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**TITLE**

**Exploring the barriers to disclosure of life-threatening  
illness to children in Blantyre, Malawi:**

*a research dissertation in fulfilment for the requirement of the*

*M PHIL in Palliative Medicine at the University of Cape Town, South Africa*

**BY**

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**DECLARATION**

I declare that **‘Exploring the barriers to disclosure of life-threatening illness to children in Blantyre, Malawi’**, is my own work and that it has not been submitted for any degree or examination in any other university, and that all sources I have used or quoted have been indicated and acknowledged by complete reference.

Mary Bunn

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Signed

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Date

University of Cape Town

## CONTENTS

	Page
Acknowledgements -----	2
Declaration -----	3
Abbreviations -----	7
Abstract -----	8
Chapter 1 Introduction -----	9
Chapter 2 Literature Review -----	17
Chapter 3 Aim and Objectives -----	29
Chapter 4 Methodology -----	30
Study design -----	30
Study site -----	30
Study population -----	30
Sampling and recruitment -----	31
Data collection Tool -----	34
Data collection Method -----	36
Data analysis -----	39
Ethical considerations -----	40
Distress protocol -----	41
Chapter 5 Results -----	42
Demographic data -----	42
Thematic data -----	44
1) Age of maturity -----	45
2) Understanding of illness -----	48
3) Issues around disclosure -----	54
4) Methods employed by families -----	60
5) How children should be informed -----	63
6) Children's experience and reactions -----	68
Chapter 6 Discussion -----	72
Respecting children -----	72
Demographic data -----	73
Exclusion of paediatric palliative care team -----	74

Cultural differences between West and Malawi	75
Hope means healing	78
Precipitating death	78
Conflict with principles of palliative care	80
Non-disclosure reduces worry	80
Limitations of the study	82
Sensitivity of the topic	83
Relating study findings to literature findings	84
Chapter 7 Conclusion and recommendations	86
Meeting the objectives	86
Recommendations for disclosure to children	89
References	92

University of Cape Town

## Appendices

Appendix I	Information sheet and consent form for adults in English and Chichewa	i
Appendix II	Information sheet and consent form for parent/guardians and children in English and Chichewa	iv
Appendix IIIa	Interview guide for Focus Group Discussions with adults English	viii
	Chichewa	ix
Appendix IIIb	Interview guide for Focus Group Discussions with children In English and Chichewa	x
Appendix IIIc	Interview guide for Focus Group Discussions with well children in English and Chichewa	xi
Appendix IV	Demographic data collection sheet	xii
Appendix V	Demographic data tables for all 81 study participants, showing gender, age, tribal group, school attainment and occupation	xiv
Appendix VI	Ethical permission from UCT research and ethics committee	xx
Appendix VII	Ethical permission from Malawi College of Medicine research and ethics committee	xxi
Appendix VIII	Letter of support from Head of Paeds. Department, QECH	xxii

## Tables

Table 1	Demographics of focus group participants	34
Table 2	Demographics of in-depth interview participants	35
Table 3	Themes and sub-themes	36

## Abbreviations

FGD	focus group discussion
IDI	in-depth interview
HIV	human immunodeficiency virus
AIDS	acquired immunodeficiency disease
ARV	antiretroviral medication
HSA	health surveillance assistant
TBA	traditional birth attendant
QECH	Queen Elizabeth Central Hospital
PI	principal investigator
WHO	World Health Organisation
UCT	University of Cape Town
COMREC	College of Medicine research and ethics committee, Malawi

## **ABSTRACT**

It is recognised in the western world that children with life-threatening or life-limiting illness benefit from sharing of information about their illness in an age-appropriate way as this enables children to feel empowered, in some control of their illness and less isolated.

Currently in Malawi, as in the rest of Africa, there are increasing numbers of children facing the diagnosis of life-threatening or life-limiting illness and requiring compassionate palliative care. However, in Malawi, children are still told very little of their illness.

This study was therefore designed to use qualitative methods to investigate the barriers to disclosure of life-threatening illness to children in Malawi. It sought to obtain information regarding Malawians' thoughts and feelings about childhood life-threatening illness and their attitudes to talking about this to children. It also explored the cultural context and concerns leading to barriers to disclosing to children and identified what children would like to know about their illness.

A set of recommendations for health workers in paediatric palliative care in Malawi have been developed from the findings of this study, to facilitate explanation and communication with children and families regarding life-threatening and life-limiting illness, in order to equip and empower children to participate in decision making and come to a position of acceptance and peace.

## **CHAPTER 1.**

### **INTRODUCTION**

#### **Information sharing in Palliative Care.**

‘Palliative care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms and of psychological, social and spiritual problems is paramount. The goal is achievement of the best possible quality of life for patients and their families.’<sup>1</sup>

In paediatric palliative care, children are described as having life threatening illness (where the illness may lead to death) or life-limiting illness (where the illness is likely to curtail the child’s life).

- ‘Palliative care for children is the active total care of the child’s body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child’s physical, psychological and social distress.
- Effective palliative care requires a broad, multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.

- It can be provided in tertiary care facilities, in community health centres, and even in children's homes'<sup>2</sup>

Honest and open sharing of information with patients is a fundamental principle of palliative care. This contributes to patient-centredness, which together with the ethical principles of autonomy, beneficence and informed consent, lead to a situation in which patients can be included and supported in decision making. There has been a trend therefore towards open communication and disclosure to patients' about their terminal illness since palliative care was established in the 1960's, in western societies.<sup>3</sup>

However, health workers still tend to moderate the information they give, such that conditional disclosure is given rather than full open disclosure. Factors such as the inherent difficulty of breaking bad news, cultural influences, and changes in attitudes where the patient is a child all play a part.

It is recognised in the western world that children with life-threatening or life-limiting illness not only benefit from being informed and included in some decision making but children invariably know more than their parents and medical staff think they know<sup>4</sup>. Sharing of information in an age-appropriate way assists children to feel empowered, in some control of their illness and less isolated. This is reflected in the increasing worldwide awareness of Children's Rights, and the need to support families in involving children in difficult decisions and treatments, which are now recognised as requiring children's assent, as well as parental consent.

There are indications that children in Africa find non-disclosure harmful, as described in a report from Uganda of a boy diagnosed with HIV at 10 years, but not told of his HIV status until the age of 16 years, despite frequent illness, the death of his step-mother and illness of his father. He described the experience as traumatising and felt he would have coped better if he had known earlier in the course of the illness.<sup>5</sup> The main reasons given to explain why parents do not disclose their children's HIV status to them is fear of stigma, and denial.

Although studies have led to recommendations by the American Academy of Paediatrics<sup>6</sup> that strongly encourage disclosure of HIV infection to school-age children, there has been considerable variation around the implementation of this, compounded by the lack of guidelines regarding how disclosure should actually be done<sup>7</sup>.

## **Research setting - Malawi**

Currently in Malawi, as in the rest of Africa, there are increasing numbers of children facing the diagnosis of life-threatening or life-limiting illness and requiring compassionate palliative care.

Malawi is a landlocked country in south eastern sub-Saharan Africa, about 94,000 square kilometres of land area, and 24,000 square kilometres of Lake Malawi, running along the eastern border with Mozambique. It has a population of 12 million, a national adult prevalence (15-49 years) of HIV/AIDS of 14%, and 70,000 HIV positive children under the age of 15 years<sup>8</sup>. There are about 25,000 people in Malawi living with cancer, and countless others with other diseases for which there is no curative treatment at this time, both adults and children.

In Malawi, children are still told very little of their illness. We consistently find that even with careful explanations of why it is felt that children benefit from some explanation about their illness, honesty and the chance to ask questions, the parents/guardians almost always refuse to disclose or allow the medical team to disclose about illnesses such as cancer, advanced HIV/AIDS and terminal cardiac failure. There is very little concept of involving children in decision making, or the need for assent to painful and invasive procedures, which may be done without warning or explanation.

Although Malawi is a changing society and whereas traditionally, men or the maternal or paternal uncle, depending on the tribal group, used to make all the decisions in the

family, there is now increasing recognition of women's roles and joint decision making is more common. Children, however, still have very little say in decisions that affect them, whilst they are still dependants and living with their parents.

A paediatric palliative care service called Umodzi (which means unity and togetherness) was set up in the paediatric department of Queen Elizabeth Central Hospital (QECH), Blantyre in May 2002. This service has been treating and supporting children and their families from across the southern region of Malawi for the past 6 years, as the hospital is the tertiary referral centre for childhood cancer in Malawi. Initially, it was essential in the management of HIV infected children, but since the advent of free antiretroviral medicines for children in Malawi in 2005, through the global fund, the patient base has gradually changed. Currently, around 60% of the children referred for palliative care are positive for HIV infection, but this is not necessarily the main reason for their referral. Around 47% have cancer, most commonly Burkitt's lymphoma and other childhood cancers, including HIV related Kaposi's sarcoma. Others have life-threatening illnesses directly related to HIV, or conditions such as severe cardiac or renal failure, or chronic neurological disability. Approximately 170 new patients are referred per year, and the total number of children seen is now over 1000. Umodzi's team consists of a part-time doctor (the Principle investigator from December 2005-2008), a clinical officer (shared with the paediatric department), 2 nurses and a play leader, with the support of the paediatric matron and paediatric oncology clinical officer, both of whom have been trained in palliative care. They work alongside the paediatric ward staff, providing symptom control for chronically sick and dying children, both as inpatients and outpatients, and this includes children also receiving active treatment aimed at cure, as well as those

for whom curative treatment is no longer felt appropriate. An important part of the role of Umodzi is to help medical staff and carers to recognise and accept when this point has been reached, and to provide a plan for discharge and follow-up as the great majority of families prefer to care for their terminally-ill children at home. These families are supported via an open access clinic, and home visits where possible to allow continuity of care by staff experienced in terminal care. In some cases, referral can be made to home-based care teams or other local hospitals if the child's home is far from Blantyre.

Despite the holistic nature of palliative care, provision of psychosocial and spiritual support to children has proved extremely difficult. Parents and guardians are counselled and prayed with, if appropriate, and offered comfort and support but this is usually done without the child being present. In order to support the child, it would be essential to be able to talk to them about the nature and prognosis of their illness, and to listen and respond to their concerns, but carers are unwilling for this to happen.

Our experience of talking to parents and guardians about disclosure to their children about serious illness indicates there are significant barriers preventing them from giving permission. Parents/guardians clearly want to protect their children from distress, as is true all over the world, and they generally want to give reassurance that the child will get better. Parents do not seem to be aware that children may know something is wrong even without being told.

One of the mothers on the ward typifies the reason for doing the study. She was a well educated mother, and both she and her 14 year old son, who had advanced

osteosarcoma and was distressed with breathlessness due to lung metastases, spoke fluent English. He had been inappropriately referred to QECH for further chemotherapy, but the illness was too advanced for this to have a role, and morphine and oxygen were given. The mother was adamant that he thought the cancer had been healed and that he should not be counselled about his current condition. He was obviously distressed, and an intelligent teenager and it was hard to believe he would not be aware of the disease progression. His symptoms were brought under control, and he was able to be transferred home, 200km away; but no disclosure was carried out. He died 4 days later.

Observation of the children, both on the ward and at home, clearly indicated that children experience distress even when being reassured that all will be well, and confirmed the impression from studies that false reassurance is not helpful. Children over 12 years in particular found it confusing to be told by their carer that they would be well, when they could see the tumour was getting bigger and causing more pain, particularly if they were then discharged in a deteriorating condition. The Umodzi team was limited to reassurance that the pain could be controlled, and that stronger analgesia was available if needed.

The cultural differences in the approaches of paediatric palliative care clinicians to breaking bad news to children are seen in the literature, and observed in Queen Elizabeth Central Hospital, where there were short term doctors from Europe, America and Australia, as well as Malawian doctors - many of whom had had some training in the west. However, cultural awareness of the patient and their family is

also essential, and there were concerns amongst Malawian staff and carers that this was not always respected.

Hence there are several factors to be considered; the need to understand the thoughts, feelings, attitudes and cultural beliefs; the need to understand the child's perspective and need for honest and open information-sharing; and the need for health workers to provide practical guidance and help in enabling parents/guardians to talk to the children sensitively.

The need for research was therefore identified within the paediatric palliative care team, to explore the attitudes and beliefs of adult caregivers towards information sharing, and the perceived needs of the children themselves for knowledge about life-threatening illness.

## **CHAPTER 2.**

### **LITERATURE REVIEW**

The issue of disclosure of life-threatening illnesses to children needs to take into account parental factors, such as the difficulty in telling; and child factors, such as psychological affects on the child including worry, anxiety, and depression –which can be due both to knowing and not knowing.

Approximately 25% of children with cancer in developed countries die of their disease, and when potentially curative treatment can no longer be offered, the challenge of palliative care is to address the physical, psychological and spiritual needs of the child and family. This was explored by Hurwitz, Duncan and Wolfe<sup>9</sup>, who concluded that holistic assessment and discussion of goals and hopes are important in improving both clinical care but also satisfaction and meaning in life for the child at the end of life.

Much work has been done about children's awareness of illness by Myra Bluebond-Langner, described in 'The Private Worlds of Dying Children'<sup>10</sup>, who observed that children at different stages of illness had different questions, concerns and needs. She categorised 5 stages of children's perception of life-threatening illness: seriously ill; seriously ill and will get better; always ill and will get better; always ill and will never get better; and dying (terminally ill). She concluded that deciding what to tell children should depend on what they want to know, what they are asking about and on their own terms.

### **Cultural factors.**

The relevance of cultural factors regarding how a community values children, and how they respond to illness in children was recognised by De Trill and Kovalcik<sup>11</sup>. Although families should be treated as individuals, knowledge of cultural differences in truth-telling, palliative care, pain control and use of alternative medicine is needed, and research in different countries is proposed. Parsons et al.<sup>12</sup> described patterns of communication at diagnosis between paediatric oncologists and children with cancer, and compared cultural differences in these patterns in the US and Japan. They found 65% of US clinicians always told the child, and less than 1% rarely or never told; whereas only 9.5% of Japanese clinicians always told, and 34.5% rarely or never told. US clinicians were primarily affected by their own sense of responsibility, whereas Japanese clinicians were affected by a range of personal factors, patient factors and work culture. The need for further investigation into the impact on children and families by these differences in practice was expressed, and this was reinforced by Surbone<sup>13</sup>, who advocated the requirement for cultural competence in oncology, including knowledge of truth-telling and decision-making practices across the world, in order to improve therapeutic outcomes and reduce disparities in cancer care.

The ACT Charter for Children with Life-threatening or Terminal Conditions and their families<sup>14</sup> encourages an open and honest approach to giving sensitive and age-appropriate communication. This was used in 2008 as the basis for the International Children's Palliative Care Network (ICPCN) Charter of Rights for Life Limited and Life Threatened Children<sup>15</sup>, which states as its fifth clause that 'A sensitive but honest approach will be the basis of all communication with the child and the child's family.' The same approach could be applied internationally, including to Malawian children

with life-threatening illness, as the United Nations Convention on the Rights of the Child<sup>16</sup>, as expressed in the 12 standards of The Child Friendly Healthcare Initiative<sup>17</sup>, includes the following statements for all children, not just those from rich-resource countries; that health workers should help to ‘share information with the child and family, and enable their participation’ (UNCRC articles 9,12,13,17);and ‘provide equal care, and treat the child as an individual with rights’ (UNCRC articles 2,7,8,9,16, 23,27,29,37).

Research into disclosure of diagnosis of cancer in the western world by Woodward and Pamies<sup>18</sup> indicates that full disclosure to competent individuals at any age is morally, ethically, legally and therapeutically appropriate. Slavin et al. found the impact of early communication to children was associated with good psychosocial adjustments<sup>19</sup>, and supports an open and honest approach in communicating with paediatric cancer patients.

### **Parental factors.**

The parental struggle over whether and what to tell a child with life-threatening illness about their illness, treatment and prognosis is addressed by Chesler, Paris and Barbarin<sup>20</sup>. Choices in information sharing depend on the age of the child, sibling structure, parental religious or existential beliefs, and access to information and support. Family reactions, illness progression and events beyond their control were also influential in telling children.

Parents are recognised as having a tension in their role as protectors of their children and managers of what they should be told. A study by Young et al.<sup>21</sup> showed that this can result in their children feeling marginalised in consultation and hamper the relationship between the patient and health professional.

Parents commonly recognise age of the child as an important factor in how much they are told. Claflin and Barbarin<sup>22</sup> report their finding that young children (under 9 years) are told less about their illness than older children, but they experience similar levels of distress and not telling children does not prevent the distress. These younger children also had less effective coping strategies. Clarke et al similarly found older children were given more information, in a study looking at children newly diagnosed with acute lymphoblastic leukaemia.<sup>23</sup> Parents differed in what they felt the child should be told, and observed that most children showed behavioural and mood difficulties after diagnosis. Kreicbergs et al.<sup>24</sup> did a retrospective study asking 429 parents in Sweden who had lost a child to cancer from 1992-1997 whether or not they had talked about death with their child. The majority had not done so, and 27% of

these regretted it – especially those who felt the child was aware of their imminent death. No parent in this study regretted talking to their terminally ill child about death. Wolfe<sup>25</sup> reflects on the need for parents ‘to feel they have left no stone unturned to find a cure for their child’, and to try to shelter the child and siblings from the idea of approaching death. However, he also expresses the importance of truth telling, in age and culturally appropriate ways ‘to allow the transition from shock towards acceptance to unfold.’ He refers to the ‘elephant in the room’, as a subject that everyone knows is there, but no one wants to talk about, and how acknowledging this prepares the way for therapeutic communication, acceptance and protects against unresolved grief.

Beale, Baile and Aaron<sup>26</sup> comment that ‘uncertainty is a major psychological burden for both children and adults with serious illnesses because they are limited in their capacity to obtain information that could potentially reassure them’. Refusing to discuss death due to worries about frightening or depressing a child is more likely to have the opposite effect, and understandably reflects the parents own grief and difficulty in accepting that their child is nearing death. Case histories were used to demonstrate that giving honest information to children and allowing the child to express their fears establishes trust and frees the child to get on with living. False reassurance was not felt to be helpful.

Further case histories reported by Hilden, Watterson and Chrastek<sup>27</sup> show the benefits of open communication to sick children, and their siblings. They comment that whilst most health workers in the United States of America believe in the principle of telling children the truth about their illness, they also believe in the parents’ right to make the

decision to tell. Clinicians need to help parents, in order to avoid psychological harm to the child. They therefore need to recognise the dichotomy of hoping and working for cure, but also acknowledging the possibility of death before this becomes imminent. Encouraging children and parents to remain hopeful, whilst preparing for the possibility of loss requires integration of palliative care principles and discussion into routine care delivery, and helping parents to be aware how much the child understands about the illness. As previously mentioned, children know when they are dying, and can feel terribly isolated if not given permission to talk openly and express both their fears and their love. Although the evidence from case histories is less robust than that from formal research, this is a valid and important indicator of the necessity for healthcare professionals to facilitate communication between parents and children.

It is also recognised that the death of a child changes forever the life and health of those they are closest to. How a child dies has a great influence on parents and siblings future functioning and relationships and is another important factor in the need to provide good end-of-life care for the child, including addressing communication and decision-making. Hinds et al.<sup>28</sup> call for further paediatric end-of-life care research into characteristics of paediatric deaths and effectiveness of interventions to reduce the suffering of the dying child and of the bereaved survivors.

### **Child factors.**

There is evidence that children want to know about their illness; Dunsmore and Quine<sup>29</sup> explored treatment experiences and preferences in 51 12-24 year olds in Australia who had cancer, to identify their information, support and decision-making needs and preferences. Almost all (49/51) wanted to be informed about bad news,

such as treatment failure, poor prognosis and imminent death, and appreciated honesty, concern, professional expertise and the ability to listen.

Last and van Veldhuizen<sup>30</sup> found children with cancer aged 8-16 years demonstrated significantly less anxiety and depression if they received open information about their diagnosis and prognosis at the start of the disease. They therefore suggested parents should be advised to inform their child soon after diagnosis and clinicians should facilitate this process.

A working committee of the International Society of Pediatric Oncology (SIOP)<sup>31</sup> looked at 16 verbatim samples of what children terminally ill with cancer said in their final days. The children were aged 4-13, and came from 9 countries (France, Greece, Italy, Nicaragua, The Netherlands, Russia, South Africa, Ukraine and the United States). Four consistent themes emerged from a content analysis; that awareness of impending death was commonly expressed as going on a journey to a faraway place, not an end, and this brought great comfort. Secondly, that they did not want to live on in pain. If they had to die, it should be peacefully without more pain. Thirdly, a child-centred view of their own role in the family and whether their parents could go on without them was voiced. Lastly, older children showed sadness but reluctant acceptance of their approaching death. Although further research was advocated, the universality across cultures regarding expressions and concerns of dying children was remarkable.

### **HIV in children.**

Disclosure of illness status to children with HIV infection has also been investigated, and the American Academy of Paediatrics, Committee on Paediatric AIDS<sup>32</sup> found

that whilst age, maturity, family dynamics and the clinical context have to be taken into account, children who know their diagnosis appear to have higher self esteem than those unaware, and the parents of these children show less evidence of depression.

In a study by Lester et al.<sup>33</sup> on how parents decide when and what to tell, only 43% of 51 HIV-infected children had been told their HIV status. Parental communication style, parental illness, child's rights, treatment adherence, child questions and provider pressures were found to be important influences on parental decision to disclose the child's status. Non-disclosure was due to concerns regarding stigma and potential emotional distress.

Instone<sup>34</sup> looked at 12 school-aged children with HIV infection whose parents/guardians had kept the child's HIV status secret from the child for between 2 and 8 years. Although parents/guardians were not aware of their children's worries, there were signs of severe emotional distress, disturbed self image and social isolation, whether or not HIV status had been disclosed. The long time interval of non-disclosure was felt to be a significant contributor to the children's poor psychosocial adjustment. As there was failure of parents/guardians to realise more supportive information was necessary, it was recommended that clinicians should monitor children's psychosocial adjustment in order to help guide families through the disclosure process.

A study in South Africa by Kouyoumdjian, Meyers and Mtshizana<sup>35</sup>, investigating the barriers to disclosure to children with HIV, found that caregivers do not disclose HIV

status to children, despite specific questioning by the children. Caregivers felt uncomfortable discussing HIV and illness with children because of stigma, lack of knowledge and skills, and feeling emotionally unprepared. Disclosure could therefore be facilitated by health care and social care professionals.

Similarly, the attitudes of caregivers of Thai children with HIV infection were explored by Siripong et al.<sup>36</sup> None of the 49 caregivers had disclosed to their child, and 37% did not intend to. The main reason given was fear of causing the child psychological harm. Only 17% intended to tell the truth if asked by the child. The caregivers were recognised to be unprepared, have limited understanding about disclosure and to be willing to lie to their child; support for disclosure was needed.

The need for support in disclosure was also recognised by Naeem-Sheik and Gray<sup>37</sup> in Johannesburg who recommended that 'every health care provider should develop a plan with the HIV-infected child's parents or guardians that will outline the process of HIV disclosure'. They described disclosure as a process that should take place over a period of time, before the child discovers their own diagnosis; and suggested the use of role-play with parents and guardians to help them prepare for difficult questions, and adverse reactions to disclosure. They felt that it was essential for the child to be informed, as an integral part of medical care, and a positive influence on drug compliance and adherence. This can also reduce high-risk behaviour and spread of HIV. However, the needs of both the child and the parent/ family must be taken into account, as parents may also be coping with their own illness, feelings of guilt and responsibility for the child's illness and for protecting them from potentially harmful knowledge; and fear of the child's reaction, both regarding the will to live, and

regarding anger towards the parent for passing on the infection. Advantages of disclosing include increased ability to cope and support each other; relief of the burden of keeping a secret and concern over accidental disclosure; empowering the child to participate in their own healthcare decisions; and increasing hope. Sadness and depression, which are often short-lived, were observed following disclosure, but suicide was described as extremely rare, though if suicidal ideation is expressed, a mental health professional must be consulted.

The recommendations of the American Academy of Pediatrics<sup>38</sup> with regard to disclosure to children and adolescents advocate disclosure of HIV infection to school-age children via a planned process, appropriate to the age and development of the child, and in response to what they already know and what they want to know. Adolescents should be fully informed of their status and its consequences, and encouraged to involve their parents in their care.

Marston and Sims<sup>39</sup> described that for Palliative Care in Sub-Saharan Africa, it is recognised that being truthful with children about the severity of their illness enables their involvement in their own care, builds self-esteem and allows them some control in a situation that often feels out of control.

The collaborative group working with Health Initiatives for Youth in UK<sup>40</sup> to support children, young people and adults living with HIV, states that children have a right to know their status at 13 years of age as by then they are questioning young adults. This will also be influenced by their maturity, any changes in behaviour or performance at school, or refusal to comply with ART medication. Young people expressed a desire

for honesty, security in place of disclosure, and that disclosure should be a process that is holistic and flexible, rather than a one-off event.

Medline and internet searches for references on HIV/AIDS disclosure in Malawi revealed no published data on this subject. There is within the Malawi National HIV/AIDS policy<sup>41</sup> a section on protection, participation and empowerment of vulnerable populations which includes policy statements on Children and Young People regarding education and protection from abuse. In addition, the Report of the Law Commission on the Development of HIV and AIDS Legislation<sup>42</sup> highlights the instance of minors as a circumstance in which the right to privacy and confidentiality regarding HIV status is waived such that disclosure should be made to the parent or guardian of anyone below the age of 18 years. However, the issue of disclosure to the children themselves is not addressed in either report. Hence, this study attempts to fill this gap.

### **Rationale for the research project**

Evidence from the literature on disclosure of life-threatening illness to children strongly supports the view that children and adolescents want to know about their own illness, and benefit from honesty and openness, so that they are not isolated with their own worries and fears. However it also emphasises the difficulties faced by parents in accepting and disclosing a child's life-threatening illness, especially in the case of HIV, due to stigma, but also in other life-threatening illness such as cancer.

Our experience of talking to parents and guardians in Malawi regarding disclosure to their children about serious illness indicates that there are significant barriers preventing them from giving permission for healthcare professionals to disclose. Issues of disclosure of life-threatening illness to children have not previously been investigated in Malawi. Hence, this study sought to fill this gap by exploring the barriers - investigating the thinking and reasons behind the resistance to disclosure, in order to better understand the cultural position. This would equip staff to facilitate explanation and communication with children and families, and be more able to help children to cope with their illness and empower them in decision making, which may allow them to achieve acceptance and peace.

University of Cape Town

## **CHAPTER 3.**

### **AIM and OBJECTIVES**

#### **Aim:**

The aim of the study was to explore the barriers to disclosure of life-threatening illness to children in Blantyre, Malawi.

#### **Objectives:**

The specific objectives were:

1. To obtain information regarding Malawians thoughts and feelings about childhood life-threatening illness and their attitudes to talking about this to children.
2. To determine the cultural context and concerns leading to barriers to disclosing to children.
3. To identify what children would like to know about their illness
4. To develop a set of recommendations for health workers in paediatric palliative care in Malawi to facilitate explanation and communication with children and families regarding life-threatening and life-limiting illness.

## **CHAPTER 4.**

### **METHODOLOGY**

#### **Study design**

This was a cross-sectional observational study using a qualitative research methodology, specifically using focus group discussions and in depth interviews.

#### **Study site**

The study took place at Umodzi, the only palliative care service dedicated to treating children in Malawi. It is based in the paediatric department of a large, government teaching hospital in the second city, Blantyre, Queen Elizabeth Central Hospital (QECH).

#### **Study Population**

The study sought to obtain views from a wide range of Malawians, representing different ages, tribes and socioeconomic groups.

Participants for the study included:

Focus groups:

- 1) groups of paediatric health workers, consisting of nurses and clinical officers in the paediatric department but not specifically involved in palliative care.
- 2) groups of key decision makers in the community, including chiefs, religious leaders and older women acting as health surveillance assistants and traditional birth attendants

3) groups of parents or guardians of paediatric patients identified as having life-threatening illness, currently on the in patient ward and referred to the palliative care service.

4) a group of older children aged 11 and above, to whom illness disclosure had already been made.

Individual interviews:

In addition, in depth interviews were carried out with two teenaged female patients at an advanced stage of illness; two bereaved parents/guardians; and three well children.

### **Sampling method and recruitment procedures**

Focus groups:

Purposive sampling was used as participants of focus groups must have some knowledge, experience and views about the subject under investigation. This is described for each group;

Nine focus group discussions, made up of 6-12 participants, were held.

Focus group (FGD) 1 was a group of nine paediatric nurses at QECH, recruited from the paediatric wards after explanation and permission from the senior paediatric sister. All nurses in the department were eligible, except those on the palliative care team, and the group was made up of the nurses at work and available that day, one or two from each of the acute, chronic, oncology, malnutrition and surgical wards. Nurses were approached individually and informed and consented by a research assistant who was not part of the department staff. The group took place during the lunch hour, so

mineral drinks were provided and a lunch allowance in keeping with government allowances. This group was all female.

FGD 2 was a group of eight clinical officers, all male. All the Malawian clinical officers in the department were eligible, and they were all approached individually with permission from the Head of Department, for a discussion in the lunch hour. The group included experienced clinical officers who had worked in the paediatric accident and emergency department for many years, as well as newly qualified.

The next groups involved community leaders and these were recruited from Health Centres just outside Blantyre, at Bangwe and Mpemba. Letters of permission were obtained from the District Health Officer, and visits were made to the Officers in Charge at both health centres to explain the study and request the participation of two Health Surveillance Assistants (HSA's) to mobilise participants for two focus group discussions at each health centre, one comprising of community leaders (chiefs and religious leaders); and the other comprising of HSA's and Traditional birth attendants (TBA's). It was requested that each focus group should have a minimum of six and a maximum of twelve participants, and transport reimbursement and refreshments at the health centre would be provided. The arrangements were made for time and place, and this was reconfirmed by telephone the day prior to the groups. FGD 3 therefore was a group of eight chiefs and religious leaders at Mpemba. FGD 4 consisted of ten HSA's and TBA's at Mpemba. FGD 5 and 6 were carried out at Bangwe Health centre, consisting of ten chiefs and religious leaders, and nine HSA's and TBA's respectively.

FGD 7 was carried out at QECH with six parents or guardians of current palliative care in patients, some undergoing long term oncology treatments and some acutely unwell. Parents and guardians were approached by research assistants and not directly by the principal investigator to avoid any concerns that their willingness or otherwise to participate may influence their child's clinical management.

FGD 8 was a group of seven children to whom disclosure of the diagnosis of life-threatening illness was known to have already been made. They were all aged over 11 years, had been diagnosed with HIV/AIDS and met the WHO criteria for starting antiretroviral therapy. They were recruited from the outpatient paediatric antiretroviral clinic at routine appointments, with permission from the doctor running this clinic, and all children over 11 years who knew their diagnosis were eligible. All were currently well. Providing information and gaining consent for participation in the study was done by a research assistant in the familiar environment of the antiretroviral clinic, to both the parent/guardian accompanying the child, and to the child. Consent was obtained from the parent/guardian and assent from the children themselves. They were asked to attend for the focus group discussion the following day after school hours, and this took place in a teaching room in the paediatrics department, as were all the hospital based focus group discussions.

A second group of six parents/guardians was recruited, FGD 9, as it was felt this group was underrepresented, and the results of FGD 7 indicated this may be a less articulate and confident group such that the meaning of some of the comments on review of the transcripts were less clear.

### Participants for individual interviews

In depth interviews were carried out with two paediatric palliative care patients who were not well enough to be part of a focus group. One was interviewed at her own home, and one on the hospital ward. The guardians of both these patients were also participants to the study, one as a focus group participant, and one in an in depth interview after the child had died. Another parent was also interviewed in bereavement, and permission to interview his child had also been given, but he sadly died before this could be done.

### Well children participants

Three well children with no life-threatening or life-limiting disease were interviewed, recruited by convenience sampling as they were known by the PI, but informed and consented by a research assistant whom they had not previously met. Two 12 year old girls were interviewed together, and one 14 year old boy individually.

Hence, a total of seven participants were recruited for in depth interviews, which followed the same interview guides as used in the focus group discussions.

### **Data Collection**

#### **Data collection tool**

‘The aim of qualitative research is to facilitate further understanding of the beliefs, thoughts and activities of the patient, relatives and health professionals, as a way of addressing the appropriateness of care within specific settings.’<sup>43</sup>

The research tool consisted of the focus group discussion guides shown in Appendices IIIa, IIIb and IIIc, designed for use with adults, children with life-threatening illness, and well children respectively. The focus groups and interviews were led by trained facilitators who raised the following general themes for exploring what participants felt children understand about illness and death;

at what age children function as adults;

the effects of giving bad news and how this is best done;

what harmful effects there might be of informing children about their illness; and what beneficial effects there might be;

any traditional, spiritual issues;

and what the parents find difficult.

### **Development and Pilot of interview guide**

A thematic interview guide was devised following discussion amongst the investigators and this was initially piloted for suitability and effectiveness.

The paediatric palliative care team were recruited as the pilot group, consisting of three nurses (one was nurse in charge of the paediatric oncology ward with whom the palliative care team works closely), two play leaders, and one clinical officer. This also formed part of the training of the research assistant, who was involved as facilitator in some of the subsequent groups.

This mock focus group discussion led to further development of the interview guide prior to the proper study. The questions themselves did not change, but the order was amended to improve flow, and allow some discussion around age of adulthood at the start of the group discussion which was non-threatening and ice breaking.

A separate interview and discussion guide was necessary for the children's group and in-depth interviews. This was initially designed as a brief questionnaire, not suitable for use with well children. It was used in this form with the first terminally ill child, but subsequently adapted to the form shown in Appendix IIIb, which uses more of the questions from the interview guide for adults and allows better comparison of adult's and children's thoughts and ideas, and probes more deeply.

### **Validity and reliability**

There was no 'gold standard' for measuring Malawians thoughts, feelings and attitudes towards talking about life-threatening illness with their children so there was no criterion validity, but construct validity based on the theory that there were barriers to disclosure based on attitudes and beliefs measured up well. The number of focus group discussions, including different types of relevant participants with health staff, community leaders, parents and children with and without life-threatening illness, ensured that the views of relevant people were obtained, and saturation was achieved. There was reliability of information obtained over successive groups, and agreement between interpreters over the content and meaning of what was said, giving inter-observer reliability. Consistency was seen in the resulting themes.

Data triangulation was provided by the in-depth interviews, which allowed inclusion of bereaved carers, sick and well children, in one-to-one interviews.

### **Data collection method**

The research method consisted of nine focus groups, each made up of 6-12 participants, using the focus group discussion guides in Appendices IIIa and IIIb; and six in-depth interviews (one involving two respondents).

The focus groups included two groups of paediatric ward staff, not of the palliative care team; two groups of parents and guardians of patients on the paediatric wards; and four groups of key decision makers in the community. A further focus group involving older paediatric patients to whom disclosure about life threatening illness had already been made was also formed.

The children's group was used to explore their experience of illness and what they would like to know and a separate discussion guide was developed for this group (Appendix IIIb).

An observer recorded the nature and type of participation by group members, and the discussion was audio-recorded in its entirety. The audiotape was then transcribed and translated into English.

The principal investigator acted as observer and recorder of paralinguistic and extra-linguistic elements and behaviour and kept field notes.

Six in-depth interviews with parents and children were carried out to obtain further information, and allow triangulation of results. The questions for these interviews followed the themes and interview guides described above.

All focus group discussions took place in a private place without disturbances at the health centres or in the hospital for convenience and familiarity to the participants. In-depth interviews were carried out in hospital, in the participant's home, or in a quiet undisturbed room at a school familiar to the children, in the case of the three well children interviewed. Written informed consent was obtained from each adult participant and parent/guardian of child participants, and assent was obtained from the children themselves prior to participation. Each participant was assigned a unique identification code (for instance, P1 for participant 1). Individual responses were

represented by the identification codes and the codes were linked to the data generated from the focus groups and in-depth interviews.

A Total of 81 participants, not including the pilot/practice group, were involved in the study. Demographic data was collected for all 81 participants in order to assess how fully they represented the different tribal groups in the southern region of Malawi. Information on age, gender, highest level of schooling attained, occupation and tribe was gathered, and age of the hospitalised child as applicable, for FGD's 7 and 9. The demographic data collection sheet is shown in Appendix IV.

#### **Appointment and training of research assistants**

The post of research assistant to this study was advertised verbally in the Community Health Department of the College Of Medicine, Blantyre, Malawi where there is experience in qualitative methods. The local supervisor and co-researcher produced a short-list of 4 applicants who were contacted by the PI by cell phone and invited for interview. Although it had been hoped that there would be post graduate applicants, no one with this experience was available in the short time frame of the study.

However, two of the applicants were felt to be suitable; the one initially appointed had a nursing background and training and experience in Palliative Care. He was trained in qualitative methodology and interview, observer and facilitator skills and research ethics and supervised in transcription and translation of audiotaped discussions and interviews. The research assistant and supervisor recruited, consented, facilitated, observed, translated and transcribed all the focus groups except FGD 9, and the first research assistant carried out, translated and transcribed the first three in-depth interviews. He moved on to another job at this point, as the study data collection was

expected to have been finished by November 2008. A second research assistant, who had performed well at interview, was appointed to complete the last focus group discussion, and the last three in-depth interviews. He also rechecked and corrected or clarified all the previous transcripts. The local supervisor and research assistants were all fluent in both Chichewa and English.

### **Data analysis**

Data analysis was performed manually. The focus groups and in-depth interviews were conducted in Chichewa, the local language. The recorded data from each focus group and in-depth interview were transcribed verbatim and translated into English. All the translations were later checked to ensure they were correct and understandable. Interpretations were agreed upon by the research team. In some cases, literal translations were made and the actual words spoken by the participant were put in brackets. The Principle Investigator then became thoroughly familiarised with the material by immersion in the data.

Data analysis involved the identification of recurrent themes from both the conceptual framework and thorough reading of the transcripts. Both the Chichewa and English transcripts were read and assimilated in their entirety repeatedly to identify themes that re-occurred across all the Focus Group Discussions and In-depth Interviews.

Information was coded and charted based on the order and structure of questions in the thematic interview guide Appendix IIIa for adults; and interview guides Appendices IIIb and IIIc, for children's views and identifying what children want to know. Direct quotes were recorded on the charts, in columns for each discussion and interview, relating to each theme, with identification of the source. Descriptions of

emerging themes were also recorded, clearly distinguishable from quotes, but identifying the source evidence. The consistency of recurring themes was clearly seen.

### **Ethical considerations**

As in much palliative care research, the issues raised were sensitive and emotive. It was therefore important to ensure the participants understood that the purpose of the focus group was to discuss a research issue rather than being a therapeutic intervention.<sup>44</sup>

Where the participants were parents or guardians of patients, there was a concern that they might have felt vulnerable and consciously or subconsciously felt that their participation or declining to participate might have affected the care received by their child. The research was explained to the participant by a research assistant not involved in clinical care provision, and opportunity was given to ask questions and be reassured that their decision not to take part or to withdraw from the research would not change the care their child received.

Even in the case of paediatric staff and community leaders, they may also have had first hand experience of losing a child as this is a frequent occurrence in Malawi. A Distress Protocol was planned and explained therefore, as described below. The lack of direct benefit to the participant and risks and burdens in terms of potential distress was explained to potential participants prior to requesting consent. However, giving participants opportunity to express their views and discuss this difficult issue may in fact have some benefit, and this is commented upon in the discussion.

The researchers recognised the sensitive nature of the research and regarded the topic as important in seeking to improve the psychological and spiritual care provided to

the child and family required by palliative care. It is only through robust but sensitive research that sound evidence can be acquired to determine what constitutes best quality care for palliative care patients, including children.

Informed consent was obtained for all participants and it was emphasised that participation in no way suggested the participant was giving permission for disclosure to their child. The study was only about enquiry, seeking information and understanding. It was also about discovering what the child needs to know to help them to cope with their illness, but it did not involve giving information to the child.

Ethical permission was obtained from both the UCT ethical committee, and the College of Medicine Research Ethics Committee in Malawi (COMREC).

### **Distress protocol**

It was recognised that some participants may find the issues discussed upsetting.

There was therefore a distress protocol for data collection as follows. All participants were fully informed as to the nature of the issues to be raised. Any respondent who appeared to become distressed would be offered the opportunity to leave the group, either completely, or to restart when comfortable. The participant would be offered support and counselling by trained palliative care staff.

## CHAPTER 5.

### RESULTS

#### **Demographic data**

This is presented as tables of the focus groups, showing number of participants, gender distribution, average age and age range, and number of tribal groups represented in each focus group.

Full demographic data is shown in Appendix V, as tables of the 81 participants, with their age, gender, tribal group, highest level of education attained and occupation.

Table 1. Demographics of focus group participants.

FGD	No. of participants	No. of females	No. of males	Average age	Age range	No. of tribal groups
FGD 1 Nurses	10	10	0	43.7	25-61	6
FGD 2 Clinical officers	8	0	8	36.9	29-41	3
FGD 3 Community and religious leaders	8	2	6	55.3	26-75	3
FGD 4 Community health workers	10	9	1	47.9	31-75	6
FGD 5 Community and religious leaders	10	2	8	45.1	33-60	6
FGD 6 Community health workers	9	7	2	47.7	25-75	6
FGD 7 Parents/guardians	6	6	0	39.3	33-50	4
FGD 8 Children	7	5	2	13.3	11-16	4
FGD 9 Parents/guardians	6	6	0	48.6	36-73	4
TOTAL	67	42	25	45.6	25-75	8

**OVERALL SUMMARY FOR ADULT GROUPS:**

No. participants	69 (includes 2 IDI participants)
Gender	43 females and 26 males (62% female: 38% male)
Ethnic distribution	18 Yao, 16 Lomwe, 11 Ngoni, 10 Chewa, 6 Mang'anja, 4 Tumbuka, 2 Tonga, 2 Sena.
Age distribution	45.5 years (25 to 75)
Highest educational level attained	9 No schooling, 13 Some primary schooling, 7 Completed primary school, 11 Some secondary school, 8 Completed secondary school, 19 Post-secondary school.

**OVERALL SUMMARY FOR CHILDREN:**

No. participants	12 (includes 5 IDI participants)
Gender	9 females and 3 males
Ethnic distribution	1 Yao, 4 Lomwe, 4 Ngoni, and 3 Tumbuka.
Age distribution	13.2 years (11 to 16)

**Individual Interview Participants**

Table 2. Demographics of in-depth interview participants.

IDI PARTICIPANT	Gender	Age	Tribal groups	Education	Occupation of family breadwinner
IDI 1	FEMALE	15	Lomwe	Some primary	Business
IDI 2	MALE	40	Chewa	Completed secondary	Business
IDI 3	FEMALE	42	Lomwe	Some secondary	Business
IDI 4	FEMALE	12	Ngoni	Some primary	Casual labour
IDI 5, P1	FEMALE	12	Ngoni	Some primary	Agriculture
IDI 5, P2	FEMALE	12	Lomwe	Some primary	Agriculture
IDI 6	MALE	14	Tumbuku	Some secondary	Business

### Thematic data

Themes and sub-themes are presented in a table and described with examples quoted from interviews.

Table 3. Themes and sub-themes.

<b>1. Age of Maturity</b>	<b>2. Understanding of illness</b>	<b>3. Issues around disclosure</b>	<b>4. Current info for children</b>	<b>5. How to inform children</b>	<b>6. Children's experience and reactions</b>
<b>1.1 age of adulthood</b>	<b>2.1 Causes of illness</b>	<b>3.1 Concerns</b>	<b>4.1 How do parents inform children</b>	<b>5.1 The right person to disclose</b>	<b>6.1 How the illness affects them</b>
<b>1.2 who are decision-makers (in adulthood)</b>	<b>2.2 Children's perception of illness</b>	<b>3.2 Benefits</b>	<b>4.2 How parents should be informed</b>	<b>5.2 Words that should not be used</b>	<b>6.2 How they felt at disclosure, and now</b>
	<b>2.3 Traditional/spiritual beliefs</b> <b>2.3.1 adult views</b> <b>2.3.2 child views</b>	<b>3.3 Harms</b>		<b>5.3 What resources would be helpful</b>	<b>6.3 Whether they would have preferred not to be told</b>
	<b>2.4 Perception of death</b> <b>2.4.1 adults</b> <b>2.4.2 child</b>	<b>3.4 Difficulties</b>			<b>6.4 Whether parent/guardian should have right to refuse them being told</b>

## Thematic framework of Major and sub-themes

### 1) **Age of Maturity**

Age at which children are regarded as adults was discussed, demonstrating a difference between the legal age recognised by the government for voting, age at puberty and initiation, and age at which children are given respect, responsibility and allowed to participate in decision making.

#### **1.1 Age of adulthood for children.**

There was agreement that the legal age of adulthood was 18 years. However, participants consistently said that there were signs of adulthood at an earlier age, varying from 11-12 years and up wards, and all were familiar with signs of puberty in boys and girls. Several commented that children now reach puberty at an earlier age, and they were aware of 12 and 13 year old girls as mothers. Initiation ceremonies were also mentioned, to advise children on behaviour on reaching puberty, and initiation marked the start of adulthood. At this stage, boys would move into a separate house called a *gowelo*, adjacent to the family house, do their own washing and would be forbidden from entering their parents' bedroom. However, respect and authority to make their own decisions was not felt appropriate until the child was married or living independently –often in their 20's.

*'Well, we give them different respect from the kids. We also expect them to give respect to us. However, as my friends have said, we give them different respect from elders because they are still under our care and support. Of course when they become independent, for example, when they get married, we respect them like any adult and independent person in the society.'* FGD 6

## **1.2 Decision-maker in important family matters.**

There was some variation in opinion as the majority felt that these days, husbands and wives should make decisions together, but the husband is still the final decision maker as head of the household. However, where the mother is alone with a sick child in hospital, she should be allowed herself to consent to urgent procedures such as operations or starting oxygen therapy in the absence of the father as seeking his permission could cause undue and potentially fatal delay. Some still felt that in accordance with past traditions, especially amongst poorer, less educated families and the Lomwe tribe, the maternal uncle of the child should also be consulted, but again this was generally felt inappropriate where it might delay urgent decision making. In one case, IDI 2, felt the authority lay with the breadwinner, so if that was the woman as in his family, she should make the decisions. However, in hospital, he felt decisions should always be made by the man but that the wife could give permission if the husband was not present. This presumably reflects the more unusual situation in his family where the wife was a police officer, and he himself looked after the children and always attended the hospital with his terminally ill son. In most families:

*'When any child falls sick, either the father or the mother can take responsibility, as the child is theirs. However, it is mostly women who are active when it comes to the hospital issues, because they are the ones taking care of them.'* FGD 9, P2

*'The man needs to have authority in the family, so that things will be going on well... But most people (women) with a sick child in the wards say that we should wait for*

*them to phone the uncle before the child is put on oxygen with tubes in the nostrils.'*

*FGD 2, P8*

Only one example was given of children being involved in their own healthcare decisions:

*'A little child has toothache and has failed to sleep at night. To be well what should we do? There is a need for tooth extraction. Therefore, in the 14 years, 15 years and above, you will see the child in pain has started going. Should I escort you? No, I will go on my own. He is thereby making the decision that I want the thing that is causing this pain to be removed... But for big illnesses... those things require a discussion between one parent and the other and also the one suffering.'* FGD 5, P1

## 2) Understanding of illness.

Understanding of illness included what adults thought to be children's knowledge and beliefs about causes and perceptions of illness, and both children's and adult's traditional and spiritual beliefs about illness and death.

### 2.1 Cause of illness

*'Most of the children know that for a person to suffer malaria it means he has been bitten by the mosquito. To prevent that, ... I should have a net. They are able to read many things or now it is what is being spoken on radios and TVs. Most of the children know that what causes AIDS is sexual intercourse. They know very well. Others know that if you are close to a person that is suffering from TB, you can catch TB. We may also mention cancer... some know that smoking tobacco causes cancer.'* IDI 3

Children with HIV/AIDS knew:

*'We took this illness from our parents. When we were born, we were born with illness'. FGD 8, P1.*

They also knew it could be transmitted from:

*'Sexual intercourse' FGD 8, P4*

*'Sharing of needles' FGD 8, P3*

*'Sharing toothbrushes' FGD 8, P3*

*'And razor blades'. FGD 8, P8*

## **2.2 Children's Perception of illness (adult's understanding)**

*'The way we understand the incurable diseases, the children are not told what they are suffering from and what is the end result? It is the parents who are told and mostly the parents do not explain to the child...so the child is ignorant of his condition' FGD 1, P5*

Many children are not told about their illness, *'Most children reach the point of death without knowing their real problem' FGD 2 P6.*

*'I think in our African culture it is very difficult for them to understand because parents do not explain to their children that they have an incurable disease or serious illness. Sometimes we hear children complaining about their health without knowing what they are suffering from. Only those parents who are educated can explain to their children about serious illnesses or incurable diseases.'* FGD 3, P5

*'We should take a child slightly older and able to understand things, every morning he is in pain. That child is in distress and has no peace. What disturbs him is that he asks himself many questions. 'My friends are there playing - what's wrong with me? What's my offence?' He asks himself many questions that he fails to answer. 'Why am I bedridden here?' While an adult can understand that I am sick ... Yet the child does not have any referencing point that I really had to be sick because of this, he thinks that to God he is the most sinful person.'* FGD 4, P1.

*'Most of the times they do not know that the illness they are suffering from is long lasting, they will be sick for a long time. They do not know unless someone, may be*

*the parents or the doctors, have told him that with this illness, young man or woman, you will suffer for a long time. Then he has a picture that I will still be sick. Above all odds he should believes that he will recover.’ IDI 2.*

## **2.3 Traditional/Spiritual beliefs**

### **2.3.1 Adult views**

Witchcraft was mentioned most commonly as the believed cause of incurable illness, especially in long lasting illness. This was described graphically by one participant:

*‘There are some with, for example, conditions like huge ascites, related to cancer. You may hear them say that they take the belly and remove it at night and use it as a pot for their witchcraft activities. This I know many people have been talking about it.’ FGD 2, P2.*

*‘Some people believe if a child is sick, then it means that the family did not handle the child properly at birth. They call it ‘tsempho’ - when one of the parents has sex outside marriage after the birth of the child but before they themselves resume sex in their own family. The child becomes sick.’ FGD 4, P2.*

*‘Some believe illnesses like cancer come because of curses and that only the person who threw a curse can reverse the curse. If it is not reversed, the cancer passes from one generation to the other and in such cases, you need to do some sacrifices to the spirits to appease them. If the spirits are pleased, the curses may be stopped from moving from one generation to another.’ FGD 4, P6.*

*'I wanted to add that sometimes because of our beliefs, people have preconceived ideas that it is witchcraft so that your explanation about conditions like cancer are not accepted because they already have in their mind that the patient is bewitched. Instead of receiving medical help they take what you have said as confirmation that it is not normal illness but witchcraft. And they want to go to the witchdoctor. End result, they don't get help because of the beliefs they have.'* FGD 1, P5

### **2.3.2 Children's views**

*'Children like parents also believe that people can be bewitched by others. They have such beliefs because whenever somebody is sick in their family they see their parents taking the patient to a traditional healer before taking them to the hospital. From this they know witchcraft is the major cause of serious illness.'* FGD 6, P2.

## **2.4 Perception of death**

### **2.4.1 Adult views**

*'So people have that perception that if one comes into the ward and writes, prescribing drugs, when they go, they give the drug that finishes the patient! The moment they (the doctors) go out people are crying!!! They think we kill people you see, that is how some think. But there are some people who are educated; they understand that this death is because of the illness that the person has suffered. But the problem of people especially we Africans, may be because of ignorance, is that we still haven't accepted that a person can die due to illness. We still have various beliefs about illness/death.'* FGD2, P 2

*'Those people that pray (religious people) know that those things came from the bible; and everybody knows that a person will be born once and s/he will die. But what will kill this person, they don't know; and the majority of them believe that it is illness. If one is involved in an accident, yes it has happened, but the majority know that for a person to die, he has to be ill; or else maybe in the village they say that it is witchcraft.'* FGD 2, P8

*'Nowadays, most of the people understand that there are diseases like HIV/AIDS which are also killing so many people. So many people associate every death with HIV/AIDS.'* FGD 1, P3

*'Death comes in different ways. It may be through illness, accident and suicide. However all these ways of bringing death are planned by God.'* FGD 3, P7

There was one comment regarding the hope of heaven bringing comfort.

*'I just wanted to add indeed in the area of Christianity we encourage each other that any person (because a child is also a person not so?), as it was written in the Bible that we shall indeed die but the time of death differs. Some die whilst they are still young. This is the devil's power because a person should be not less than 70 years when dying. Some die in their old age. So, this child knows according to Christianity as my friend in the kingdom has already said. It is true in Christianity that there is another life in the future after death. This gives hope that to him to die or to live both profit as Paul said it.'* FGD 5 (religious leaders), P2

#### **2.4.2 Adult's understanding of children's views**

It was generally acknowledged that, whereas in the past, death was hidden from children

*'We were hidden in the house when there was a funeral procession,' FGD 1, P 5;*

nowadays children are aware of death and that after death, bodies are put in coffins.

Most know from Sunday school that:

*'They know when one is dead he goes to God in heaven. And when you are dead you don't breathe, you don't eat, you just stay that's all.... The sinner goes to Satan to be burnt with fire, according to the teachings the children are receiving.'* FGD 1, P5

Children's understanding of death is age-dependant;

*'Nowadays because of religious teachings most children have a picture of what it means to die... With these issues of HIV/AIDS children see their friends and relatives dying and they have a picture that any one can die regardless of age. So the issue of death is no longer a secret as it used to be in the past. May be the issue of age, when they are younger they cannot fully understand what is exactly meant.'* FGD 4, P1

*'Many children know that there is life after death. They know there is hell and paradise. They usually say that when one dies they go to heaven if you are good to God, and to hell if a sinner. Most of them have learnt this from their churches. I heard a certain child saying, "This body is only clothing; we will put off this when we die and the body will be rotten but our spirits will go to heaven." This shows us that children know what death is religiously.'* FGD 4, P1

*'I know what death is all about, when a person dies it means the soul and the body have been separated. The spirit goes somewhere and the body is thrown away. The body is thrown in the cemetery but this time the spirit is already gone.*

*When the person was righteous, the spirit goes to heaven or we should say to eternal life waiting to go to paradise. If the person was doing wayward things may be was always found in bars and may be he died in an accident, he just stays with the devil waiting for the day of judgement to be thrown in a lake of fire.'* FGD 8

However, it was also stated that, *'A child fears death.'* FGD 2

Parents' views similarly reflected children's knowledge that everyone will die one day.

### **3) Issues around disclosure**

The concerns and difficulties around disclosure of life-threatening illness to children were discussed, and whether there were any beneficial or harmful effects.

#### **3.1 Concerns**

Comments were made that culturally in Malawi, they do not tell directly that a patient has an incurable condition, so might continue to give treatment even though they know the prognosis is poor.

*'It happened here in a nearby place whereby a child was told that he was HIV positive. He eventually stopped taking food until death. This is our fear for not telling children if they have an incurable disease.'* FGD 3, P7

*'Sometimes he may resort to taking poison to eliminate life.'* FGD 3, P4

*'If he is diagnosed with malaria, there is no problem in informing him about it... but if it is HIV/AIDS or cancer, then there is no need to inform him for fear of him losing hope in life.'* FGD 6, P5

*'In our culture, it is not allowed to inform children about the serious illnesses they are suffering from. If you know the disease is incurable, there is no use in involving the child... knowledge of the disease can make him die fast or lose hope.'* FGD 6, P2

Even older, dependent children should only be told if it is felt they will react well to the news.

Another concern expressed was that mothers might stop giving the child the care they need if they know the prognosis.

*'May be when the mother knows the problem of the child, sometimes she loses the love and instead of taking good care of the child, she now concludes that the child will die anytime. So the care of the child is lessened.'* FGD 1, P3.

Nurses and clinical officers expressed concern that carers may also abscond with the child.

Hostility was a concern for health staff:

*'There are some people whose reaction is hostile, some may even hurt you. Sometimes we may be afraid of such things ...so sometimes we just leave things and wait and see how it ends.'* FGD 2, P2.

They also complained of lack of time; and lack of counselling skills, including knowing how to deal with distressed reactions.

*'Most of the times the difficult conditions are cancer, HIV/AIDS and others which are frightening. So you observe the reactions from the person, sometimes you actually fail to say exactly what you want to say because of how the person is.'* FGD 1, P3.

### **3.2 Benefits**

*'We do see some children on ARVs who were told their status. They participate in their treatment and they are living well. They take their drugs properly because they were told.'* FGD 4, P6

They recognised benefits to the family in saving them from wasting resources on private hospitals and traditional healers.

*'The other benefit is that it helps to allay their fears. Because they have expectations, as already mentioned, that if s/he cannot be treated at the hospital, it might be that it is witchcraft. So explaining to them helps a lot'* FGD 2, P5

Also;

*'If the child also knows, he will be encouraged and start to pray that only God can help him'. FGD 7. participant unknown.*

Other groups could not see any benefits in telling the child about their illness, and especially that it is incurable, but emphasised that the child should be encouraged and shown love.

*'There aren't any benefits to these children, because the concern is about worries.'*

IDI 2

### **3.3 Harmful effects**

*'Those children who are older, from 8 years and above, they find out and ask sometimes. And sometimes they are sad like in the medical bay we do have very sick patients and nothing is working; thus they are depressed and they speak like an adult that I should just die.' FGD 1, P2*

Many advocated telling the child that they would be OK, and should pray that he would be healed.

*'We should not tell him that with the condition you have, you will die because if we tell him, he will have worries that will take him to death; he will pass away because of worrying.' FGD 5, P4*

### 3.4 Difficulties

#### Difficulty in telling

*'It is difficult to tell a child that she is suffering from this incurable illness. Because she may tend to think that she is going to die. Then the child is disappointed.*

*However, even if the parent realizes that the child has this problem you love the child and sometimes you may be chatting and discussing stories that cause laughter to ease the pain in his or her body. You should not show solemnity to the point that the child begins to realise that I am not fine. Do not show a solemn face in her presence. Be happy before her so that he or she should not be disappointed.'* FGD 9, P2

#### Difficulty in telling the truth

*'I think one of the difficulties is to tell the child the truth. They say the truth hurts and I am sure that it is not easy for parents or guardians to tell their children the truth when you are dealing with incurable diseases. That's why some of us are saying there is no need to inform the child about any serious illness.'* FGD 6, P6

*'I think that it is better to tell the child what he is suffering from because it is not good to conceal it from the child. The child may ask that 'Mother what am I suffering from?', and you are found in a fix. But it is good to tell the child that you are suffering from this or that illness. He will know that he is suffering from such a disease. Then give him a message of hope, not despair that you will not be cured. The child may be very much disappointed. But tell him that he will be cured.'* FGD 9, P4

#### Difficulty explaining discharge

It was also difficult when a child was discharged;

*'After two days they say you should take the ill person home. Thus she sees that her sick friends are still there. They are not chasing them away so why are they chasing you away? So disappointment and worry lead to the early loss of her life. The health personnel need to think about this.'* FGD 5, P8

### Difficulty in parental acceptance of diagnosis

Some recognised that the difficulty was because parents could not accept themselves that their child could not be cured.

*'What parents find difficult is when we are saying serious illness that is incurable... As a parent it is difficult to tell him that 'My child, as we are staying in the hospital, we are just staying to wait but any day you will die', it is difficult. It is difficult to accept that my child will die, no! To accept it, there is no one who accepts it. Even if you know, there is no one who accepts that now it has reached that or this point, no one accepts. You still try that here, can I not find a way that I can save her... Acceptance is a problem in our culture.'*

She explained, as others had, that people know there is a day to be born and a day to die, but even for those with faith in God, belief in heaven and knowledge that they will die one day, accepting a child's life-threatening illness is very hard.

One mother expressed the difficulty most poignantly;

*'If I see that the illness is difficult to explain, I cannot explain it to the child. I can only remain silent. Because even you (the parent) are overwhelmed with sorrow'*  
FGD 9, P5

Most felt that explaining to the child about life-threatening illness would cause worries, such that the child would think it would be better for them to die, and stop taking their prescribed drugs. They should be told about the illness, and the drugs, but not that the illness is incurable.

#### Difficulty caused by what others say

However, a concern was expressed that if a child is told the diagnosis, he might then be told by peers that this is incurable, and told to take poison to end his life.

*'His friends may tell him to take medicine... The child may develop negative feelings as a result of the influence of his friends.'* FGD 9, P3

The negative publicity through posters about HIV/AIDS was discussed:

*'Previously we have given negative messages likes AIDS is a killer...now those messages are not giving out hope to people'* FGD 2, P4.

#### **4) Methods employed by families to inform children about their illness**

Background information on how families currently talk to children about their serious illness was sought, how the parents/guardians themselves should be informed.

*'You give a message of hope that does not destroy the patient's hope of recovery even if you know that the disease is incurable.'* FGD 6, P3.

This was echoed by parents, that the illness should be explained but not that it is incurable; patients should also be encouraged to take medicine and to pray.

It was felt that timing of disclosure was important, that the child should be calm and relaxed, and there should be some privacy. Some felt it was better to explain at home, where there is a more tranquil environment.

*'I cannot manage to explain to the child right there in the ward... I may explain at home' FGD 9, P3*

*'Telling the child at home is not good, but telling him right here in the hospital. You can whisper to that child right there; My child, you are suffering from this and that. Do not be disappointed, you will be healed. Can you hear that? Yes, fine Mum. When you are going home you should keep this secret. Do not tell anybody what you are suffering from. FGD 9, P4*

All felt it was important to encourage the child so that they would not be disappointed.

*'It is essential that they should tell the child about her illness. However, they should not tell him or her that you will die. The idea of telling the child that you will die is not good because in that way you are not loving the child. Surrender the child in the hands of God that she will be cured. Even if she has a serious illness, encourage her that she will be healed.' FGD 9, P4*

They were aware that parents/guardians may be afraid to ask about the child's condition, and therefore might not be told; and also that the mothers permission was essential before telling a child about the illness.

They recognised that as well as explaining to mothers, children should also be told.

*'I think it is necessary to do that (tell the child) but it is supposed to start at an earlier stage; and by the time we come to the point of saying this condition is incurable, we will have psychologically prepared the person. Those of us who meet the children from the beginning, we mention at least in passing until the time they will be told everything, that this condition is a serious incurable condition.'* FGD 1, P9.

Within the community leaders groups, the way in which bad news was broken was a concern – particularly the need to maintain hope.

*'The doctors are supposed to encourage and give hope to the parents by telling them that the child is suffering from serious illness, but the child is not dying today neither is he dying tomorrow. They should be advised to feed the child well; when he is sick, he must be given painkillers and if the situation becomes worse, they have the right to come back to the hospital for proper check-ups. In this way hope and encouragement is given to the parents.'* FGD 3, P1

#### **4.1 How parents should be informed**

There were also some comments about benefits of disclosure to parents/guardians, such as P6:

*'If the guardian or parent knows the serious illness his or her child is suffering from, he/she will be informed about what to do next. The counselling given by the doctor will help them to accept the situation– they will also learn how they could handle the*

*patient when they go back home unlike when they don't know what the child is suffering from. In addition, they might decide to seek some divine interventions or go to other health care providers who could provide some care. In fact ignorance about the disease the child is suffering from is like a car that is moving at night without lights and ends up falling into a ditch. So, knowledge about the disease is very beneficial to the parents or guardians.' FGD 6, P6*

But most would not disclose to the child because of fears of precipitating death.

*'They should not disclose it to the child because this can speed up his/her death. If the child knows that he/she is suffering from an incurable disease, he/she will become depressed and might decide just to die. He/she can commit suicide.' FGD 6, P3.*

## **5) How children should be informed**

Views were obtained regarding who should inform children, and what they should and should not say. The use of resources to help in the process of disclosure was discussed.

### **5.1 The right person to communicate about serious illness**

There was a clear contrast between the adult response and the children's response to this question. A strong theme emerged from the adults – parent/guardians and community leaders and health workers, that the doctor should explain in full to the parent/guardian, and the parent should then explain to the child at their own discretion; but the children, both in the focus group and individual interviews mostly felt they should be told about their illness by the doctor

*'The doctor (should explain because) he is the one who knows everything.'* *'My mother, she can even hide some (information); she does not want me to know, she is afraid I will be worried'* IDI 1.

This comment is representative of all the adult focus groups:

*'The hospital workers should tell the mother and the mother will just be encouraging the child.'* FGD 4, P 6

*'The doctor should not even dare to mention to the child because they have already said that child will be disappointed and die quick.'* FGD 4, P4

*'The parent is the one that knows how to handle and encourage the child. Because the child always has faith in the mother, that she will do something for me to get better.'* FGD4, P9

*'Children are not supposed to be informed about the serious illnesses they are suffering from. Parents or guardians are the right people to get such bad news. It is up to them to inform the child or not and I know most parents or guardians would not do it unless the child asks for it.'* FGD 6, P6

One child was told together with her mother by the doctor:

*'They diagnosed me here (pointing at the upper part of her arm), then after diagnosing me he wrote on a paper. Then he asked my mother. They asked can I tell you the results*

*Facilitator: In your presence?*

*Respondant: Yes. Then I said you can tell me. Then they said won't you worry? I said no and they told me.' IDI 4*

*'They did well in telling me'. IDI 4*

One child found out by looking at her own health record book, so was never properly told. This was the only child who was not satisfied with what they had been told, as she still never really had the illness properly explained.

*'I want them to explain what I am suffering from, that I cannot be cured – why I am always sick and never cured. I can not be free (to discuss this with my mother) because she does not tell me.' IDI 1*

This contrasted with another child's experience:

*I know that my mother loves me and she is telling me enough to protect myself.' FGD 8, P4*

Others agreed that they should be told by the doctor, but one felt it should be explained by the mother at home, which was her own experience:

*'On that day when we went to the hospital they told my mother to enter and that I should go and play outside. After they told her, we went back home after leaving the hospital, then she explained to me that the sickness you have is this so I accepted. Then she said you do not need to be worried then I said yes. 'FGD 8, P4*

Well children also felt they should be told by someone who knew a lot about the illness, such as the nurse or doctor.

*'I may wish that the doctor should tell me first because the doctor is the one who knows about illnesses. He/she knows a lot more. Therefore, I may ask that the doctor should come first.'* IDI 5, P1

## **5.2 Words not to be used when discussing life-threatening illness and why**

*'My view is that it is essential that they should tell the child about his/her illness. However, they should not tell him or her that you will die. The idea of telling the child that you will die is not good because in that way you are not loving the child. Surrender the child in the hands of God that he/she will be cured. Even if he/she has a serious illness, encourage him/her that he/she will be healed.'* FGD 9, P4

This was expressed in all the focus groups.

*'There are words we can not use at this time. Words like you are going to die. Did you not see your sister and your brother also died? These words are very painful they should not be used. They should not be told that so and so died of the same disease you are suffering from.'* FGD 5, P1

Only the clinical officers said the truth should be spoken,

*'When you are explaining, you are supposed to speak the truth,'* FGD 2, P8

There was a perception, particularly amongst health workers, that patients in the developed world are able to accept an incurable diagnosis, but that disclosure cannot be done so directly in Malawi.

*'The way it is here in Malawi, I think how we are brought up in our setup it is difficult to receive such a message. It is a very bad thing, may be because we are not used to facing reality, to explain like the English; they just say you have cancer and wait at home or go to nursing homes. And yet here to tell a patient that your condition is incurable and you are not supposed to receive treatment, they don't feel good.'* FGD 1, P9

Other views invariably indicated the child should not be told the illness was incurable.

*'If people are going to the grave, it is because of those words.'* IDI 3

*'So the thing that they can avoid is supposed to be disclosing the disease. But they should just be saying that the disease you have suffered is this or that illness and they take time to be healed; not that the illness you have will lead to death. No! But the illness you have takes time for a person to be cured. So having that picture, he will have that in mind that one day I will still be healed.'* IDI 2

### **5.3 Resources they would find helpful**

Both the hospital health worker groups suggested there should be increased public awareness about life-threatening illness, so that they are more familiar to people. It was suggested that chiefs could be mobilised to encourage people to attend open days, using drama, music and health talks, and posters and leaflets in all the local languages.

Palliative care staff can be a useful resource.

When asked why it was important not to tell the child that the disease was incurable because they feared he might then die sooner, but they knew the child was dying anyway, a participant replied:

*'That is a good question. This question was already answered by Mrs Chapalapata (paediatric palliative care nurse). She said that 'what I can tell is that this child is sick and his illness will take him to the grave no matter what but what you can do, care for him until when and where God will say he will take him'.'*

There was a sense that there was a right time for the patient to die, but it should not be brought sooner because of worries.

In IDI 3, following on from discussion about the difficulty in accepting life-threatening illness in a child, the participant talked about the need for spiritual care, and how that could help with coming to terms with a child's terminal illness.

*'Spiritual care in the period we are passing through, I think that can help us very much, so that we are able to accept these things.'* IDI 3

No other resources were mentioned.

## **6) Children's experience and reactions**

Children talked specifically about their own experiences of disclosure and how they felt about this. They also discussed the roles and rights of parents and children.

### **6.1 How they were affected by their illness**

Many commented that they had been sick for a long time, with frequent illness and recurrent hospital stays. They also mentioned disruption to schoolwork and exams, and provocation from friends because of weakness and frequent illness.

One felt concerned

*'Because people were hiding the disease that I am suffering with.'* IDI 1

Some also expressed concern about discrimination from other children.

*'Some of my friends used to provoke me, saying that you are not strong. If you fall just a bit, you start getting sick.'* FGD 8, P2

### **6.2 How they felt at disclosure, and how they feel now**

The girl in IDI 4 said she had felt concerned when first told, but now no longer thinks about it, as long as she is taking medication.

All seemed to have come to terms with their illness, sometimes with the help of God through prayer.

*'When I was told I felt quite okay and my heart did not feel bad. I knew that that is how things are nowadays. So I was just praying to God every thing as He has written.'* FGD 8, P4

*'I first cried, but when I reached home, I saw that aah! there was no need to be crying but it's better to just rejoice that I have known what was troubling me in my body and caused me to be frequently sick.'* FGD 8, P unclear

*'I do not think about anything and I am just happy that the Lord is keeping me with life, provided you are drinking drugs in good time.'* FGD 8, P2

Now, *'It's ok, I even stopped worrying. (It stopped) on its own and I was praying.'*

IDI 1

### **6.3 Would they prefer not to have been told**

All agreed that it was right that they should be told, and that all children should be told if they have serious illness.

*'They did well in telling me.'* IDI 4

*'It is because some children are not told; they are being given the drugs to take every day. Then you find that parents have gone out to another place, they leave the drugs with the child. The relatives (siblings) forget and the child says that 'These things are tasty'. Some children just throw drugs (in the mouth) and eat and then they die in the bedroom; so it is good to tell them.'* FGD 8, P2

### **6.4 Whether the parent/ guardian be told first and have the right to decide whether the child should be told or not**

There was agreement that parents should not be able to refuse for children to be told.

*'The child should be told because he should know how to protect his/her body.'* FGD

8

*'Because the mother is not the one suffering from the disease. It's me who has been found with the illness. Therefore, they have to tell me.'* IDI 4

However, when asked if parents should be told first, several said

*'The doctor should tell the parents first and parents should explain to us.'* FGD 8, P3

There were also several comments, as in the adult groups, that:

*'There are some people who are temperamental, may be adults who when they are told they may hang (strangle) themselves with a rope or else to buy Termec (used for killing rats), drink it and die because of this illness.'* FGD 8, P2.

Well children also felt that the mother should not have the right to hide the illness from the child, as the illness is not theirs but it is the child who is experiencing it.

*'I have the right that my mother should tell me my illness. If she tells me a false illness, or if she refuses to take me to the hospital, I have to compel her until she takes me, so that the doctor should diagnose the illness that I am suffering from.'* IDI 5, P1

*'They should just tell me that you are suffering from this illness not that they should reach an extent that, the way we look at it you will die. Not to that extent. Then it means that my life is going to change from there and I can longer enjoy it because thoughts about death will always preoccupy my mind. Ultimately, a person just commits suicide.'* IDI 6

He felt the doctor should be the one to explain to the child, at the hospital, probably at discharge, and it should be confidential. Up to 16 years, he felt parents could refuse to allow a child to be told, but it was better that they should be told – but not that the illness is incurable.

## **CHAPTER 6.**

### **DISCUSSION**

**There is a Chichewa proverb that says, ‘nchiuno mwa mwana simufa nkuku’. Literally translated, this means, ‘you can’t slaughter a chicken in the hips of a child’, which actually means ‘young people cannot provide sensible contributions/ they are not wise.’**

One of the research assistants told of his experience at the age of 10, when he went on a journey with his family from where they lived in the north of Malawi, to the south. He was not told where they were going or why as he was only a child. It was only some days after arriving in the new place that he realised from the conversations of adults around him that they had left their previous home, and moved permanently. He discovered the name of his new hometown only when he specifically asked. He had not been informed or involved in any way about the families decision to move, had not been given an opportunity to say goodbye or have any say in what had been packed to bring with them. This had clearly made an impact on him which had stayed with him into adult life, but at the same time, he recognised that this was the way it was. Children are not consulted, they just have to accept what happens to them.

#### **Respecting children.**

In discussing age of adulthood and whether children should be given respect, including the right to participate in decision making, there was recognition that children are physically reaching puberty earlier, but they were not regarded as having

adult rights and responsibilities until their twenties, usually when they got married or had children themselves, or moved out of the parental home to live and work independently. Even then, in the village communities, there is still the influence of significant family members, most commonly the maternal uncle, who has the final say in decisions even involving healthcare of another's children.

There was a lot of time given to discussion around knowledge and signs of puberty and adolescent sexual behaviour, and age/stage at which children acquire respect.

This discussion seemed relevant to the Malawian facilitators and age of maturity was felt to be closely related to talking about breaking bad news and involvement in decision-making.

### **Demographic data.**

The demographic data demonstrates representation of all the Malawian tribal groups, especially Yao, Lomwe, Ngoni and Chewa. This reflects both the fact that QECH is a tertiary hospital and a centre for training of medical staff, so people come here from all over Malawi; and the distribution of people groups in the city and surrounding areas. Sixty-two per cent of participants were women and 38% men, giving reasonable representation of both gender groups. Four of the focus groups were single gender; the nurses group was all women as there were no male permanent nursing staff in the paediatrics department. Although there were a few female clinical officers, two were not Malawian, and one worked primarily as part of the palliative care team, so the clinical officers group was all male. For the parents groups, the vast majority of carers on the wards with children were female and it was felt that participants would be much freer to talk openly in a single gender group. All the community leaders and

HSA/TBA groups were mixed and this was appropriate as these participants were more confident and used to interacting in an official capacity and public speaking. The age range amongst the adults was 25-75 years, with an average age of 45.5 years, giving a wide distribution and good representation of views at different stages of adulthood. The age range for the children was 11-16 years, with an average of 13.2 years, which was representative of the age group of children the study sought to address.

Highest educational attainment shows a variation from no formal schooling at all, to post-secondary education. The groups with the greatest number of participants with little education were the parents groups, FGD 7 and 9.

There was also representation of rural, agricultural workers, those involved in small businesses, and professionals, such that within the total sample of participants, a wide range of backgrounds was included. Relating these to individual participants' views is beyond the scope of this dissertation.

### **Exclusion of the paediatric palliative care team.**

The paediatric palliative care team were excluded from focus groups with nurses and clinical officers, not because of their palliative care experience, but solely because they had been exposed to the views of the principal investigator over the past 3 years and may have wanted to give what they perceived as right answers, whereas it was their own views that were required. However, some of the nurses in FGD 1 and clinicians in FGD 2 did have some palliative care training and experience.

It was very useful to do a practice group with the team both to try out the questions, train research assistants and also hear their thoughts as if they had grave reservations about telling children about their diagnosis, it is unlikely that they would explain to

parents in such a way that they would agree to disclosure. In fact, the ideas and attitudes they expressed were very much in agreement with the findings of the study overall. They were particularly aware of parents concerns as they talk everyday with the carers of sick children, and it is hoped they will benefit from the guidelines for disclosure to children resulting from this study.

### **Cultural differences between Malawi and the West.**

Health workers in particular felt distinction had to be made between the Malawian cultural situation and the western world. Doctors come to work at QECH from European countries, America and Australia, for short and long time periods, with altruistic motives but also western concepts and ways of communicating. It was felt they need to realise that their ways of communicating and breaking bad news were often too blunt and direct, and did not leave room for hope.

General health knowledge in the normal population was understood to be better in the West, leading to greater acceptance in receiving information about life threatening illness. There was therefore a need for more health education, particularly using posters and leaflets in all the local languages, giving a positive message. Comment was made that if parents spoke more freely with children from a young age, they would be able to communicate more openly if the child becomes sick.

Foreign doctors were felt to be too direct in their approach, in talking to both children and their parents, without respect for cultural attitudes and the comfort of their translator.

Strong views were expressed about how the parents should be told through the following points:

- 1) Parents/guardians do want to know what the child is suffering from, but want the right to choose whether or not to tell others, e.g. neighbours.
- 2) They should be called to a private place, and asked first whether they were willing to hear the message.
- 3) The child should not be present.
- 4) The doctor should 'tell it as it is'. If it is cancer, inform them that it is cancer, but he should not say there is no hope of being cured. He should give words of hope, not condemning the child to death.
- 5) They should be told how to care for the child. Counselling can help them to accept the situation, and to know how best to care for the child.
- 6) When they are told an illness is incurable, they may then try traditional healers.

They can then decide whether and what to disclose to the child. If the child is old enough to understand such information, it is up to the parent or guardian to find the most suitable time to disclose this information. However when disclosing this information, they must be very careful to ensure that the child does not lose hope.

It was expressed that information should be given in an appropriate way and that there was a need for privacy. QECH is a busy hospital and in paediatrics, there is frequently more than one patient to a bed. There are no curtains between beds, so consultations are generally overheard. It is easy to accept this situation and forget how distressing this must be for patients, many of whom will have the experience of sharing a bed – and even an oxygen concentrator, with another patient who may die beside them. In the palliative care team, we always ask parents to come to a quiet, private place, either the nurse's office on the ward, or our own office. We have also been told that this request can engender anxiety as carers then expect to hear bad news but the study

results suggest privacy is valued, and allows greater patient-centredness, and needs to be encouraged even in the overcrowded environment of limited-resourced African hospitals.

The necessity of offering comfort and hope was also identified, '*after that she will relax and you talk with gentleness*'; and detailed explanation both about the disease, and also about ongoing care. This should be done when all test results are available, or at discharge i.e. after symptoms have been stabilised. If it is done too soon, the patient may abscond. The debate over timing of disclosure depended on severity of sickness of the child; for a very sick child who could die imminently, the parent should be counselled straightaway, but otherwise, they should be counselled at discharge, so that they would not abscond.

They emphasised the need to say in counselling that the illness is incurable but we can help you to improve your life and continue to live normally - that '*this is not the end of this person's life*' –right now; and suggested patients or their guardians should be counselled in groups with the same diagnosis '*so the problem becomes lighter.*'

Several community groups commented on changes and that nowadays, people are more educated and informed, which dilutes their beliefs in witchcraft and ancestral spirits. They said that most parents now take a sick child to hospital first, and this is encouraged by local leaders; but some try local medicine first, and more may seek help from traditional healers on discharge from hospital if not cured. They were able to differentiate which symptoms were appropriate for traditional healers, and which for hospital care e.g. fever – as traditional healers were known not to measure temperature, which is associated with malaria and other acute infectious diseases.

A need was identified for increased public awareness about disease, especially life-threatening and life-limiting diseases in children, such as cancers; and the role of palliative medicines for symptom relief and to improve quality of life so that life is shown to be valuable, even where there is no cure. This could be achieved through newspapers and radio broadcasts, and through local health education involving drama and music, as is already done for other aspects of health.

**Hope means healing.**

Once they have gone home, patients may be prayed for and told that they are cured. This can be through churches or traditional healers. Although there was widespread acceptance that all must die, and a belief in life after death, this was rarely expressed as bringing comfort and the emphasis was entirely on prayer for healing, not for comfort and help in coping with serious illness and impending death. There seemed to be a lack of certainty about going to heaven.

There was also a lot of confusion and mixing of Christianity and witchcraft.

The need for maintaining hope was frequently expressed, and this invariably meant hope of cure. Helpful counselling for parents and children clearly needs to offer hope, but this **hope needs to be realistic and honest.**

**Precipitating death/bringing death closer.**

**Palliative care aims to neither hasten nor prolong the process of dying, but focuses on improving quality of life.**

A very common concern was that of causing the child to die sooner (which may mean sooner than their allotted time, ordained by God) by telling them the disease is incurable or the treatment has failed. As in other African countries, such as South

Africa, this reflects the superstitious belief that talking about death is ‘inviting death in’.

A surprisingly common theme was that a patient with an incurable illness, even a child, might feel it was better to die straightaway, even by taking their own life. This was mentioned by adults and children in the study, including the well boy. In considering why this should be, it is possible that in this harsh and resource-limited environment, there is a general sense of futility if it is accepted that there is no cure, and that quality of life is not yet an acceptable or understood concept. This is understandable at one level, where there is not enough food to go round, but **it is another palliative care principle that all life is to be valued.**

It is very important for health staff to be aware that telling a patient there is no curative treatment may be perceived as if they’d said ‘You might as well die now.’ It was difficult to verify the risk of suicide; elsewhere, this is described as very rare<sup>37</sup>. Health workers confirmed that ‘it happens’, but did not give examples.

There was one patient in the experience of the principle investigator; a 12 year old orphaned girl with severe malnutrition associated with HIV/AIDS. She was felt to be depressed during her second admission to the malnutrition unit, and improved on amitriptyline, but stopped coming for follow-up after discharge. Although she was initially doing well, she started refusing to eat again, telling her guardian she wanted to die, and died three months after discharge.

There were some descriptions of patients being told of life threatening illness and then dying within a very short time, but these were probably more a reflection of the severity of the illness, which was why it was disclosed. It is well recognised in palliative care that predicting when someone will die is very difficult, and important

in Malawian society not to actually say directly that someone is dying, but that they are very sick and we cannot be sure what the future holds. In fact the term for serious and life-threatening illness is ‘matenda a kaya kaya’, (kaya meaning maybe) implying uncertainty as to whether the patient will die or recover.

### **Conflict with principles of palliative care.**

Three issues arose

- a) Palliative care aims to neither hasten nor prolong the process of dying, but focuses on improving quality of living in the present, not on death.
- b) All life should be valued and affirmed.
- c) Hope must be maintained, but not false hope; this may be hope of continuing care and love, but not of cure.

It is useful to hear and gain understanding of views which may conflict with the aims and ideology of palliative care, in order to work towards therapeutic resolution. One aspect of this is raising the status of life after the diagnosis of incurable illness, and recognising the importance of emphasising with the family that having an incurable illness does not mean the child will die straightaway, and helping them to be able to continue to care lovingly and meaningfully despite the knowledge of prognosis. It might then be possible for carers to see that the child could also continue to live a meaningful life with the same knowledge – with hope of symptom control and love and support, as Dame Cecily Saunders said, ‘to live until you die’.

### **Non-disclosure reduces worry.**

As shown by these typical comments, ‘*To minimise anxiety is by not telling him of his illness*’, and ‘*Acting as if nothing will happen and hiding tears is the way to show*

*love*’, there was a strong conviction that not telling children protects them from worries and anxiety. There was no concept that a child could know something was serious even if not told. Parents themselves recognised the implications of being told to take the child home, when clearly they were not better; but did not seem to think the child would have the same realisation.

However, from personal observation of patients over three years, it seems very unlikely that paediatric patients in Malawi are different from those described in studies in the literature review <sup>21, 22, 26, 27</sup>. As an example, one of the patients who participated in this research project, was well known to the palliative care team as she lived close to the hospital and we were able to support her and her guardian with regular home visits during her terminal weeks. On more than one occasion, her guardian had called church elders to come and pray for healing because she seemed to be gasping. The patient subsequently recovered and later told her guardian she had seen a vision of angels, dressed in white, in a beautiful place which was heaven. She asked her guardian not to call the elders next time but to let her go to that beautiful place. I asked whether the concept of heaven was comforting or frightening, and the guardian categorically stated it was comforting. It was therefore surprising that this was not mentioned during the study discussions, and there may be a lack of confidence about whether they would be going to heaven – though not in this case. As already discussed, even amongst Christian believers, beliefs about witchcraft were common and confusing.

The guardian of this child was interviewed in bereavement and said she did not think the child was aware that her death was imminent on the day she died. However, she was also visited by the Principle Investigator on that day, who felt she did understand, and felt ready.

### **Limitations of the study.**

The major limitation was Language. The principal investigator was an English doctor from a different cultural background than the participants and with limited language skills in Chichewa. Malawian research assistants acted as focus group facilitators and advisors to the study. The principle investigator had to rely entirely on the facilitators to probe appropriately on subjects on the discussion guide, and there were times on subsequent reading of transcripts when she would have chosen to pursue questioning differently. This was compounded by the significant time delay between Focus Group Discussions and completion of English transcripts such that there was not the opportunity to adjust or identify additional lines of questioning from early groups, as these transcripts were not available until most of the groups had been done. The exception was FGD 9, which was an additional group to those initially planned as it was felt that participants in the previous parent group (FGD 7) were less articulate and confident than those in other groups. They were all women, mostly with little education, and 4 of them brought small children with them, strapped to their backs with cloths called chitenje's, 3 of whom were breast feeding, and one was sick with breathlessness and cough. There were also some overly leading questions in this group, so a second group of mothers was also recruited as the views of parents of children with palliative care needs were particularly wanted.

A further constraint was that obtaining children's views was limited by the fact that it was rare to find children with life-threatening illness to whom disclosure about their illness had been made - confirming the need for study in this area. Therefore, although the study hoped to explore the barriers to disclosure about all life-threatening illness, in fact only children with HIV/AIDS were participants. It was emphasised in adult

discussion groups that their thoughts, feelings, attitudes and beliefs regarding illnesses other than HIV/AIDS were also being explored.

In the original study proposal, a focus group of well children from a local school was planned, with whom to explore children's views around what they felt they would want to be told if they had a life-threatening illness. However, obtaining parental consent for well children would involve gaining permission from the headmaster of the school to identify suitable participants, then contacting and visiting parents for consent, and then organising appropriate venue and timing for the focus group discussion. Feedback of results would also need to be organised. It was decided instead that the principal investigator would contact children and parents known to her as a convenience sample. At least six children aged over 11 years were identified and an introductory approach made to parents/guardians and children. This was to be followed up by formal presentation of the participant information and consent and assent by a research assistant on the day planned to carry out the focus group.

Unfortunately, not all the parents were available for explanation and consent on the appointed day and it was not possible to rearrange another appointment due to time constraints on the PI and facilitator, so two in-depth interviews were carried out instead, as there were not enough children for a focus group discussion. The numbers of well children were too small to be representative, but were a convenience sample for triangulation of children's attitudes.

### **Sensitivity of the topic.**

The investigators were aware that the topics of discussion were sensitive and a distress protocol, as described in the method, was explained to all participants.

However, no one became distressed during discussions or interviews. Parents were

serious but animated when discussing perceptions of death, and seemed to benefit from having an opportunity to express their thoughts and feelings, in a safe and sympathetic environment, where their views were regarded as important and valuable and potentially able to make a difference to the care of children like theirs. Of particular note was the fact that after the parents' discussion in FGD 7, several of the mothers then said they were now willing for the palliative care team to disclose about the illness to their child. Discussing the subject together seemed to have either helped them see benefit in the child knowing about their illness, or reassured them that this would be done appropriately and would not cause harm.

### **Relating study findings to literature findings.**

The study results indicate that many issues highlighted in the literature review also apply to the Malawian context. The need to encourage hope, even whilst preparing for loss,<sup>27</sup> and parental fears of causing psychological harm by breaking bad news to children<sup>33, 36</sup> were both identified. The need for health care professionals to help and facilitate communication between parents and children, as emphasised in the literature<sup>35,37</sup>, was also applicable in our Malawian situation, as parents/guardians felt breaking bad news was very difficult.

Although there are obviously important culture –specific issues, there are indications that Malawian children have the same wish to be told the truth about illnesses affecting them, and feel they benefit from this knowledge, as found in studies in the more developed world<sup>29, 30</sup>. This agrees with the universality of children's thinking at the end of life suggested by the International Society of Paediatric Oncology<sup>31</sup>.

This study did not explore what children know from their own observation, but found the parents and guardians understanding was that children do not know about the seriousness of their illness if they are not told. Further study into children's perceptions would be useful in informing whether children in Malawi follow the same stages as identified by Myra Bluebond-Langner<sup>4</sup>, gradually coming to a realisation that their illness is not getting better and may end in death. Not being told does not protect them from this knowledge, but does deprive them of being able to discuss their feelings and fears, and gain comfort from openness, trust and support. Malawian parents could benefit from reassurance that European parents who talked with their child about death did not regret doing so<sup>24</sup>, and information that refusing to discuss death is more likely to cause worry and fear, than open, honest, loving and sensitive information-sharing<sup>26</sup>.

The idea of talking to children about their serious illness is a new concept in Malawi. Disclosure to children goes against societal norms, and parents are not yet equipped to cope with the consequences of their children knowing their diagnosis; but Malawian parents, like parents everywhere, want the best for their children, and particularly that they should not worry or be frightened but be reassured and cared for. The following chapter suggests recommendations to help compassionately support adults in accepting disclosure to children against societal norms.

## **CHAPTER 7.**

### **CONCLUSION AND RECOMMENDATIONS**

#### **Meeting the objectives**

The aim of the study was to explore the barriers to disclosure of life-threatening illness to children in Malawi, in order to improve the psychological and spiritual support to children and their families.

Obtaining information regarding Malawians thoughts and feelings about childhood life-threatening illness and their attitudes to talking about this to children; and determining the cultural context and concerns leading to barriers to disclosing to children.

A good volume of information was obtained from the nine focus group discussions and six in-depth interviews, from a total of 81 participants, representing men, women and children from all the tribal groups. Perceptions about serious illness and death in children, and concerns and difficulties in discussing these with the children themselves led to the following conclusions:

- 1) The child must believe he will recover. Children should therefore be told of their illness, but not that it is incurable; and parents should be encouraged and informed about how to continue to give appropriate care.

2) If the child is told the illness is incurable, he will worry, lose hope and die sooner, and it is believed may even feel he should die straightaway and take his own life.

3) Long standing illness, which medical doctors have no medicines to cure, are often believed to be caused by witchcraft, and therefore may be cured by witchdoctors or traditional healers. This seems to maintain hope of cure.

4) Adults generally felt doctors should disclose to parents, and parents could then disclose to children. Children felt they wanted to be told the truth about their illness, but not necessarily that it was incurable; they felt they were more likely to be fully informed by doctors, as the parent might hide the truth (and parents admitted this).

5) Parents/guardians find disclosure difficult because of their own sadness and lack of acceptance and desire to avoid causing the child disappointment.

Parents and community participants universally felt that doctors should tell the parent/guardian about a child's illness and prognosis, without removing all hope, and advise them how to continue to care for the child; and the parent should then explain to the child as they saw fit. They also expressed the need to know the doctors had tried their best.

However, they also said they found telling the child difficult and would tend to reassure them that they would get better. Providing reasons for realistic hope needs to be facilitated by health staff, and might be able to relieve the family from spending money on traditional healers.

It would be important to provide hope of continuing care and support, and specifically to offer spiritual care and psychological support, including help with how to approach the process of disclosure to the child.

### Identifying what children would like to know about their illness

Children felt that they wanted to be told the truth about the nature of their disease, and that this was their right because they were the ones suffering. They felt that they should be told by the doctor, as he had the knowledge to explain properly and answer questions, and would not hide the truth.

Some gave the caveat that they should not be told there was no cure.

Most felt their parents should also be told the diagnosis, and some felt the parent should be told first, and could then inform the child, but all felt that parents should not be entitled to insist on information being withheld from the patient themselves.

Amongst the children infected by HIV, there was good knowledge and understanding about cause and spread, and all seemed to have come to terms with long standing illness.

The children were comfortable discussing death, and had a shared belief in heaven and hell.

Unfortunately, because of the lack of disclosure, none of the children with terminal cancer could be interviewed.

Developing a set of recommendations for health workers in paediatric palliative care in Malawi to facilitate explanation and communication with children and families regarding life-threatening and life-limiting illness.

This research has been valuable in informing the following set of recommendations for communicating with children and families in the event of life-threatening or life-limiting illness. It is hoped that these will be incorporated into the clinical practice of Umodzi palliative care for children at Queen Elizabeth Central Hospital, Blantyre, Malawi, and disseminated to other health workers. The advice for HIV Disclosure in Children by Aneesa Naeem-Sheik and Glenda Gray has been helpful in formulating these recommendations.

### **Recommendations for disclosure to children about life threatening illness in**

#### **Malawi:**

##### **Preamble:**

Children want to know and feel they should be told about their own serious illness because they feel they have a right, and it will enable them to comply with treatment. They feel parents should also know but should not be able to refuse for children to be informed about their own serious illness.

Children mostly feel illness disclosure should be done by the doctor so they can be fully informed; however, some would prefer the doctor to tell their parents, and the parents in turn to tell them. The individual child's preference should be elicited where possible.

Parents universally find it difficult to tell their children because they find it hard to accept it themselves and to cope with the potential reactions of the child and to observe the child's disappointment and sorrow.

**Recommendations:**

Parents should be reassured of the benefits of disclosure to the child; that there will be greater openness and support, and the child will be empowered to participate in their own healthcare decisions. Telling the truth is essential for the development of trust. Disclosure should be a process of information sharing over time, appropriate to the age and development of the child, and should be done before the child finds out accidentally. The individual child's preference for who should explain about the illness should be elicited where possible.

Disclosure should be planned, private, not rushed, loving and reassuring, and responsive to the child's knowledge, questions and mood. The child's readiness for disclosure would be agreed by parents and health care professional.

Parents may benefit from leaflets in their own language about disclosure, and coaching and role play with medical staff prior to disclosure could also be offered.

Parents also need to be advised how they can continue to help and care for the child such that they have hope of meaningful life and purpose to the end.

Hope of effective pain management, a chance to go home and be with the wider family, and spiritual care should be offered; and reassurance that life does not end at diagnosis.

The child must be informed that this does not mean you will or should die straightaway, but that your life is still important and valuable and our aim is to ensure you are comfortable and free from pain.

Children's reactions may include denial and depression and they require reassurance, love and support in exploring and coming to terms with feelings, fears and anxieties. Health professionals should be proactive in eliciting signs of clinical depression or suicidal ideation.

With very young children or those with developmental delay, and children with severe emotional disturbance it may be necessary to delay or withhold disclosure.

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