treatments by unauthorized healers.

The listed treatment resorts have habitually been categorized based on the notion of polarization across the world; such as the concepts of ‘Western’ versus ‘non-Western’, and

that of “modern” versus “traditional” medical treatment. Bradley Stoner (1986) has criticized the efforts by authors and social scientists to describe and define medical systems as conceptual, as well as to develop typologies of the systems. According to Stoner, this polar representation of health care systems has created a falsely restricted view of the complexity of the environment and the multiplicity of therapies within a society. By swearing to such categorizations one fails to consider how various health care providers incorporate elements of both traditional and modern medical practices into their healing. Stoner argues that we can only understand the complexity of medical pluralism if seen in light of the total life patterns of individuals within any society. This analysis includes an understanding for the interconnected nature of many spheres of existence; social, biological, cultural, political and medical. With this critique, Stoner called for a new approach to the study of medical pluralism that is of practical significance to the fieldworker investigating therapy management in a society.

Our understanding of medical pluralism has evolved from mere reflections on how medical systems may differ in their general characteristics to a better understanding of how they mesh and articulate in particular societies and settings (Janzen 1978:80). Recent research represents the existence of a multitude of alternatives, “in which decision making develops in response to the availability of actual health care options, rather than systems” (Stoner 1986:46). In the early eighties, Kleinman (1980, 1984) widened the view of a society’s entire “health care system” as a complex of overlapping and interconnected sectors. This, he refers to as the *popular-*, *folk-* and *professional* sector; each sector with its own way of explaining and treating ill health, defining who is the healer and patient, as well as specifying how healer and patient should interact in their therapeutic encounter (Helman 2007:82). This contributed to a more clear picture of *how* and *why* the decisions to utilize one option over another were made.

The discussion of this thesis is in line with Stoner’s argument and not concerned with medical systems. My approach to the study of therapy management in Cameroon is based on an investigation of the various treatment resorts that the families turn to in the times of illness. I argue that an investigation of the actual health care options used by members of the community, rather than an investigation of medical systems, provides a more accurate picture of the treatments acquired. Along with Stoner, I stress that in times of illness, the immediate material of health care decision making is neither systems nor sectors, but available health

care options (Stoner 1986). I refer to the available health care options as ‘resorts’ and elaborate upon these with reference to Kleinman’s (1980) usage of the ‘three sectors’.

In the mid-nineties Gery W. Ryan (1998) conducted a quantitative study of people's choice of medical treatment for 429 non-chronic illnesses in a small Kom-speaking village in the North-West Region of Cameroon. He refers to the treatment-seeking behaviors of his informants as their ‘pattern of resort’, defined as “the sequences of health actions that caretakers perform” (Ryan 1998:211). Ryan carried out his research among members of 88 randomly selected households where his findings suggest that the families commonly considered seven resorts when someone fell ill: *Waiting, home remedies, pharmaceuticals, traditional healers, clinic, nurse and hospital* (Ryan 1998). The resorts were, according to Ryan’s findings, commonly sought in this rank of order, based on the severity of the illness. I have on the basis of interviews with 33 families affected by Burkitt’s lymphoma at Bansa Baptist Hospital developed a tentative model of resort, which reflects a dominant pattern in the therapy management of the illness in the North-West and West region.

THE BURKITT’S PATTERN OF RESORT	
Day 1	Wait for improvement
Day 4	Home remedies
Day 7	Pharmaceuticals
Day 15	Traditional Healer/Health clinic
Day 31	Hospital

Table 1.

In coherence with Ryan, I distinguish between the six resorts: *waiting, home remedies, pharmaceuticals, traditional healer, health clinic and hospital*. I exclude the category *nurse* from the model, as the caregivers did not point to this as a resort of consideration. The model indicates the treatment resorts commonly visited by caregivers prior to hospital admission, but also gives an indication of the time commonly allocated to the various resorts by the caregivers whom I interviewed. The caregivers had also visited other treatment resorts, such

as ‘prayer bans’ in church. There was less frequency in the use of this resort, and I have consequently decided not to include it in the Burkitt’s pattern. This could be a weakness. Prayer bans were normally sought having tried the three first resorts without result.

I have chosen one month as the outset of discussion, as the caregivers on average spent one month to get to the hospital. In some cases, the time from the first to the last resort was doubled and even tripled. The construction of a pattern of resort among the affected families is undertaken with realization that it is merely an analytical product of the view-point of the investigator (Stoner 1986). The patients and families do not themselves use this term, nor do they organize or reflect upon their therapy management strategies in such patterns. Yet, the model indicates a tendency, which I wish to further investigate.

Romanucci-Ross (1969) was the first medical anthropologist to launch the term ‘hierarchy of resort’, which implies that people to whom the resorts are available give them a rank order. In recent years, anthropologists have questioned whether it is correct to think in terms of a hierarchy of resort. Janzen (1978) and Stacey (1988) both highlighted that it appears to be a mistake to imagine that people hold treatment alternatives ready ranked in their heads. More likely does it seem that people store a variety of information, which they use as seen appropriate and feasible (Stacey 1988:23). In the late fifties, Nadel suggested that “ decisions and choices . . . are more diffuse than any massive social transformations; they affect not any total shift, but move-by-move rearrangements and they happen all the time, in the manner of readjustments to never-quite-identical circumstances” (Nadel 1957:136).

These ‘circumstances’ are of interest to this discussion. In the following chapters, I take a closer look at the various resorts in the Burkitt’s pattern and investigate how therapy management and explanatory models are negotiated in the process of finding appropriate care. The empirical examples illustrate how the therapy management is a process open to ad hoc questions and issues that may arise in the midst of a situation. In spite of its flexibility, I argue that there are certain reoccurring factors which influence their therapy management. This has impact on the Burkitt’s pattern, in which it tends to take a certain shape. I argue that it is no coincidence that home remedies become the first, while the hospital, located far away and becomes the last resort.



## Chapter 4: Behind Home Remedies and Delay of Treatment

*Rosaline and her four-year-old daughter Immaculate went to work on the farm. After they had started working, Immaculate pointed to her navel and cried, “it di hot”. Rosaline removed the child’s clothes and got some herbs from the farm, which she told the child to ingest. She brought the child back to the house, convinced that the treatment would make the child vomit and resolve the stomach ache. Throughout the night, Immaculate was vomiting and crying in pain. Rosaline looked to the child the next morning and noticed that her navel was protruding. The child’s condition was deteriorating, but Rosaline decided to wait and see if the problem would resolve itself.*

In this chapter, I set out to illuminate the families’ therapy management strategies in the initial stages of Burkitt’s lymphoma. Among the majority of families admitted to the Burkitt’s ward during the time of my research, the first treatment modality of the illness was to wait and see if the symptoms would pass without medical interference. If the symptoms did not pass on its own, the second resort was to administer home remedies. With these findings I investigate: *What are the reasons why therapy management starts at home and with home remedies?*

My empirical findings suggest that in its initial stages, underlying concepts of health and illness, in co-relation with socio-economic factors, are the main structuring factors behind the families’ therapy management. The reader is introduced to the potential differences in the health personnel and patients’ understanding of Burkitt’s lymphoma and the ways in which this influences therapy management. I discuss culturally meaningful disease explanations through the dichotomy of ‘natural’ and ‘unnatural’ illnesses and illustrate how Burkitt’s lymphoma is commonly considered as ‘natural’ or ‘not serious’ in its initial stages. This is demonstrated through empirical examples, in which the outset of discussion is a home visit conducted to former patients of the Burkitt’s ward. The example indicates various levels of *distance* that the families commonly experience between the village and the hospital.

## Home visits

Professor Hesselning and Dr. McCormick made a one-week stay at Bansa Baptist Hospital in March 2009 to review the Burkitt's lymphoma treatment protocol. Having spent two months with patients and health personnel at the Burkitt's ward, I was thrilled to meet the founders of the treatment program. An important feature of their review was, together with the program nurse, to conduct home visits to their former patients. The visit to Cameroon had therefore been planned well ahead of the rainy season, as roads would become impassable in most rural villages. The evening before the doctors and nurse were going to conduct the home visits, I was invited to join them on their journey to the West Region.

I left my house 06.30 a.m. As I reached the Resthouse at the hospital premises, Dr. McCormick and Nurse Holike had found their seats in the back of the white hospital vehicle decorated with green CBCHB logos. The doctors had agreed to rent the hospital vehicle, though expensive, as they both considered themselves too old to be riding on motorbikes for several hours. Driving a private car was a luxury that I learned to appreciate, as my following home visits were conducted by motorbike. Professor Hesselning was doing last minute preparations, making sure we had sufficient supplies of snacks and drinks for the long day ahead. We were ready to depart at 07.00 a.m, but before the journey started our driver Joseph abruptly uttered "let's pray". I sensed that Joseph's prayers for protection on the road were well grounded, as we had a 'potholed day' ahead of us. The jagged road conditions and capricious guards along the sign posts towards the West region could cause unforeseen problems. Driving a hospital vehicle was thus considerably safer than to ride a taxi, bus or bike. A loud "Amen!" rung in the car as Joseph started the engines.

We had reached the village of Koupa Matapit, west of Fouban town, when Joseph slammed the brakes. I frantically shouted "stop, stop, stop!" A man wearing a blue and green track suit had caught my attention. The man was Aboubakor; the father of Muhammad, a patient recently discharged from the ward. Aboubakor, who was sitting on his motorbike at the taxi station, had also noticed the hospital vehicle and quickly got off his bike. Waving his hands to catch our notice, we pulled over to the side and waited for Aboubakor to come and greet us. Handshakes were shared, and we were grateful to hear that Muhammad was in good health.

Aboubakor insisted that we should come and see the boy, as their compound was ‘just down the road’. The doctors elaborated upon the matter and decided to take time for a visit.

Aboubakor squeezed into the back seat, while I shared the seat in the front with Professor Hesselning. The professor looked at me with a smile: “We are lucky to drive the hospital vehicle”. I could not imagine travelling this route by motorbike in the rainy season, and less so with a sick child and luggage on the bike.

I had followed Muhammad from his first admission to the hospital until discharge. The family had delayed two months before consulting a doctor at the hospital, and the child was consequently in poor health and severely malnourished on admission to the Burkitt’s ward. During their time at the ward, I inquired Aboubakor about the course and management of the illness. Aboubakor explained that one of the reasons why the family had decided to delay treatment was the poor road conditions and the long distance to travel from their house to the hospital. Driving to his house, I was thus surprised to discover that ‘just down the road’ meant a thirty minute drive on a barely passable path. On arrival, Aboubakor invited us into a spacious room, which appeared to be an extension of three large households in the quarter. In spite of the simplicity of the red-soiled floor and the yellow plastic chairs aligned with the walls of the room, it appeared to be a high standard household. I imagined that the large room was used on special occasions, such as a wedding celebration, a funeral, or in this case, a doctors’ visit.

During my conversation with Aboubakor at the Burkitt’s ward, I had asked him to what extent finance had been a factor in his choice of medical treatment. My limited knowledge of Pidgin-English at the time of the interview had led me to ask Nurse Ngang for help with translations. Aboubakor started to respond, but was cut short by the nurse who commented: “People from the Fouban area earn much money because of their good soil”. An important aspect of the nursing job at the Burkitt’s ward was to sort out those who were in need – and those who could manage without – financial assistance from the treatment program. Aware of that the family’s income was above 25.000 CFA, Nurse Ngang considered them financially sturdy compared to most other families at the ward. Aboubakor did not protest with the nurse’s assessment, but maintained that he delayed hospital treatment because of the long distance to travel and that he did not think the illness was serious. It was not until the symptoms of

disease became visible that he had started to worry about the child's condition, as he had witnessed several children in their village die from the same signs. At this point, he had tried a wide variety of home-based and pharmaceutical treatments. As the condition continued to deteriorate, he decided to go to a traditional healer. Without results and being afraid that Muhammad would suffer the fate of the other children, Aboubakor saw no other option but to pack his bags and bring Muhammad to the hospital.

Several women and their children appeared in the room; along with them, Muhammad. The five year old boy was barely recognizable from our first meeting at the hospital. His swollen abdomen and the tumours that had disfigured his face were completely regressed. To make sure that there were no signs of relapse, Professor Hesseling greeted the child and lifted him up on a small wooden table for his examination. Well aware of the little time on our hands, we hastened to the car on completion of the medical inspection. Travelling at night would be dangerous due to the many armed bandits lurking by the roads after dark. I had overheard the caregivers sharing horrific experiences with each other at the ward; stories of being robbed of everything they owned, while forced to lie on the ground, fearing for their lives. Such incidents had happened to several of the families on their way to the hospital. This was also a situation, which caused me to worry about travelling alone in Cameroon.

Our next destination was a small village located inside a river valley. We were going to visit five year old Chemsiatou who had been treated for Burkitt's lymphoma one year prior to my field work. Driving further inside of the densely forested area, Dr. McCormick attentively looked out of the window. The humidity increased as we continued inwards the valley. Constituting ideal mosquito hatching conditions, Dr. McCormick exclaimed: "This is a typical Burkitt's area!" Professor Hesseling did not seem to take notice of the scenery or Dr. McCormick's comment. Instead, he was intently studying the patient's journal and a picture taken on admission. In the journal there was a description of the child's residence and address. The information provided by the caregiver was thus an explanation of the nearest church and the school district that the child belonged to. With no street names in the rural areas, the only way to find the compound was to ask people we met along the road. It felt like doing detective work, with slight disbelief that we would be able to locate the girl.

After a long trip on dusty and meandering roads, we finally reached the boundary of the village. The only French-speaking traveller, Joseph, got out of the car as we spotted a local chief whom we had high hopes might know Chemsiatou's family. After a quick glance at the photo, the chief confirmed that the slender roads ahead would lead us in the direction of their compound. Joseph drove until we spotted a farmer who was working on his crops. Our driver slammed the door and walked towards the man who wiped his hands on his beige pants before he received the picture handed to him by Joseph. A quick glance at the photo was followed by a thorough investigation of the hospital vehicle and the four of us sitting in the car. The man looked uneasy as Joseph was asking questions about the girl.

On his return to the car, we knew that Joseph had received dire news, as his eyes faced the soil. With great conviction, the farmer had told him that the child was deceased. Disenchanted, Professor Hesseling maintained that a stopover to see the parents was still of significance. The farmer reluctantly mounted into the car and squeezed into the back seat, as Joseph had talked him into leading us to the compound. Approaching the child's residence, the farmer nervously confessed that the child was not late, but utmost alive. Overwhelmed with relief and little time to argue, we hastened out of the car and walked down the trail leading to the quarters. The farmer's decision to lie about the child's death troubled my mind and caused me to suspect that he was somehow trying to protect the family.

Women and men were out on their farms preparing their crops for the rainy season. Their eyes were swiftly on us as the sound of the vehicle had caught people's attention. I watched the farmer enter a tin-roofed compound encircled by a variety of palm trees. The compounds made of red clay were beautifully adorned with black and white drawings on the walls, making each house different from the other. A child was playing in the courtyard, but her activities were abruptly replaced by tears as she spotted the three 'white men' who approached her house. The farmer reappeared outside the compound, this time accompanied by the head of the household. He introduced us to the old man who presented himself as Chemsiatou's grandfather. Professor Hesseling asked Nurse Holike to ensure him about the purpose of our visit and that we were concerned about the child's health. The girl who had run inside was forced to come out and greet us; we had found our patient.

The atmosphere that had weighed us down in the car changed as the child's grandfather invited us to sit down in his living room. Within a couple of minutes, women were hastily running in and out of the room, serving groundnuts, bananas and palm wine. With the permission of the grandfather, Professor Hesseling examined the child who reluctantly complied with her grandfather's command. Nurse Holike asked the grandfather to find the child's hospital card, in order for the doctor to make notes of his visit. A young boy was sent to find it, while more and more people gathered around the compound to observe the medical examination. On completion of the check-up, the grandfather politely handed Professor Hesseling his own hospital card and asked whether the doctor could prescribe him some tablets. He was suffering from 'short breath' and the hospital was located far away. A small conversation followed about the medication he had been taking and where he had gone for treatment. Professor Hesseling suggested going to a local clinic, in which they could make further examinations. Leaving the family's house that afternoon with the trunk full of appreciations, such as plantains and palm wine, I suspected that the grandfather would not follow up on the doctor's advice.

After several hours of driving and a number of dead ends, we reached the gates of our last stop. Unable to get past the gates of the village, a crowd of people gathered around the vehicle. Joseph and Nurse Holike found it to be an appropriate time to get out of the car and ask people about ten year old Glory's residence. Holike navigated through the dense crowd, but I could read from her facial expression that she was becoming increasingly uncomfortable. Her usually firm voice was shaking as she shouted for help to locate the girl. What I experienced as initial curiosity among the people in the crowd had been replaced by hostility and anger. Our quest to locate the child had provoked an argument between two parties. The dominant group was telling us that the family did not live in the village anymore and that the child had passed away. One boy was particularly pervasive, asking questions about what we wanted from the family. Nurse Holike asserted that we only sought to make sure that the child was doing fine. The other group of people seemed less hostile, in which a man finally raised his voice and told us that he would take us to the compound. The boy who had told us that the family had moved out of the village started a dispute with the man, a time in which we saw a chance to drive through the gates that had been opened.

People were running ahead of the car, seemingly to alert the family about our arrival. We had only reached the beginning of the road, when a man pointed in the direction of a small house. Headed by the crowd of people, we approached a woman who was standing in the doorway of the compound. The woman invited us to come inside shortly after greetings were exchanged. It was a one-room household, in which the sleeping space was separated from the common room by two pieces of fabric. There were enough seating for five people and the mother found a small corner in which she placed, and sat down on, a wooden stool. Speaking in Pidgin-English, Nurse Holike gave a brief description of the purpose of our visit. As the nurse asked the mother to tell us what had happened to Glory, a cross situated in the middle of the yard caught my attention.

The child had died on December 6<sup>th</sup> the former year. The dim lighting of the room made it difficult to read her facial expressions, but I sensed that the mother was struggling to keep tears away when talking about Glory. Being miles away from the nearest hospital and having had all their resources drained on the previous hospital admission, there was no money left to pay for treatment when the girl suffered a relapse. All other treatment options were exhausted, and the mother had no alternative but to watch her daughter die in their compound. Concerned with the contributive factors to the delay of hospital treatment, Professor Hesseling asked the mother about how much the transportation from her house to the hospital would have cost them. The woman looked worried, as if fearful of the doctor's reaction. His calm nod and smile thus seemed to bring her at ease and she replied that fees for transportation were 6500 CFA (about 10 dollars).

The boy who had met us with initial hostility appeared in the room and sat down on the floor, next to the woman. Nurse Holike looked at the boy. Now, with a firm tone, she voiced: "lies will get you nowhere. One should be friendly and welcoming when a hospital vehicle comes to the village". The boy, whom I quickly realized was Glory's brother, appeared to have accepted that we had not come to his compound to cause more grief. There was an unmistakable look of sorrow on his face, which seemed to block any sense of relief that one might expect from our friendly visit. Leaving the family, I faced the tough realities of people dealing with Burkitt's lymphoma in Cameroon. Yet, another was soon to come. The following morning, I learned that another family shared their heartache.

With great sadness, Dr.Njume told us that his five year old patient, Amza, had died while waiting to receive chemotherapy. The boy had returned to the hospital prior to the scheduled treatment due to a measles infection and pneumonia. The health personnel had tried to fight the co-occurrence of the measles, in order to proceed with chemotherapy. His immune system was completely broken down by the cancerous cells and severe malnutrition. All they could do was to hope that the immune system was strong enough to deal with the infections. I was surprised to find that the mother had decided to return to the ward with Amza. Only a few days after the child's first admission, the mother approached me, as she had mistaken me for a doctor. Before I had the chance to tell her that I was not a member of the hospital staff, she asked me about the child's prognosis. I answered truthfully that I did not know. To my bewilderment, the mother told me that if the odds for survival were low, she would rather take the child home than to *pay* to see him die in the hospital. It appeared that she was weighing the chances of cure relative to those of treatment failure, which guided her decision of whether the child should receive treatment.

The home visits provided valuable knowledge on affected families' socio-economical background, as well as environmental factors that could potentially influence their choice of medical care. The empirical example that I have presented points to *various forms of distance* that may influence why families affected by Burkitt's lymphoma do not bring their child to the hospital until the disease has reached an advanced stage. It also gives an indication of reasons for abandonment of treatment. At its most basic level, the example demonstrates distance in terms of kilometers, poor road conditions and dangers associated with travelling.

Illustrating the lack of access to medical care, such as to health centers and hospitals in the rural villages, the grandfather of Chemsiatou exemplifies how 'short cuts' are made to restore health. The fear of money collectors from the hospital becomes evident as people resort to lies in order to protect their fellow villagers. These dishonesties demonstrate not only a physical, but also a social distance between the patients and the hospital workers. The disinformation was clearly not an expression of not caring about the child's health. This is rendered visible in both examples, in which the uncooperative farmer was a friend of the affected family and the hostile boy was the brother of the deceased child. Rather, it seems to be the result of the social and economic marginalization that constituted their daily life. This marginalization becomes



even more evident when looking at the choice a mother must take of whether to pay for the treatment of her weakest child, or to watch him die, while trying to care for her other children. It appeared that her experiences were similar to those of the mothers in Brazil, creating a distance between the mother and her weakest child.

Arora and colleagues (2007) report similar findings in their report on abandonment of treatment among children affected by cancer in developing countries. They conclude that abandonment is higher among patients with poorer prognosis (Arora et. al. 2007). The empirical example of Amza gives suggestion to why this could be the case, as it is not only a decision that affects the individual, but the family as a whole.

I have earlier argued that we must investigate both individual and collective understandings of illness in order to gain an understanding of the management of Burkitt's lymphoma in Cameroon. I have until now attended focus to the therapy management of individual families and the socio-economic context for their therapeutic action. The story of Muhammad in the previous section highlights another aspect of therapy management, in which the child's father interpreted the symptoms of the disease as 'not serious'. This had, according to the father, an impact on his decision of not to bring the child to the hospital in the initial stages of the disease.

In the following discussion of this chapter, I examine the affected families' therapy management in light of popular medical knowledge that dominates public discourse in Cameroon. I start off this discussion by introducing the health personnel and patients' seemingly contradictory interpretations of Burkitt's lymphoma. By closely investigating the caregivers' explanatory models, I elaborate upon the problem of seeing medical knowledge as 'static'. Rather, it must be seen in light of a social context.

## **Cultural Understandings of Disease**

Several studies have addresses the reasons for why some people consult, while others do not consult, a doctor for equal complaints (Zola 1966, 1973, Hackett 1973). Kenneth Zola's

“Pathways to the doctor – From Person to Patient” published in 1973, investigates *how* and *why* a person seeks professional medical aid. Zola highlights that the statistics show that the delay of treatment is the norm, rather than the exception in most societies. Yet, when a person does not seek, or delays too long in acquiring professional medical care, we begin to question his rationality (Zola 1973:678). In the case of a serious ailment like cancer, the affected person is generally expected to seek medical care from a health practitioner based on the symptoms of the disease (Zola 1973:678). Yet, research on the matter indicates that people who suspect having cancer, in many instances, delay and even avoid going to the doctor (Hackett 1973, Balsheim 1991, 1993).

In order to approach the reasons for delay and abandonment of treatment, Zola argues that we must go beyond what is often taken for granted; that a person goes to the doctor when he or she is sick. He proposes that we rather ask, “What does it mean for a person to be sick”? This, he contends is much clearer to those who use the term, namely the health personnel and researchers, than it is to those upon whom we apply it – the patients (Zola 1973:677). Zola contends that the study of selection and definitional process (therapy management) must include such questions. According to Zola, ignoring what constitutes a deviation in the eyes of an individual and his reasons for action “may obscure important aspects of our understanding and eventually our philosophy of the treatment and control of illness” (Zola 1973:687).

Zola brings attention to the variations between the patient’s and physician’s understandings of ill health. This distinction was brought to a new level by Eisenberg (1977) who investigated the experience of ‘illness’ versus the bio-medical treatment of ‘disease’. In his work, he characterizes the physicians’ acknowledgement of ill health as the management of ‘disease’ viewed as “abnormalities in the function and/or structure of body organs and systems” (Eisenberg 1977:9). Disease is treated as a discrete and clinically identifiable entity. ‘Illness’ on the other hand, may by the patient be experienced as “discontinuities in states of being and perceived role performances” (Eisenberg 1977:9). The patient’s experience of illness is often not visible, like the symptoms that constitute the physician’s diagnosis of disease. It is rooted in individual experience and interpretations-, as well as the social context of their suffering. Consequently, professional healers and patients may reach very different conclusions about the nature of the problem and what it means to be sick and to be healed.

Eisenberg underscores the physicians' failure to meet their social responsibilities when they treat disease as *truth* and experiences of illness as *belief*. Zola similarly concludes that the physician who does not pay attention to the patient's experience of illness is most likely to find that their patients do not complete treatment (Zola 1973:686). Instead of using the terms to 'illness' and 'disease' as a dichotomy, Lambek (2003) proposes:

One way to phrase the distinction between 'illness' and 'disease' [as these terms are used in medical anthropology] ... would be to suggest that 'disease' refers to a literalization of phenomena whose experience is always culturally, socially and psychologically mediated and hence open to interpretation (Lambek in Singer and Baer 2007:66).

By literalization, Lambek means "that health personnel in the biomedical tradition treat the signs and symptoms of disease as direct, natural expressions of a malady, rather than expressions of a human body and mind shaped by culture, social context, and the emotional state of the patient" (Singer and Baer 2007:66). From this perspective, 'disease' is no less a cultural construction than 'illness', but the former is a construction accomplished by healers and the latter by patients and their support network (Singer and Baer 2007:66). To avoid the pitfalls of the mentioned terminology, I use 'disease' in accordance with Lambek's suggestion, in which I attend focus to *who* defines the disease.

Having established that there are potential differences between the health personnel's understandings of disease to that of their patients, the question is still the same: what does it mean for a person to be sick from Burkitt's lymphoma and how does it influence therapy management? To get closer to an answer to this question, I found the health personnel's point of view to be of interest. Interviewing doctors and nurses working with Burkitt's lymphoma at three different hospitals in Cameroon, I posed the questions: "What perspectives do the patients have on the disease?" and "Are these explanations often in contrast to the one offered

at the hospital?” Posing these questions I hoped to get an idea of the patients’<sup>12</sup> explanatory models associated with Burkitt’s lymphoma, as understood by the health personnel. I found that the health personnel made clear-cut distinctions between their own and the patients’ explanatory models, applicable to Eisenberg’s use of ‘illness’ and ‘disease’.

One physician explained:

It is difficult for them. We had our culture before our religion. Many people still believe in it. It scares the parents when they see the sudden swellings. It is not ‘natural’ to them and they attribute it to witchcraft. Some conclude that it is a punishment from their ancestors. People are usually not educated, and the lucky ones are told by others to go to the hospital.

Another physician working with Burkitt’s lymphoma made a similar comment during our conversation:

When the parents see the symptoms of Burkitt's lymphoma, they often think it is ‘unnatural’. This is due to a general lack of knowledge of disease and often erroneous information. Most Cameroonians think that *someone* causes illness. It is not just ‘natural’, as most medical doctors would conclude.

Similarly, this physician notes:

They see it as witchcraft. They believe that the child has ‘crossed over something bad’. They do not believe that a small child can have cancer. They realize it first as they arrive in the hospital and are admitted to the ward where other children have the same illness. In Africa, most of the times when people die, the relatives will have to look for

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<sup>12</sup> The term ‘patient’ is in this chapter used to describe how both the patient *and* the therapy management group experience the illness. This is because the patient’s experience alone seldom influences the choice of medical treatment.

a cause. It is almost never considered natural. There is always *someone* who is behind the ailment. This is also often the case with HIV patients. Yet, there might be differences between rural and urban populations.

Asking a nurse about her thoughts regarding the patients' understanding of the disease, she replied:

They often think that it is witchcraft that has caused the disease. They are often scared to say that loud because they are worried that they will not receive treatment. They are also in a setting where this is not a valid belief.

Another nurse adheres to these thoughts, as she explains:

From my interviews with some of the parents, I have experienced that when they come they will just tell you that it is witchcraft. That it is man-made. Some come in doubt and think it might be a natural disease, but are surprised that cancer can affect children.

Another health worker suggests that there are broadly three types of patients at the hospital:

We have three groups of people here in Cameroon: Those who are educated. They will know that man was made to live in this world and that we at some point will encounter sickness. The second group of people will try to understand that there is natural sickness, but when something happens they will seek the advice of others and then they shift and think that it is 'unnatural'. The third group thinks that anything that comes their way cannot happen 'just because'. They believe that it happens because of something.

The health workers' narrative suggests certain characteristics of popular medical knowledge and about the patients' explanatory models associated with Burkitt's lymphoma. Drawing on our own explanatory models we usually seek to explain important questions that arise in the

event of disease, such as the plausible cause, its course, treatment and prognosis (Ingstad 2007:55). In their narrative, the health personnel highlight what they have experienced among the caregivers to be regarded as the cause of the ailment, while simultaneously giving indication of what will most likely be looked upon as the appropriate treatment. I find this to be an important topic for discussion, but also one that demands critical evaluation. I propose to the reader that the popular knowledge described by the health personnel is a reflection of a specific social setting. This setting is the interview, where I experienced “a tendency to elicit an exaggeratedly clear and coherent picture of what people think and feel on all kinds of topics, including medical knowledge” (Van Der Geest 1991:81).

Being a temporary resident with the goal of obtaining an understanding of the affected families’ therapy management of Burkitt’s lymphoma, the health personnel were very helpful in generating an idea of popular understandings of disease. Yet, the health personnel’s awareness of my interest in cultural beliefs presumably laid basis for the topics that they regarded as relevant. Based on similar observations, Van Der Geest argues that what is presented as knowledge depends on “who is the speaker and who is the listener”, as well as the questions asked (Van Der Geest 1991:69). The questions that I asked were colored by my own assumption that there *were* differences between popular and professional medical knowledge. This expectancy might have triggered the health personnel to emphasize a group of patients who did not share the biomedical views of health and disease, rather than the situations where these views did not appear to have significance.

I adhere to Van Der Geest’s experience from the interview situation, in which the people whom he talked to considered him to be ‘knowledgeable’ while at the same time being ignorant. In a similar sense, I became a novice whom the health personnel tutored on Cameroonian popular medical knowledge. The tendency to address the general, rather than the complexity and nuances of popular medical knowledge was most likely a result of the health personnel trying to create a comprehensive image to a person who was unfamiliar with culturally meaningful disease explanations in Cameroon.

In the health personnel’s narrative the patients’ explanatory models are described as guided by beliefs in witchcraft; an explanation drawn from traditional philosophies in Cameroon regarding illness and misfortune, in which the social cause of impairment is granted much

attention. These beliefs have attracted considerable attention by researchers coming from the outside, studying Cameroonian cultural beliefs (Lantum 1985, Azvedo 1991, Pool 1994, Smith 2009). Meeting with an anthropologist, this may also be a potential influence on the health personnel's accounts. Van Der Geest argues that "culture is not only culture-bound; it is situated-bound as well" (Van Der Geest 1991:69). Our common ground, sharing the hospital as a work site, undoubtedly created a context where it became important for the health personnel to over-communicate their understanding of 'disease', while simultaneously under-communicating their resonance with 'illness'. Dichotomies such as educated/uneducated, modern/traditional and natural/unnatural were used to demonstrate this point; underscoring the alleged gap between the patients and health workers' medical knowledge. I also experienced that being representatives of the Christian faith, it was important for the health personnel to disassociate themselves from 'traditional beliefs'.

In reality, I found the boundaries between notions of 'illness' and 'disease' to be fluid. This is equally much the case within the conjectured categories, where I found patients and healers to constantly negotiate their own medical knowledge in accordance with new impulses from their social surroundings. Indeed, at the hospital, the patient and healer's transactions of knowledge during consultation appeared to be characterized by both parties adjusting their understanding to fit with the other. This is exemplified by a nurse working at the hospital:

Most of the patients believe in witchcraft. The people working here know that, so they will incorporate it into their preaching in order to reach the patients. There is no sharp contrast between the traditional beliefs of the patients and the hospital treatment.

This negotiation can be seen in light of Barth's argument, mentioned in chapter one, in which people involved in a transaction attempt to make sure that the value gained is greater than the value lost (Barth 1966). This is illustrated in the nurse's account in which the health personnel adjust their form of communication in order to reach as many patients as possible. The health personnel are, according to the nurse, conscious about their mode of communication. By doing this, they hope to increase the level of resonance with the recipient. In spite of it being a conscious act, it requires that the health personnel have a certain degree of knowledge and resonance for their patients' experience of illness. The caregivers at the Burkitt's ward appeared in a similar way to adjust their medical knowledge to that of the health personnel.

During my own interviews, the caregivers signaled that they were grateful for guidance and medical advice from the health personnel. After consultation with the nurse on admission, most caregivers gave indication of having incorporated the newly obtained knowledge into their explanatory models. Going back to Janzen's theories on medical knowledge (1978), this illustrates on the one hand, how knowledge is shaped by categories and values of an ideational system, and on the other, how it is adjusted and negotiated within its social context. Neither the patients' nor the health personnel's knowledge may thereby be treated as static, or as a firm basis for medical actions.

Kleinman (1980) argues that the explanatory models of patients, to a greater extent than that of the health workers are processual; one reason being that the patient's model is constantly negotiated with the people who constitute the therapy management group, another that social factors may alter therapy management strategies and consequently medical knowledge. In the following discussion I go deeper into the discourse of popular medical knowledge, and to the explanatory models for Burkitt's lymphoma in its early stages. Based on my own empirical findings, I argue that the early symptoms are usually interpreted as something that will pass without medical interference or by the use of home remedies. These understandings are later altered; being a reflection of the child's deteriorated condition, but also of consultations made throughout the course of the disease.

## **Natural and Unnatural Illnesses**

Medical pluralism is not only a term used to describe the variety of health care resorts available in a society; it also refers to "the various sources of disease explanations within us" (Ingstad 2007:47). This point made by Ingstad, is also elaborated upon in Zola's *Culture and symptoms – an analysis of patient's presenting complaints* (1966). In his study, he highlights how people's sociocultural background may lead to different definitions and responses to initially the same symptoms (Zola 1966:630). Zola refers to this as a selective process, in which individual and social conditions influence what is formulated as illness. Such selective processes are most likely present at all stages through which an individual and his condition must pass before he ultimately gets counted as 'ill' (Zola 1966:620).



Defining illness, Zola argues that there are commonly two ways in which people identify problems in one's own population. The first being "the actual prevalence of the sign" and the second "its congruence with dominant or major value-orientations" (Zola 1966:617). In the first instance, a sign is interpreted and considered to be either 'normal' or 'unusual'. This depends on the social context of the signs and who interprets them. Zola also indicates that when the aberration is fairly widespread, this may in itself constitute a reason for not being considered as symptomatic (Zola 1966:617). In the second instance, it is the 'fit' of certain signs with a society's major values which accounts for the degree of attention they receive (Zola 1966:618). Among the caregivers, both these processes seemed to be at work when deciding on the appropriate care for the sick child in the initial stages of the disease.

Ryan (1998) provides example to Zola's mode of thought in his research on home case management of acute illnesses in Kom, Cameroon. When people in the village encountered illness, Ryan experienced that they were often unsure about the correct diagnosis, the cause of the ailment and the likelihood that a particular treatment might cure the illness. One way to reduce uncertainty was by categorizing each episode into a particular type of illness. Ryan identifies three factors that his informants regarded as contributive causes to illness: the natural breakdown of the body, from overwork, or as sent by evil people. Based on the caregivers' therapy management strategies, I have in line with Ryan found that illnesses were sorted into categories of causation. Commonly, in an analogous wisdom referred to as *natural* and *unnatural* illnesses<sup>13</sup>. This distinction is rooted in popular medical knowledge, where the interpretation of visible signs and symptoms gives indication for what will be the appropriate treatment.

Dr. Melodie Smith (2009) has worked at Bansa Baptist Hospital and published an article on the use of traditional medicine in the area. Trying to grasp the difference between the dichotomous pair of natural and unnatural illnesses she interviewed a traditional healer who

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<sup>13</sup> This distinction is 'emic', in that Cameroonians themselves describes illnesses through these categories. It is also 'ethic', as anthropologists have used the terms to describe illness distinctions in a wide variety of settings.

explained: “a *natural* illness occurs because man is sick” (Smith 2009:7). In other words, we live in an imperfect world where the human body is susceptible to various afflictions. Everyone is bound to experience minor ailments like the common cold, stomach ache, toothache, constipation and fever at one point in time. This understanding of illness is the one that most resembles the biomedical view on health. Nonetheless, it is among religious people commonly described as sent from God. This adds another layer to the causation, in which God becomes the link between the affected person and the illness.

An *unnatural* illness on the other hand, may befall a person because of a personal wrongdoing, the breaking of a taboo causing ancestor wrath, or through sorcery<sup>14</sup>. In the second instance, a person who wishes harm to you or one of your family members has commonly consulted a sorcerer who has the ability to deposit illnesses in others (Smith 2009:8). A characteristic of an unnatural illness is its sudden appearance, accompanied by physical deformities. Unnatural illnesses usually befall children, as they tend to become the objects of revenge during disputes. To identify an unnatural illness one must go to a sorcerer or diviner who will tell you what caused the illness to emerge. The sorcerer, who is often also a traditional healer, may treat the illness him/herself, or the affected person is sent to another healer for treatment. These illnesses are regarded to be ‘hidden’ in the blood and therefore ‘invisible’ to Western treatment. The healers have, on the other hand, the ability to heal unnatural illnesses because they deal with all aspects of the patient’s life, including relationships with other people, with the natural environment and with supernatural forces.

In this mode of deliberation, questions such as *how* the illness happened, next *why* it aroused in this particular person at that exact time are commonly asked. This is a characteristic of popular medical knowledge on disease, in which people seldom find themselves content with illness happening by ‘coincidence’. In Cameroonian popular knowledge, it is among many people important to identify an answer to these questions. A conversation with two hospital

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<sup>14</sup> Sorcery is defined by Landy (nr45) as “the power to manipulate and alter natural and supernatural events with the proper magical knowledge and performance of ritual” Helman 2007:137).

chaplains at Bansa Baptist Hospital provides example to this, in which a mother seeks an explanation for why her child became ill with malaria.

A woman brought her child to the hospital with suspicion of malaria. The doctor provided the required treatment and advised her to remove old cans and garbage far away from the compound. This was because the garbage would attract mosquitoes and cause them to breed by their house. The mother accordingly asked the doctor, “Why do the mosquitoes like to breed in *those* cans by *my* house?”

Such interpretations of illness and misfortune are comparable to the findings of Evans-Pritchard (1937) from his fieldwork among the Azande of Southern Sudan. This book was the first and is arguably still the most important modernist text in medical anthropology (Good et. al. 2010:66). Evans-Pritchard found that poor health and misfortune among his informants was explained through notions of witchcraft. He describes witchcraft as “the particular conditions in a chain of causation, which relate an individual to natural happenings in such a way that he sustained injury” (Evans-Pritchard 1937:18). The additional layer of interpretation that relates man to ill health was among the Azande, like the mother in Cameroon, granted great importance. In both instances, illness was not thought to ‘just happen’, - it happened for a reason.

Interviews with the caregivers at the Burkitt’s ward, gave indications that most of them had a conscious relationship to the distinction between ‘natural’ and ‘unnatural’ illnesses. The explanatory models of the child’s condition were characterized by the caregivers’ attempt to identify the cause of the ailment by interpreting the signs as either ‘normal’ or ‘unusual’. As Yara’s father mentioned in the interview; “I started to question whether this was a disease caused by God or a sorcerer”. An answer to this question would give Muhafiz an indication of how he should go about with treatment.

In spite of the severity of Burkitt’s lymphoma, the child’s general health is usually remarkably good in the early stages of the sickness. The first sign of a facial lesion is usually the loosening, or displacement of the child’s molar or pre-molar teeth. These symptoms are commonly mistaken by families as caused by a dental problem. The sign of an abdominal

tumour can be fluid build-up, causing the child to vomit and on occasion to experience pain. In both cases, the child usually loses appetite. These signs were often interpreted by the caregivers as caused by constipation, or as a result of having ingested contaminated food or drinks. These are common ailments among children living in poverty, but are also diseases that anyone may get in touch with at some point in time. It is not surprising then that the first symptoms of Burkitt's lymphoma are considered *natural*. Ingstad (2007) similarly point to how chronic diseases, such as cancer, are characteristically not visible until it has reached an advanced stage. They are therefore commonly ignored or mistaken for other, minor illnesses.

There are usually no restrictions for where a natural disease may be cured. Depending on how the symptoms are interpreted they may be taken to all of the resorts in the Burkitt's pattern. Yet, the first visible symptoms of Burkitt's lymphoma are usually attempted to be cured in the compound as it is regarded 'not serious'. Kleinman (1980) similarly highlights that between 70 and 90 per cent of health care in both Western and non-Western societies are thought to take place within the 'popular sector' of medical treatment. Treatment administered in the popular sector is usually conducted by non-specialists, such as self-treatment, or from the assistance of a relative or friend. Among the patients at the Burkitt's ward, the caregiver was usually the one to administer treatment in its initial stages. The first treatment is usually to use 'time' as a remedial tool; one waits and sees whether the disease will pass without medical interference. As symptoms become either more or less prominent, it enables the person to better identify what could and should be done about it (Ryan 1998). In addition to reducing uncertainty, the delay requires no immediate outlays of capital or labour, which makes this treatment alternative the least expensive. On average, the families at the ward had first spent between 1-4 days observing the condition, while simultaneously evaluating various treatment options that might cure the illness. Ryan (1998) has also noted in his research from the North West Region that 83.5 per cent of his informants had first attempted to solve the illness within the compound, in which the most common strategy was the delay of treatment.

Ingstad argues that in countries where the national health services are malfunctioning, people become to a larger extent dependent on their explanatory models for health (Ingstad 2007). Cameroon is no exception. Those who could not afford to go to the doctor would usually consult a neighbour or relative for advice. All families that I interviewed had ultimately made

it to the hospital. Yet, for most families it had been a long and winding road to get there. When the delay of treatment does not cure the ailment, the caregivers will usually consult the members of the therapy management group before making any new decisions. The child's grandparents were likely to share their experiences and recommendation of the appropriate treatment. In some families the generational gap would create situations in which the parents and grandparents disagreed on the appropriate therapeutic measures, and in others, the parents would themselves disagree. One father told me that his wife had a preference for going to the sorcerer because he would be able to tell them whether to go to the hospital, or not to go and waste their money. The father, on the other hand, preferred to take the child straight to the hospital and not waste any time. Under such circumstances, there would often be negotiations that included the advice of the larger extended family. The advice of random villagers would also occasionally be acted upon. In fact, the main point of reference to the Burkitt's ward in the village was caregivers and former patients of the Burkitt's ward.

Delay of treatment is usually followed by the use of home remedies, such as the use of medicinal herbs available in one's own garden, mixtures of traditional medicine or pharmaceuticals kept in the house. One caregiver told me that the first symptom of disease was the child's loss of appetite. He decided to wait and see if it would resolve itself with time, but after two weeks of observation the father noticed a swelling on the child's neck. Few days after, an ulcer appeared in the child's mouth. The father decided to try a home remedy. He rubbed an herb concoction on the swelling and waited for a few days to let the treatment work.

A mother similarly explained that she discovered her son's enlarged stomach when she was giving the child a bath. She had noticed for some time that he was losing weight and complained about abdominal pain. This particular evening the child was crying in pain from the stomach ache. The mother assumed that the boy had been drinking contaminated water or eaten something that made his stomach upset. She mixed an herbal powder inherited from her father with red palm oil and gave it to the child to consume. When her children had similar complaints in the past, this had normally cured the stomach ache. This time, the remedy did not work as usual, but she decided to give it one more attempt and observed the child for another four days.

Both parents started with treatment options at home, in which the caregivers functioned as therapists. Looking back at the empirical examples in which the devastating consequences of leaving the household during rainy season were illustrated, this should not be surprising. In addition to not having to leave both family and farming responsibilities, the use of home remedies is the treatment option of least financial burden. Importantly to note, these treatment options are used because they have from experience cured similar ailments previously. What was earlier questioned as an ‘irrational’ act of not taking the child to the hospital is on the contrary for most families, in all corners of the world, experienced as highly rational. It is consequently not sufficient to ask why patients delay treatment; we must closely examine how the affected families read the symptoms of Burkitt’s lymphoma and what is regarded the appropriate – but also most accessible – treatment. We may conclude that rather than the actual severity of the disease, it appears that in its initial stages, therapy management of Burkitt’s lymphoma is influenced by a number of non-physiological factors; social, cultural and emotional.

## Chapter 5: The Informal Sector of Pharmaceuticals

*Two days after the child's belly got high he started passing hard stool, almost like the goat's one. I thought he had 'Nyan', which is an enlarged spleen. I decided to make cuts on his abdomen and to apply an herbal mixture that I got from my father before he died. He made the mixture out of fried herbs, which he grinded into a powder and mixed with parts from a fowl, salt and red palm oil. I had never used the mixture before because I only had a small quantity. The child's condition only got worse and I decided to buy some tablets from a hawkker. I just went to the man; he examined the child and gave drugs for ten days. There were two kinds; one to swallow and one to chew. The drugs came in a see-through bag without instructions. The hawkker explained how I was to give it to the child, but I only gave the medicine for five days, since the belly just continued getting high.*

Alexander Rödlach (2006) argues that the lack of efficiency of a particular health care system often triggers a shift in which alternative treatments are sought. When caregivers at the Burkitt's ward experienced that home remedies did not cure the symptoms of Burkitt's lymphoma, pharmaceuticals bought from the informal sector of medical care usually constituted the third resort. This treatment resort is part of what Kleinman (1980) refers to as the folk sector; characterized by untrained healers, not part of the official medical system, who specialize in forms of healing that are either sacred or secular. In this chapter, I set out to investigate: *How do access and availability of pharmaceutical treatment affect the therapy management of Burkitt's lymphoma?* I was curious to learn why the caregivers bought treatment, often of inferior quality, rather than to purchase medicine from an authorized pharmacy. In the following discussion, I investigate *who* prescribes the medicines, *how* and *what* pharmaceuticals are being prescribed, as well as the possible consequences of their prescriptions. I am concerned with pharmaceutical products purchased without the recommendation of a recognized medical specialist. Empirical examples illustrate how pharmaceuticals purchased from drug vendors may offer advantages, but also serious disadvantages to the child's health.

## Health Talks

It was a Wednesday morning in March. Ready to start another day at fieldwork, I left my house followed by the sound of the young nursing students singing psalms while making breakfast and hanging their wet linens out on the laundry line. Having stayed in Kumbo for close to two months, I was used to the constant wave of sounds beginning at 05.00 a.m. Prayer calls from a mosque waking me up at sunrise, band rehearsals at church before the morning service and the sound of footsteps as the farmers carried their heavy loads to the farms; sounds that I have later come to associate with life at Banso Baptist Hospital. Approaching the hospital entrance, rays of sun were reflected on the red benches in the corridors of outpatients department (OPD). A few chickens were running down the hallway as the patients started to arrive at the hospital. Women, men and children were climbing off motorbikes, unloading their luggage, perhaps unsure about the duration of their stay. Women were dressed in colorful tailored Kabas, which offered beautiful nuance to the ocean of white-coated hospital employees leaving the chapel, hastily walking to their posts.

This morning was much like any morning at Banso Baptist Hospital. Yet, for a couple of reasons it stands out as a memorable morning. It was Nurse Holike's first day on the job as the Burkitt's nurse, and she was going to give a health talk about Burkitt's lymphoma to the patients in OPD. A noticeably nervous, but determined Holike, appeared in OPD after the morning service. Nurse Ngang and I had already found our seats among the patients and observed Holike moving hectically back and forth; curious about how she would handle the task. Nurse Ngang looked at her watch and commented on the chaplain's delay, as the health talk could not start without initial prayers. Nurse Holike pulled out a piece of paper from her pocket and appeared to be doing last minute preparations. Patients were resting their heads on whatever available to them; some were leaning on their luggage, others on the shoulder of a comforting mother or a supportive spouse. The stress going on behind the scenes did not appear to affect the patients.

The chaplain showed up after some time, obviously stressed, as she told nurse Ngang that she was coming straight from prayers in the maternity ward. The prayer was initiated with expressions of gratitude and was concluded in a similar tone, as the chaplain uttered "the



doctors can treat, but the healing comes from God”. Nurse Holike’s strong voice rang through the corridors as she greeted the patients. Her greetings were respectfully echoed by the crowd who loudly exclaimed: “Good morning”. Confident that that she had everybody’s attention, Holike started the health talk. People listened carefully as Holike systematically listed the causative factors, presentation and appropriate treatment of Burkitt’s lymphoma. Nevertheless, facial expressions revealed that for most of them, this was unfamiliar ground.

Having reached the end of the talk, Holike asked the listeners: “What do you do if your child’s belly gets high?” Hands were raised and a woman was called to answer: “We must go to the hospital”. Holike confirmed and added that parents should not try to hide the affected child from other villagers, but to be open and talk about the disease. Holike opened up for questions, in which a young mother raised her hand and asked how she could prevent the disease from affecting her children. Holike responded that one should keep the house clean, and in this way not attract the mosquitos. She added the importance of buying malaria treatment from a pharmacy, not from a local drug seller or hawker.

A middle-aged man, noticeably agitated, raised his hand and asked the nurse what he should do to protect his children; living in a malaria area with no available pharmacies, health clinics or hospitals. I suspected that the nurse found the question hard to answer, as she passed on the challenge to the people in the audience. Another man raised his voice and spoke in favor of buying drugs from local drug sellers. Nurse Ngang appeared to be frustrated with the man and whispered; “I think he must be a hawker”. The man who had raised the question demanded an answer from the nurse who was now seeking the advice of Nurse Ngang. A health worker from OPD stepped in and encouraged everyone to buy malaria treatment from the hospital pharmacy. “You can bring the treatment home and keep it in the house”. Yet, it appeared that the patients and caregivers did not feel content with the answer.

## The Context of Distribution

Anthropologists have illustrated how Western pharmaceuticals are differently distributed and handled in various localities and groups. Singer and Baer argue that the global distribution of pharmaceutical drugs has “contributed to the use of commercial laboratory remedies in ways that go far beyond their intended purposes and patterns of use” (Singer and Baer 2007:22). Van Der Geest has similarly described the informal sector of pharmaceuticals in Cameroon as an ‘articulation’ of two apparently competitive systems that merge into one (Van Der Geest et. al. 1988:17). In this merge, practices of the popular sector are blended with those of the professional. Unauthorized vendors and hawkers are selling prescription drugs outside of the official channels, such as hospitals, health centers and pharmacies. A consequence of high prices on imported pharmaceuticals has been that people go to hawkers or drug sellers to buy medicines that are sold at a cheaper rate. There is considerable evidence that such articulations of healing occur worldwide.

In Cameroon, it has been estimated that about half of modern health care occurs outside the public services. This is according to Van Der Geest a result of the major inefficiencies of the drug procurement system, which have led to a virtuous informal sector selling drugs (Van Der Geest 1991). The informal sector usually exists where the public services do not achieve their objectives. It is, as a consequence, particularly well-established in the rural areas of Cameroon, where there are few pharmacies, health clinics and hospitals. Van Der Geest and colleagues argue that the informal sales of medicine has consequently become an indispensable part of the Cameroonian health care system, in which it fills the gaps in the formal distribution, but on a similar note, maintains them (Van der Geest et. al. 1988:17).

In the discussion of this thesis, I have in line with Stoner (1986) and Kleinman (1980) argued that a focus on *sectors*, rather than medical systems, may prove a fruitful way to describe a society’s entire ‘health care system’, offering a variety of therapeutic options to health seekers. Stoner highlights that the studies of medical systems, such as ‘Western’ and ‘Traditional’ medicine are mere analytical constructs, as they in real life are blended and mixed in order to meet the needs of the patients.

Kleinman designed the model of the popular, folk and professional sector with the knowledge that there is no such thing as 'pure' sectors that are ready to be studied. Studying medical sectors, one finds that boundaries are blurred. Health care alternatives of the popular sector in one community may simultaneously be interpreted as folk remedies or as "professional" therapies by others. This mesh comes to view in my own distinction between the resorts of 'home remedies' and 'pharmaceuticals' and their categorization into sectors. Following Kleinman's model, the first treatment alternative befalls as a modality of the popular sector. The sales of pharmaceuticals in the informal sector have the characteristics of being a treatment modality of the folk sector. Nonetheless, a number of anthropologists studying pharmaceuticals outside the biomedical context have referred to this as a resort of the popular sector. Pharmaceuticals purchased from the market are brought back to the house where non-professionals administer the treatment and may therefore be considered as a treatment modality of the popular sector. From my experience there is, however, one important difference between the uses of home remedies available in one's home to that of going to a drug vendor and buy pharmaceuticals, and which I, therefore, wish to emphasize. This difference lies in the transactions of knowledge and who defines the ailment.

Among the caregivers at the Burkitt's ward, home remedies were administered by the caregiver or other members of the therapy management group. The members gave advice and shared medical knowledge regarding the symptoms of the ailment. When home remedies did not work, this usually triggered a shift in which other kinds of treatment were sought. What was regarded to be the next appropriate treatment was commonly discussed in the therapy management group. When therapy management involved the use of pharmaceuticals, the caregiver would enter a transaction with a drug vendor or hawker in which former explanatory models of the disease were subjected to alterations. In this transaction the vendor usually functioned as the 'expert', whose advice the customer may choose to take or not to take. It appeared that the therapy management group would then become less participatory than in the former treatment resort.

Ferguson (1988) found similar transactions of knowledge in the informal sector of pharmaceuticals in El Salvador, where drug stores were the main retail outlet for imported pharmaceutical drugs. Ferguson found that the untrained vendors were the primary source of health care for poor people, providing them with advice and information, as well as over-the-

counter pharmaceuticals. In such instances the therapy management at the drug store is not only the purchase of pharmaceuticals, but it is also a place where knowledge of the disease is negotiated and possibly altered.

Van Der Geest has similarly illustrated how buyers and sellers of pharmaceuticals at a local marketplace in Ebolowa in the South-West Region of Cameroon construct their ideas about illness and medicines in reaction to the socio-economic situations in which they find themselves. During interviews with buyers at the market, he found that what people told him about illness and medicines did not agree with biomedical knowledge; nor was it ‘traditional knowledge’. Rather, there was an instant production of popular medical knowledge during market transactions. The market situation induced people to adjust their medical beliefs to the economic transaction. Sellers were likely to inflate the efficiency of medicines and customers adjusted their medical concepts to fit their limited financial means (Van Der Geest 1991:69). In this sense, Van Der Geest underscores that culture ‘works’ all the time (Van Der Geest 1991:80). In the following discussion, I attend focus to these transactions and how the caregivers’ explanatory models are negotiated based on availability and accessibility of treatment.

The empirical example presented from a health talk in the outpatient department at Banson Baptist Hospital gives indication of how access to – and availability of – pharmaceutical treatments may influence the therapy management of various ailments; including Burkitt’s lymphoma. In this example, the health workers underscored the importance of buying pharmaceutical treatment from authorized pharmacies, while some of the patients were speaking in favor of the informal sector and unauthorized drug vendors. The health personnel indicated a discontentment with the sales of pharmaceuticals from the vendors, as they did not regard the treatment to be satisfactory. In such situations, there were grounds for interpretations of patients being ‘non-compliant’. Non-compliance is often associated with patients who do not follow the doctor’s prescriptions on how to take prescribed drugs. Yet, in this case, some of the patients’ uttered predilection for buying pharmaceuticals from the drug stores did not appear to be structured by preference of treatment, but rather the inaccessibility of authorized pharmacies.

This example brings me back to the initial discussion of this section, in which the sectors of medical care in Cameroon were elaborated upon. I adhere to Stoner's argument, "that as a first step to understand the 'logic' of health care decisions, instead of focusing solely on sectors or systems; one should concentrate on the actual health care options used by members of the society" (Stoner 1986:47). Based on these observations I found it important to get the caregivers' point of view, as well as that of the drug vendors who constitute an important role in the production of popular knowledge on Burkitt's lymphoma. In the following section, I investigate the sales – and use of – pharmaceuticals, based on the reflections made by two drug vendors during interviews at their shops at the Squares- and Kumbo market.

## **Drug Sellers of Kumbo Town**

I met thirty-three-year-old Pascal at the Squares market in Kumbo town. Mr. Tsemi had earlier visited the drug seller's shop and asked him whether he would accept an interview with 'a white man' about the sale of pharmaceuticals. I waited impatiently for his response, as I had already experienced being turned down by drug vendors who did not wish to be interviewed. Pascal was on the contrary eager to talk. The person whom I met at the market was a proud drug seller who had grown up within the informal sector of pharmaceutical drugs. Pascal inherited the family business when his father passed away. According to Pascal his shop had a good reputation in Kumbo for selling affordable high-quality drugs. The sale of drugs from his shop was thus unauthorized and consequently illegal. Unable to display the drugs, Pascal was dependent on the shop's good name and reputation to obtain customers. On average, between 25 and 30 customers stopped by his shop every day to buy various pharmaceutical drugs. Trying to keep attention away from the sales of pharmaceuticals, Pascal was also selling general provisions. For several years, the authorities had come to raid the shop, in which the officials usually created a big fire outside, where the drugs were destroyed.

The vendors and hawkers usually obtain drugs from three sources: pharmaceuticals smuggled into Cameroon from neighboring Nigeria that were distributed throughout the country, drugs purchased without prescriptions from legally established pharmacies and sold at profit, or

from medical service personnel trying to earn some extra income (Van Der Geest 1991:72). Pascal had bought some of the pharmaceuticals from various sources in the nearest town, Bamenda, and from the black market of Nigeria. A lower tax in Nigeria made it according to Pascal more affordable to buy drugs there and import them to Cameroon.

According to Pascal, the drugs most people would buy were paracetamol, cough medicine, antibiotics, anti-malaria treatments and drugs for gonorrhoea, asthma and rheumatism. The average buyer would have little or no knowledge of the drugs he or she bought. As stated by Pascal: “people come and ask for a drug because a friend has told them what to buy.” This caused Pascal to function as a ‘pharmacist’ of his own shop. Taking pride in reputedly offering the best care at the Squares market, Pascal often assisted the buyers on how to take the drugs. In his opinion, selling drugs and giving advice was a way of giving back to the people who had been loyal to his shop for many years. Nonetheless, when customers would ask him to consult illnesses that he did not know how to treat, he would refer them to the doctor. In such instances, most customers would rather go to another shop. This was according to Pascal because the drug vendors offered a less expensive option than going to the pharmacies at the hospitals. There, the customers knew that they would have to buy a hospital card and pay for a consultation.

Pascal’s interpretation of the financial aspects of the purchase of pharmaceuticals is supported by Van Der Geest (1991) who conducted research on the distribution and use of Western pharmaceutical drugs in his the Ntem division of Southern Cameroon in 1980. He found that pharmaceuticals sold by vendors and hawkers were generally more affordable than in the pharmacy. Jude, a twenty-two year old shopkeeper at the Kumbo market tells a similar story about the sales of pharmaceutical drugs at his store.

Three years prior to the interview, Jude and his older brother Dennis bought a shop where they sold general provisions. Thinking that it would be profitable to sell pharmaceuticals, they started one year later to sell paracetamol, chloroquine (malaria treatment) and tetracycline (antibiotics), as people were requesting these medicines. Dennis had desired to become a medical doctor, but did not have the financial means for an education and decided to sell pharmaceutical drugs instead. Dennis shared all his knowledge of Western pharmaceuticals

with Jude, in which he became responsible for sales. Dennis provided the drugs. Sometimes he would go to Nigeria and buy pharmaceuticals. In other instances, he bought drugs from Nigerian hawkers who sold pharmaceuticals 'out of their suitcase'. Asking Jude about how Dennis got the drugs across the border from Nigeria, he replied: "You put the drugs in another box and then you pay the guards". According to Jude, the guards and vendors would usually have made prior arrangements.

Unlike Pascal, Jude and his brother would on average only have five customers per week. The diseases most commonly brought to the shop for cure were malaria, cough, pains of various types and stomach problems. As most of the buyers did not know how to take the drugs, Jude would give instructions on how to administer the treatment. According to Jude, the shop functioned as a first aid for the customers. When I asked Jude why the customers preferred to come to his shop, Jude answered: "People are living in poverty and buy drugs for a certain amount of money, not being able to buy the full treatment. They simply do not have the means to buy the drugs". At a drug store, the buyer was able to purchase pharmaceuticals based on the 'money at hand', whereas at a pharmacy one usually had to buy the whole package.

Jude and Pascal highlight possible advantages, but also disadvantages of buying pharmaceutical drugs from an unauthorized vendor. Van Der Geest notes that well-to-do people will not visit the market to buy medicine; it is the poor man's alternative (Sjaak Van Der Geest 1991). He argues that there are several potential reasons for why informal drug vendors respond better to the needs of poor people than the formal institutions. According to Van Der Geest, they are all related to availability and attainability (Van Der Geest 1991:70).

Market vendors are often more accessible than the pharmacies because they are available day and night. Van Der Geest highlights that geographically and socially, it is usually a smaller distance between the vendors and their clients, than in the formal sector. In villages and small towns, the customers are usually acquainted with the vendors and know them not only as a sales clerk, but also as a fellow villager. This could be experienced as more comfortable for the buyer, as they usually experience uncertainties about the illness. The father of one of the

Burkitt's patients indicated to me that he was uncertain about both the nature of the illness, as well as the appropriate treatment. He decided to trust the advice of a hawker:

I discovered that the child was sick because the child had a swollen jaw. I thought it was a dental problem. It is a man that sells drugs from the road and we bought some tablets from him. We gave the tablets for one week, but it did not help. I do not know what the tablets were. It was only to make it cool. The hawker then told me to go to the big hospital because he could not treat it.

The example also illustrates that the hawkers and drug vendors will in some instances refer the patient to the hospital when they cannot cure the ailment. This will create a sense of security among the customers, as the drug vendor will give his opinion of whether he is able to treat the symptoms.

To go to a hospital or pharmacy in the bigger towns and cities would require extra outlays on transportation, which could in reality be spent on medicines. One will, therefore, usually start with the least expensive option and see whether this will cure the ailment. Only when this fails will other, more costly and more inconvenient steps be taken (Van Der Geest 1991:73).

There are unfortunately also some disadvantages to this strategy. Clients know, for example, that the products they buy are of inferior quality, the choice of medicines is limited and vendors are known to have little medical knowledge (Van Der Geest 1991: 73). Some of the drugs have expired and are therefore ineffective or perhaps even toxic (Helman 2007).

Talking about the disadvantages on buying medicines from unauthorized vendors with the caregivers at the Burkitt's ward, it appeared that most of them were aware of its inferior quality. This carries interesting resemblance to a point made by Festinger called 'reduction of cognitive dissonance', in which he views knowledge as a "cultural device to assuage or avoid the pain of any discrepancy between what is and ought to be" (Festinger in Van Der Geest 1991:80). This does, according to Van Der Geest, for the poor customer mean that he manages to believe in the efficacy of the few medicines he can buy (Van Der Geest 1991:80). In that way they rationalize their inability to buy all the drugs they would like to buy.



Inappropriate treatment of malaria may lead to drug resistance. Asking the parents whether the child had been presenting with any other ailments before the symptoms of Burkitt's lymphoma, most caregivers expressed that the child had signs of malaria. Only a small number of caregivers told me that they had gone to a pharmacy to buy treatment. In most instances, malaria was treated with drugs purchased from a drug vendor. A father at the Burkitt's ward told me in an interview that he would usually buy pharmaceuticals from hawkers. Here he describes his initial reaction towards the symptoms of Burkitt's lymphoma.

The first time I saw that the belly was getting big I was mentally disturbed. I thought it might be malaria because the child had yellow urine. I therefore went to buy medicine from a hawker. This did not help and I treated the child for yellow fever because the child had belly bite and there was blood in his diarrhea. We bought more medicine from the hawker and the diarrhea stopped, but the child did not feel any better.

This example illustrates how the treatment of malaria and Burkitt's lymphoma walk hand in hand. Not only are the diseases associated biologically, but they are also managed with the same resources.

## **The Customer**

In his research on therapy management of non-chronic illnesses in the North-West Region of Cameroon, Ryan (1998) found that to wait and administer home remedies were most likely to constitute the first and second resorts in people's therapy management strategies. The third resort was most commonly the use of pharmaceuticals. When the illness progressed, the proportional use of pharmaceuticals dropped (Ryan 1998:221). These findings are of interest to the discussion of thesis, in which I have formerly argued that the initial signs and symptoms of Burkitt's lymphoma cause the caregivers to regard the illness as 'not serious'. Ryan's research similarly depicts how pharmaceuticals functioned as a *first aid*. I also found this to be the case with the caregivers who had utilized pharmaceuticals in the informal sector as a treatment resort. One father at the Burkitt's ward described during an interview that he

preferred hospital treatment when someone in the family became ill, but this treatment option was not used until the symptoms and signs of disease were regarded as serious.

It is better for me to go to the hospital than buying drugs from the vendors because they carry out consultations, but I will not go to the hospital for minor illnesses. I will go to the chemist (drug vendor) when the child has mild fevers or headache. If the drugs work, then I will not need to go to the hospital. If it is serious, then the chemist cannot meet up with this. It is ultimately the distance that decides where I go.

The interpretation of Burkitt's lymphoma as natural and not serious in its initial stage is most likely an important reason for why people try to cure the symptoms with medicines. Yet, this does not explain why people tend to buy medicines of inferior quality. During the interviews, it became very obvious that the reasons for buying medicine from drug vendors rather than a pharmacy was associated with distance from the house, as well as financial restraints. It appeared for example that families living nearby a health clinic were more likely to buy medicine from an authorized seller, than those who had to travel a long distance. One father underscores this point:

I do not keep any drugs in the house since the health center is so close. I will rather go to them and ask them what to buy. They will know how to treat it right and the appropriate amount of drugs to give. If I was to go to the drug store I would not know what to buy or how to give it to the child.

Another caregiver at the Burkitt's ward similarly indicated that availability and access played a crucial role in his therapy management of the illness. "I first go to the hawkers to get medicine. I wait for three days and if it does not help, I will take the child to the hospital. I prefer to go to the hospital because they do the total check".

Max Ntangsi is a research fellow in International Health at Harvard school of Public Health who has revealed dramatic inequalities in health expenditures across income groups in Cameroon. He recorded a per capita 5.4 dollars household expenditure on health by the poorest 10 percent of the population, whereof the richest 10 percent spent 90.4 dollars

(Ntangsi 2008). The great difference between rich and poor becomes particularly evident in the therapy management strategies of families affected by Burkitt's lymphoma. In this chapter, I have argued that the interpretations of the presenting signs of Burkitt's lymphoma is a reason for why people do not regard it as serious, and consequently something that can be resolved with pharmaceuticals. The fact that the illness very often starts during the rainy season, when the caregiver most of all should take care of his farm, together with long distances and very bad roads during the rainy season, which will also influence the costs for the remedies to be bought "cheap" or "expensive" is the context in which the caregiver must decide whether treatment should be administered by a drug vendor or by health personnel.



## Chapter 6: Traditional Healers and Health Clinics

*Zakari came home from the farm and discovered that his twelve year old daughter Julienne was crying in pain. He asked the child what was troubling her and Julienne pointed to her mouth. Zakari did not notice any visible swellings or wounds, but called his senior brother's wife for advice. She directed him to buy some herbs that would fix dental problems. Zakari bought the herbs at the market and applied it to the child's mouth. The family waited three days for improvement, but the child did not feel better. Zakari decided to bring the child to the health center, where she was admitted. In doubt of what was causing the ailment, Zakari went to a sorcerer to look for an explanation. The symptoms were described to the sorcerer who concluded that it was a natural illness. He gave Zakari a concoction, which had to be boiled and breathed in. Zakari brought it to the health clinic where it was administered to the child.*

In this chapter, I set out to investigate: *How do the caregivers at the Burkitt's ward utilize medical care in the later stages of the disease?*

When pharmaceuticals had been used without result, I found that most caregivers would bring their child to a health clinic or a traditional healer. Among the caregivers, 83 per cent had gone to a traditional healer one or several times during the course of the disease. The World Health Organization's statistics indicate similar numbers in which they have estimated that in developing countries, over 80 per cent of the local population choose to go to a traditional healer for their health care. The use of traditional medicine has commonly been contrasted to the biomedical treatment regime, in which one of them is given priority over the other. I wish to illustrate that these boundaries are often indistinct. I argue that the caregivers seek to maximize the chances of cure by using different, seemingly contrasting types of treatment.

## Culture as Barrier

An important contribution made by medical anthropology has been the exploration of different conceptions of sickness events in a sociocultural context (Singer and Clair 2003). One of these contributions was made by Robert Pool (1992) who in his study of the protein deficiency syndrome ‘Kwashiorkor’, in the small village of Tabenken in the North-West Region of Cameroon, discovered that the biomedical name for the disease invited to misunderstandings among his informants. Pool’s intention was to explore people’s illness explanations of Kwashiorkor and how these related to its dissemination. He was thus surprised to find that the people in Tabenken related the symptoms of Kwashiorkor to a broad assortment of ailments that did not match the biomedical understanding of the disease. In order to get closer to his informants’ understandings, Pool decided to change his focus from the biomedical definition of the disease, to how people dealt with its symptoms.

I similarly experienced that the caregivers at the Burkitt’s ward had little or no prior knowledge about cancer before the child’s hospital admission. Their knowledge was limited to a general idea that it affects grown-ups, either as breast cancer, a cancer of the stomach, or most commonly, as a ‘cancer of the leg’, entering the body through a wound. None of the caregivers had heard of childhood cancer. This should perhaps not be surprising, as information on cancer is unavailable in most rural settings of Cameroon, where Phillips (2010) estimates that 99 per cent of the children affected by Burkitt’s lymphoma live. This problem was underscored by a mother who told me “In the village there are so many children that die from a hard and high belly, but people say that it cannot be treated by the doctor”.

On admission, the caregivers often expressed a suspicion that witchcraft or sorcery could have affected the child. At this point in time, most caregivers were still unsure about the cause of the ailment because they had not yet seen the child cured. The caregivers often shared this concern during the interviews, which were normally held after first round of chemotherapy. The interpretation of the symptoms as being *unnatural* stands in contrast to most of their explanatory models of the illness in its early stages. The shift in the caregivers’ explanatory models was an interesting discovery, as it appeared to be associated with a change in symptoms of the disease. Interestingly, these interpretations were in contrast to Ryan’s (1998)

findings from Cameroon. None of his informants directly attributed witchcraft as a cause for their non-chronic ailments. This is an important point to elaborate upon, as the caregivers at the Burkitt's ward shared his informants' views on the natural cause of the ailment in its initial stages. Ryan explains that the natural causation theories among his informants were most likely a result of people in the Kom-area associating witchcraft and sorcery with either chronic illness, or illnesses where otherwise healthy adults or children would get sick and suddenly die (Ryan 1998).

This is in line with the descriptions of unnatural illnesses discussed earlier in this thesis, in which illnesses that appear to come out of nowhere and cause deformities were regarded as mysterious or unnatural. These symptoms are all associated with the advanced symptoms of Burkitt's lymphoma. What we then must elaborate upon is how these interpretations may affect therapy management strategies.

The discrepancies between Ryan's and my own findings suggest that there could be a difference in how chronic and non-chronic illnesses are interpreted and what is regarded the appropriate treatment. It stimulates the assumption that the use of traditional healers would be more frequent among the caregivers of the Burkitt's ward than among Ryan's informants, as unnatural illnesses have traditionally been brought to a traditional healer for cure. Natural illnesses have earlier been described as being brought to traditional healers and western treatment alike.

Azevedo and colleagues (1991) have in their report *Culture, Biomedicine and Child Mortality in Cameroon* investigated people's 'attitudes' and 'beliefs' related to child mortality. They raised the question of whether their informants' beliefs had a negative or positive bearing on the rate of morbidity and child death, as it could lead to inefficient use of health clinics (Azevedo et. al. 1991:1344). Their data was collected from literature on child mortality in Africa, and Cameroon in particular, as well as from a field study conducted in the East Region of Cameroon in 1987 and 1988. From the study, the researchers drew the conclusion that "one of the government's most difficult tasks was to change people's perceptions about casual relationships and introduce the concept of natural causality of disease and death, without destroying cultural pride and identity" (Azevedo et. al. 1991: 1346). The authors continue to

argue that such popular medical attitudes must, nevertheless, eventually change as reasons for not utilizing health centers included “the belief that the traditional healer was more effective in the treatment of certain diseases and some fear of the child being treated by an unknown Western-trained doctor or nurse who could poison him or force him to leave the parents’ environment” (Azevedo et. al. 1991: 1345). According to Azevedo, their informants most commonly perceived God, witchcraft, and sorcery to be the causes related to childhood diseases.

Azevedo and colleagues mention that poverty and a lack of access to medical provisions are other obstacles for seeking treatment at health centers; nonetheless, the greater emphasis is placed on cultural barriers for seeking appropriate care. This is exemplified by statements such as, “one realizes, of course, that the process of attitudinal change is long because values and attitudes are part of an individual being, however, the earlier in the life of a child the process of change begins to occur, the greater is the chances of success” (Azvedo et. al. 1991: 1347-1348).

Based on my own empirical findings, I argue that the strong emphasis on ‘traditional beliefs’ and ‘attitudes’ carries potential for masking other factors that influence therapy management. This critique is grounded on the ambiguities that I experienced among the caregivers in regards of their own motivation for using traditional healers and health clinics, as well as the many pressing concerns that I found to influence therapy management at all stages of the disease.

Looking at Ryan’s research (1998), his findings indicate that illnesses regarded as natural were structured by similar therapy management strategies as those of the caregivers at the Burkitt’s ward. In fact, the dominant pattern of resort among his informants was the same as the dominant pattern for the patients at the Burkitt’s ward. Ryan found that home remedies and pharmaceuticals together accounted for 81 per cent of all treatments used (Ryan 1998:216). As the illness progressed, there was a dramatic drop in the use of pharmaceuticals, whereas the utilization of health-care providers outside the compound steadily increased (Ryan 1998:218). He found that both traditional healers and health clinics tended to be used *in the middle* of the pattern of resort, whereas the hospital was usually the last. The major



strategy for seeking care outside the compound was through traditional healers. These indications suggest that both illnesses regarded as natural and unnatural were brought to the traditional healers for treatment. The empirical example presented in the introduction of the chapter underscores that this can also be the case when people bring their child to a health centre. One might expect a caregiver who suspects an unnatural cause of the ailment to bring the child to a traditional healer for cure. Nonetheless, the caregivers seemed to be using apparently contrasting treatment alternatives simultaneously, as if trying to maximize the chances of cure (Ryan 1998).

## **Adjusted Medical Concepts**

In the interview, Zakari described the transition from the use of herbal remedies purchased from a vendor at the market to the child's admission on the health centre. The failed attempt to treat the child with remedies bought from a hawker triggered a shift, in which the child was brought to a health centre for further examinations. Nonetheless, Zakari was contemplating on what had caused the ailment and decided to consult a sorcerer who could provide answer to his questions. I find Rödlach's (2006) use of the term 'anchoring' as a useful tool when approaching reasons for utilizing traditional medicine and health clinics as treatment resorts.

Conducting fieldwork in Zimbabwe, Rödlach attends focus to what he considers to be people's universal and fundamental quest for meaning in the event of misfortune (Rödlach 2006). Investigating conspiracy theories on AIDS used by Zimbabweans, Rödlach illustrates how "people look for the familiar in order to understand the unknown" (Rödlach 2006:11). Among the caregivers at the Burkitt's ward, cancer is unfamiliar. Hospitals are correspondingly located far away, both in thought and geographical distance. What constituted the familiar among most of the caregivers were home remedies, the use of pharmaceuticals, traditional healers and health centers. I believe that this anchoring is an aspect of why Zakari went for advice to a sorcerer when I doubt of what had caused the illness.

There is a multitude of names for a traditional healer in Cameroon. The caregivers referred to traditional healers as country doctor, traditional doctor, Hausa man, medicine man and Passisi in the Bamoun dialect. Traditional medicine finds its roots in the world-view and culture of a society. The healing takes place in a familiar setting, such as the home or a religious shrine. They also provide culturally familiar ways of explaining the cause and timing of the misfortune and its relation to the supernatural worlds (Helman 2007:87). Lantum defines traditional medicine as “all actions mounted by a people to foresee evil, a disease or a human problem. To prevent these, heal and rehabilitate those individuals or communities already afflicted, using as necessary, the wisdom of the ancestors and spirits, as well as material elements such as plants, water, earth and air, within a cultural context” (Lantum 1985:21). This definition indicates the broad assortment of diseases that may be treated by a traditional healer. Most folk healers share the basic cultural values and world view of the communities in which they live, including beliefs about the origin, significance and treatment of ill health (Helman 2007:85).

In Cameroon, the traditional healers by far outnumber the health centers in rural areas. Traditional healers are found in large numbers, often in smaller villages where no other form of health care is available (Smith 2009:6). I have earlier referred to Van Der Geest (1991) who highlights that the folk sector exists where the public health services do not obtain their objectives. In societies where ill health and other forms of misfortune are blamed on social or supernatural causes, sacred folk healers are particularly common (Helman 2007:85). Smith (2009) suggested a number between 80 and 100 traditional healers in the Kumbo area in 2009. This figure she compares to the 10 doctors working in the corresponding area.

During Zakari’s consultation with the healer, a natural cause was attributed to the ailment, indicating that there was no need for spiritual protection. The healer gave Zakari some medical herbs. The herbs were brought back to the health centre where he gave the treatment, while the child was simultaneously receiving western-based treatment. Ryan found, correspondingly, that his informants tended to try both a traditional healer and a health clinic; suggesting that they tried one and then moving to the other (Ryan 1991:222). In both our research, people appeared to view the traditional healers and health centers as complementary ‘outside options’. These discoveries suggest that explanatory models continued to be

negotiated, and that ‘cultural barriers’, as found by Azevedo and colleagues, did not apply to the ethnographic findings in this thesis. This illustrates how cultural understandings of disease are at work all the time. They are flexible and adapted to the context of the ailment.

The following interview with Mousiss, a church worker and the father of one of the patients at the Burkitt’s ward illustrates this point.

Her first complaint was a stomach bite. Then for two-or three days she continued to complain. She eats sugar canes and that can cause stomach bite, so I asked her to stop eating those things. One week later, I started to see that the stomach was growing. It became strong, - ‘the belly be high’. I suspected that it was an enlarged spleen, but then I saw that the entire belly started to be high. That got me thinking it could have been a poison that had affected her. Some of my relatives said: “this be no sick for hospital. This is sick for country”. Because in our way ‘a man be tying you’ (a sorcerer ties your stomach so you cannot defecate). Some of my relatives had seen the same symptoms before and this had been treated by traditional healers where the child was cured.

I started to find traditional medicine and went to two or three places. As I went to the first traditional healer I showed him my daughter and told him: “I don’t know what type of sick this is. Do you know this one?” He touched the belly and then said: “This is a work for poison. They have poisoned this child”. He said that it was a poisoning intended for me, but had affected the pekin. He started to cut, cut and cut and then rubbed medicine to start for work. He cut some grasses to drink for the belly to go down and for the pekin to drink; all this to no work. I decided to change from that man to another one. The other healer also said that it was a poisoning. He said I owed someone money this had to be paid before the pekin could get well. I could not recognize the man (who he owed money). He gave me some powder so that the pekin would drink and shit it all, but all that one did not work.

From there I went to a clinic. The doctor and the nurses said that it was water inside the belly. We were at the clinic for one week and three days. They removed four liters

of water from the pekin's stomach, but it did not go down. So, I decided to go back to the house in Foumbot. We made one week in the house, but there was no improvement. At this time I was not doing any types of treatment. I decided to go my home village because they have some country medicine there that I hoped would help. I know this man who can 'treat and un-treat'<sup>15</sup>. He can treat all kinds of illnesses, so I went to see that man. The traditional healer told me that the water inside the stomach was too much. He could not work with it. I had to go to a clinic and reduce the water before he could start his own work. I went to the clinic but they told me that they were unable to treat it. So from then on I started to think "what can I then do?" I had wasted money a lot, because the child was almost at the point of dead. Then this hospital came to my brain. I have been hearing about BBH and that they can treat. It is the best hospital. It was around five o'clock in the afternoon that I decided to take the moto from my home village to BBH.'

I have been here four days and I have seen a change. Since they started to give her the medicine – it is different from what it was. I thank the doctor that has consulted my pekin. He really knows the medicine for this disease. The stomach has gone down; it is no longer strong as it was. That was my dream. I had heard that this hospital is a hospital that can treat and this has been proven to me.

This example highlights the complexity of therapy management. Unable to find a cure, Mousiss tried various forms of treatment. Advice on medical actions moved from the therapy management group to that of the health personnel at the health clinic and various traditional healers. His decision to go to the hospital appeared to be the very last resort, as Mousiss states that the child was almost dead by the time she was brought to the hospital.

What I found from conversations with the caregivers was that there was not one, but a multitude of reasons for going to the traditional healers. Some caregivers expressed to have

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<sup>15</sup> A person who has the ability to heal, but also to cause harm through sorcery.

been guided by religion and culturally meaningful disease explanations; other related their use of traditional medicine because it was regarded as an inexpensive treatment option.

Patrick Ngwan was 48 years old when I met him. He was a Kumbo resident who had been practicing as a traditional healer for twelve years. I was introduced to the man through one of the nurses at the hospital who knew him personally. The nurse knew that I was interested in talking with traditional healers about their healing practices and familiarity with the symptoms of Burkitt's lymphoma. This afternoon the nurse walked with me to his compound in order to conduct an interview. His house was beautifully encircled by plants and trees, which I later learned was part of his herbal garden. Patrick told me that he decided to become a healer as he had a vision at a time in which he was having some 'mental' problems. He sought a healer who told him that Patrick was destined to become a healer. His grandfather was a healer and in this way he grew up with the 'traditional practices'.

Patrick made an interesting comment when I asked him why people preferred to come to him: "I think the economical aspect is important. In the early seventies people would go to the hospital because they had money, now they go to traditional healers".

Mr. Tsemi underscored the traditional healer's explanation of finance as an important aspect of the use of traditional healers as he told me:

Three quarters of the people go to traditional healers because it is cheap. They classify it to be cheap because they give payments bit by bit. One might ask you for a hen or a cock, another for red oil. Then it is seen as a small quantity and they can afford it. They will go to the healer until they have gotten to the stage where they are forced to borrow money to go to the hospital.

Patrick suggested that the trend of going to the hospital for treatment changed in the context of the economic crisis that hit Cameroon during the period 1986 to 1995. This illustrates how people's health related practice must be investigated as far more than static 'traditional' beliefs.



## Chapter 7: Conclusion

The objective of this thesis has been to illuminate the structuring factors behind affected families' therapy management of Burkitt's lymphoma. The families' interpretations and management of the symptoms of the disease have been at the center of analysis. In my approach to the research question of this thesis, I have used the 'Burkitt's pattern of resort' as an analytical tool to investigate the various forms of treatment that the families turned to when their child became ill. I have proposed a dominant pattern of resort, in which hospital treatment symptomatically becomes the last resort. To come to grips with why it becomes the last, when uttered as their first choice for treatment, I have closely investigated their therapy management strategies in light of the cultural and socio-economic context of the disease. Following the footsteps of some of our time's most prominent critical medical anthropologists, I have emphasized that culture alone cannot explain why patients delay treatment. I adhere to the arguments of Paul Farmer who contends that it may in the furthest sense serve as its alibi (Farmer 2004). Culturally meaningful disease explanations must be investigated with consideration of real-life complexities and challenges.

In my attempt to understand the therapy management of Burkitt's lymphoma, I have found it essential to investigate the cultural assumptions and values, behavioral processes and social and economic structures that influence the therapeutic processes (Janzen 1987:68). I have suggested that the decision to take the child to a hospital involved a balance between the interpretation of signs and symptoms and an evaluation of the economic means available. I found, in coherence with Ryan (1998), that in the attempt to identify the illness, a tactic was to simultaneously increase variation between the treatments in hopes of finding at least one that would provide a cure. This is also done to reduce the expenses.

Looking at the socio-economic context of Burkitt's lymphoma, we find that it poses serious limitations to the families' therapy management. Most children become ill during the rainy season when roads are impassable and farms must be taken care of. In spite of the difficulties to get to the hospital, the number of children admitted to the Burkitt's ward during the rainy

season doubled from that of the dry season. This illustrates the determination behind the caregivers' effort to find cure. The empirical examples of this thesis have illustrated that people's explanatory models of disease are flexible and open for negotiations. The caregivers expressed during medical consultations and health talks an aspiration for acquiring information about various diseases that could affect their families.

In this thesis, I have referred to the hospital as 'the last resort'. Whether or not the child received cure, it is in reality not the end of the families' management of the disease. Most families are faced with long-lasting and devastating consequences of the disease. The devastating consequences of losing one child had in several of the families already been experience once, or twice. The genetic aspect of Burkitt's lymphoma creates in some families a double burden, in which more than one child suffers from the disease. During the time of my field work one family had two children admitted to the ward, whereas several other families described the loss of their other children with the same symptoms.

Going beyond the biological factors of Burkitt's lymphoma, I argue that what one finds are the forces of social inequality that fuel its dissemination. These forces of social inequality do not only influence who become ill, but also who are likely to receive a cure. The anthropologist studying therapy management of disease does in such stance have a responsibility to critically investigate the social, cultural, political and economic context of the disease. This is a task, in which I can only offer a modest contribution. Nevertheless, I consider my field work to be of importance because it illuminates the need for action to change the present situation of Burkitt's lymphoma as a leading cause for child mortality in Africa. There is a need for further research on what measures might be undertaken to achieve better outcomes for these children.

The problem of access to treatment was addressed at the 9<sup>th</sup> annual International Society of Pediatric Oncology (SIOP) meeting held March, 2010, in Accra, Ghana. On the basis of information exchange with nurses and doctors, I learned that the problems of late hospital admissions and abandonment of treatment were also highly relevant to other Central African countries dealing with childhood cancer. One physician reported that the average delay of treatment for Retinoblastoma among her patients in Kenya was 39 weeks. Nevertheless, the



social aspects of cancer in resource poor settings have until recently been neglected in social and medical research. I am proud and grateful to present the stories of the people presented in this thesis. Taking all their complexities together, I find them to tell a story that represents a larger social body of knowledge on the lived experiences of the disease.



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***Appendix 1.***

**Cameroon Baptist Convention Health Board**

**Letter of Consent**

**Information sheet on voluntary research  
participation**

**Contact**

Name: Miss Benedicte Sebjørnsen

Principal investigator's telephone: +47 47274177

Permanent address: Sjøgata 4, 0250 Oslo

Temporary address: Banso Baptist Hospital, Resthouse

Temporary telephone:

**Research Purpose**

I am doing research to help understand the experiences of children and their families who are affected by a serious childhood disease. I am trying to learn how the child and the family manage the disease and how it affects their lives.

## **Information on Research**

I will learn about the childhood disease by participating in the daily life of the Burkitt's lymphoma treatment ward and through interviews. The nurses and physicians involved in the programs are an important source of knowledge, but I would also like to interview children and members of their families who come to the hospital for treatment between January-July 2009. After learning about my research you will have the opportunity to participate in the study, or to choose not to participate.

### **Why is this research carried out?**

This research will fulfill one of the requirements for my Master's degree in social anthropology at the University of Oslo, Norway. I am interested to find out how this disease affects those who live in other countries, as well as the experiences of the patient and their caregivers. I would be very happy to speak with you and your family. Maybe you have some stories about your experiences of disease that you want to share?

### **What type of research will be done with your information?**

This research will be examined at the University of Oslo. It will also be available online. The research will be written in English. Sometimes I will write down what you tell me, because then I can better remember what you have told me. Feel free to ask to read my notes after the interview. In my research I will not confuse what you have said and what is my understanding of your information. If you tell me something private that you do not want someone else to know, I will not use this information in my research.

### **Benefits**

I hope to learn about your experiences from the disease. These experiences are of importance to educate others on the effects of the disease in your country and to highlight the need for available and affordable treatment. Participation in this research provide you with the chance of sharing your experiences to a wider audience. Your information and stories will be taken

seriously and I want us to have a mutually good experience from your participation in this research.

### **Risks**

It is my responsibility to not use information in my report that in any way could hurt you, creates a misleading image of you or a situation. There are no risks of participating in the research in regards of the treatment you receive in the hospital. You have the right to choose what information you want to share with me and if you decide that you do not want to continue your participation in the research, you can withdraw at any time.

### **Protection of your Privacy and Confidentiality**

Because this research is conducted in a hospital, I use the principal of *confidentiality*. This means that you, as a participant in the research, have the right that all information you give me will be handled in a way that protects you from being recognized by others. I will create fictional names instead of using your real name in the report. I do not change the information you give me.

### **Whom do you call if you have questions or problems?**

You can call me if you have any questions concerning your participation. If you experience any problems due to your participation in the research, feel free to let me, or the nurse know. This way, we can talk about whether you wish to continue your participation in the research. There will be no consequences if you choose to withdraw your participation, or if you do not want to complete an interview. If you choose to withdraw from the research, I will help you fill out a *study withdrawal letter*, which you find attached to the consent form.

## Voluntary Participation-Participants Rights

- As a participant in the research you have the right to informed consent and information about the research
- A child has the right to protection and this will always be of main importance to Miss Benedicte
- You have the right to choose what information you want to share with the researcher
- The researcher must ask for your consent before the research is published
- You have the right to withdraw from the research at any time during the research



# Letter of Consent

Someone has read this information sheet and explained it to me. Yes No

I have asked the questions I wanted to ask, and now I understand the purpose of the study.

Yes No

I agree to participate in this study about serious childhood diseases and I agree for the researcher to ask my child some questions. Yes No

I understand that I can refuse to answer some questions and can still continue to participate in the study. Yes No

I understand that I can withdraw from the study at any time and I will still get my normal care at this hospital. Yes No

Name of parent or guardian \_\_\_\_\_ Signature of parent or guardian \_\_\_\_\_ Date \_\_\_\_\_

## For children over seven years of age:

This study has been explained to me and I understand that Miss Benedicte wants to ask me and my family some questions. Yes No

I will like to talk with Miss Benedicte and I will answer her questions as much as I can.

Yes No

Name of child participant \_\_\_\_\_ Signature of child \_\_\_\_\_ Date \_\_\_\_\_

Name of person obtaining consent \_\_\_\_\_ Signature of person obtaining consent \_\_\_\_\_ Date \_\_\_\_\_

# Study withdrawal letter

I wish to withdraw from the research \_\_\_\_\_

Reason for withdrawal (Optional) \_\_\_\_\_

\_\_\_\_\_

Name \_\_\_\_\_ Signature \_\_\_\_\_ Date \_\_\_\_\_

or thumbprint

Person Obtaining Consent

Name \_\_\_\_\_ Signature \_\_\_\_\_ Date \_\_\_\_\_

## ***Appendix 2***

### **Interview Guide Caretakers**

Date of interview:

Name:

Relationship to child:

Child's stage of treatment:

Profession:

Address:

Religious views:

### **Record of disease**

- *When was the disease discovered?*
- *How was the disease discovered? What was the child's complaint?*
- *How did you react to the symptoms?*
- *What was your first thought when you discovered the disease?*
- *Did you have any thoughts about whether it was a natural or unnatural illness?*
- *Did you go to a traditional healer to consult?*

- *Did the healer tell you whether it was a natural or unnatural illness?*
- *Do you still have the same opinion about what could have caused the disease?*
- *Do you recall whether the child had any other illnesses before getting sick with this illness?*
- *Have you ever treated the child for malaria?*
- *Do the children in the family sleep under an impregnated mosquito net?*

### **Preference of treatment**

- *When you or your child is ill, what type of treatment do you prefer and why?*
- *Are there any disagreements in your family about preferred medical treatment?*
- *Why do you think that some parents prefer traditional treatment (or why do you prefer traditional treatment)?*
- *Is it important for you to know the cause of the illness before you can start treatment?*
- *Do you have a 'home pharmacy' where you keep drugs, traditional or western to give when you or one of your family members is sick?*
- *In what ways is Western based treatment different from traditional medicine?*

- *Are there any diseases that you think that cannot be treated in a hospital?*
- *Would you accept treatment of the child if it involved surgery?*

### **Religious beliefs and medical care**

- *Does your religion guide you in what medical assistance you choose?*
- *Do you prefer to go to a hospital with a religious foundation instead of a general hospital? If yes, in what ways do you think they are different?*
- *Is going to traditional healers in any way in conflict with your religious beliefs?*

### **At the hospital**

- *How did you get to the hospital from your home/transport used?*
- *How far did you travel?*
- *Did you worry about the financing of the treatment before you came to the hospital?*
- *Has it been financially difficult to be in the hospital?*
- *Is it easier for you to pay in commodities than to pay cash for medical services?*

- *How have you experienced being at the hospital (encouraging/discouraging etc...)?*
- *Where do you sleep when you are at the hospital?*
- *If you could improve anything at the hospital what would it be?*

### **Learning about Burkitts lymphoma**

- *How did you feel when the nurse told you that the child has cancer?*
- *Was this the first time you heard of the disease?*
- *What do you know about cancer?*
- *When was the disease explained to you?*
- *How do you experience that the child is feeling about being sick?*
- *Have you talked to the child about the disease?*
- *In what ways has the disease affected your lives?*

### **In the village**

- *Have you talked /or will talk to anyone in your village about the disease?*

- *Have you seen the same symptoms in other villagers?*
  
- *Is there a name for the disease in your village?*
  
- *What do most people eat in your village?*

