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Psychosocial and Health System Factors in Disclosure of HIV Status to Children Living with HIV in Malawi: A formative Evaluation of a Disclosure Resource

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AUTHOR'S DECLARATION

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgment has been made.

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

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ABSTRACT

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Background

Malawi is one of the countries in the world that has been worst affected by the global HIV pandemic. Despite a significant reduction in the number of new infections in recent years, HIV/AIDS remains a major public health problem. In 2015, approximately, one million people were living with HIV in Malawi out of a population of just over 18 million, and 10% of those affected were children under the age of 15 years. In the same year, more than half a million children living in Malawi were orphans due to HIV related deaths of their parents.

The provision of antiretroviral therapy (ART) to children at no direct cost to their families in Malawi has resulted in a marked reduction in new cases of HIV among children and substantially increased the life-expectancy of children with the disease. There is now great hope for many children to lead fulfilling lives who can contribute significantly to the socio-economic development of the country. While this success in the prevention and treatment of HIV is to be applauded, there are consequences for children living with HIV and their families that have not been fully recognised. One of the key issues is that many children are growing up with no knowledge that they have HIV. These children are at increased risk of a range of poor health and developmental outcomes and they pose a risk to others through the inadvertent spread of HIV. The World Health Organisation has recommended that disclosure of HIV status to children living with HIV should take place as early as possible in an age-appropriate manner with full disclosure between the ages of 6 and 12. Even though disclosure of HIV status to children living with the virus is recommended, reports from healthcare workers from different parts of Malawi, indicate that the rate of disclosure is very low. In addition, very little is known about the approach or model used by healthcare workers or primary caregivers to disclose HIV status to seropositive children. This study aimed to evaluate the current practice of HIV disclosure to Malawian children and to assess the acceptability of a series of age-appropriate, culturally acceptable story books intended to help with the disclosure process.

The research aims were addressed by three studies namely primary caregivers' survey (Study 1), healthcare workers' survey (Study 2) and a qualitative study (Study 3). Each study had its own research questions. The primary caregiver survey was addressed by the following research questions: (1) What are the knowledge and practice of primary caregivers in Malawi with regards to HIV status disclosure to their children living with

HIV? (2) What are their views regarding the need, acceptability and benefits of the proposed children's story books for guiding the process of informing their children about their HIV status? (3) How does their decision to disclose HIV status to their children differ by demographics, child and family psychosocial factors, and child health factors? (4) How do their reports of emotional and behavioural problems of their children living with HIV in Malawi differ by demographics, child and family psychosocial factors, and child health factors? The healthcare workers' survey had the following research questions: (1) What are the healthcare workers' responses regarding knowledge and practice of HIV status disclosure to children living with HIV in Malawi? (2) What are their views regarding the need, acceptability and benefits of the proposed children's story books intended to guide the process of telling children about their HIV status in Malawi? (3) How does their decision to disclose HIV status to children differ by demographics in Malawi? The qualitative study addressed the following questions: (1) What are the thoughts of primary caregivers, healthcare workers, teachers and community leaders regarding the importance and process of disclosing HIV status to children living with HIV? (2) What are their views regarding their involvement in the process of disclosing HIV status to children? (3) What are their barriers and facilitators to their involvement in disclosure of HIV status to children? (4) What are their views regarding the need, acceptability and contents of story books intended to guide the process of disclosing HIV status to children.

Methodology

A formative evaluation was undertaken using a mixed methods approach. Three concurrent studies were undertaken as part of the formative evaluation. The first study was a survey conducted with 429 primary caregivers of children living with HIV. The study assessed primary caregiver's knowledge, attitude, and practices of HIV disclosure to children, and their views regarding the story books. This survey also asked primary caregivers about the prevalence and associated factors of emotional and behavioural problems among children. The second study was a survey conducted with 168 healthcare providers working in antiretroviral clinics. The survey investigated the healthcare workers' knowledge, attitude and practices of HIV disclosure to children, and their views on the need and acceptability of the story books. The third study was a qualitative study, which was carried out to better understand the level of knowledge, attitude and experiences of primary caregivers, healthcare workers, teachers and community leaders regarding disclosure of HIV status to children and their views on the story books. Data for the qualitative study were collected from 106 participants using focus group discussions and indepth interviews. Data from the three studies were collected concurrently and analysed separately before the results were compared and contrasted. The study was conducted from March to July 2015 in the three administrative regions of Malawi. Ethics approvals were obtained from the Curtin University Human Research Ethics Committee and the Malawi Government Health Science Research Committee prior to the commencement of data collection.

Trained research assistants with a background in nursing, public health, and clinical medicine recruited primary caregivers in the waiting rooms of ART clinics and collected questionnaire data by interview in rooms assigned for this purpose. With regard to healthcare workers' survey, the purpose of the study was discussed with senior nurses who recruited healthcare workers in their respective health facilities. Following informed consent, questionnaires were completed anonymously and returned to the researchers. Data were collected using validated and reliable instruments. The study questionnaire was translated from English to Chichewa (Malawian local language) and then back-translated to English by language experts following the WHO process of translation and adaption of research instruments. The questionnaire had six sections: (a) family demographic data; (b) child demographic and clinical data; (c) child emotional and behavioural problems; (d) stressful life events (e) impact of illness on the family; and (f) caregiver's support.

Primary caregivers and teachers participated in focus groups while healthcare workers and community leaders participated in one-on-one interviews. Four interviews and focus group guides (one each for healthcare workers, primary caregivers, primary school teachers and community leaders) were developed through a review of literature guided by the research aims and questions. After initial development, the guides were translated to Chichewa, the local language of Malawi, and then back translated to English by professional translators following the World Health Organisation (WHO) instrument translation process. Once all language issues were corrected the instruments were piloted with participants who were not included in the sample prior to the commencement of data collection. The candidate facilitated all focus groups and interviews and a research assistant audio recorded the proceedings. Following informed consent, an interview or focus group guide was used to ensure the topic of HIV disclosure was discussed uniformly. The number of interviews and focus group discussions was determined by saturation of data. Chi-square test and multiple logistic regression were used to analyse quantitative data while thematic analysis was used for the qualitative data.

Results

The first study, the primary caregiver survey, had a response rate of 99.3 per cent with 429 questionnaires collected from participants. According to primary caregivers, 64 per cent of children were not aware they had HIV. The main reasons for non-disclosure of HIV status were the child's inability to cope with the news (29%), a lack of knowledge on

how to disclose HIV status (19%), and fear of stigma and discrimination (17%). Ninety-eight per cent of the primary caregivers strongly agreed or agreed with the proposal of developing a series of story books to help with disclosure. Non-disclosure of HIV status was more likely for children who were younger (aOR 3.8; 95% CI: 2.1-6.8), underweight (aOR 1.9; 95% CI: 1.1-3.3), in WHO HIV clinical stage one (aOR 2.8; 95% CI: 1.6-4.7). In terms of the child's mental health status, higher scores for emotional and behavioural problems were identified in 31 per cent of the children. Children had higher scores in prosocial, peer problems, emotional and conduct subscales, while lower scores were identified in the hyperactivity subscale of the Strengths and Difficulties Questionnaire. Factors that independently predicted difficulties were primary caregivers' young age, low level of education, and lack of employment, as well as their report of a substantial impact of the illness on the family and a low level of functional support ($p< 0.05$). Child demographic and health factors were not significant in multivariate analysis (p>.0.05).

A total of 168 participants were recruited in the second study, the healthcare worker survey, representing a response rate of 99 per cent among the eligible participants. A significant proportion (37%) reported that they had never disclosed HIV status to a child and about half estimated that the rate of HIV disclosure at their facility was 25 per cent or less. A lack of confidence to disclose appropriately and the lack of guidelines and materials were cited by healthcare workers as the main reasons for non-disclosure. More than 96 per cent of participants strongly agreed or agreed with the idea of developing a series of story books. Female healthcare workers (aOR) 2.4; 95% CI: 1.1-5.5) and lack of training on disclosure (aOR 7.7; 95% CI: 3.4-10.7) were independently associated with never having disclosed HIV status to a child.

With regard to the third study, the qualitative study, a total of 19 interviews, and 12 focus groups were conducted involving 106 participants. Three themes were identified through thematic analysis, namely: talking about HIV and disclosure, sharing responsibility for disclosure, and open communication. With regard to the first theme, 'talking about HIV and disclosure' participants expressed willingness to meet and talk about disclosure of HIV status to children, however, they reported that this was not happening because of the complexity of the process of HIV disclosure and the potentially negative consequences of HIV status disclosure to the child and family, inadequate knowledge about HIV disclosure, the lack of a standard tool for disclosure, and the lack of training on disclosure. The second theme 'open communication' emerged after many participants emphasized the need for stakeholders to have an open communication regarding disclosure of HIV status to the child. The participants reported that closed communication between stakeholders as opposed to open communication was common among them. While most participants expressed their wish to be able to discuss HIV and disclosure

much more openly, they reported that hierarchical relationships between stakeholders were a major obstacle and that there was a perception that primary caregivers lacked knowledge and understanding regarding HIV. The last theme ‘shared responsibility’ emerged after many participants expressed the necessity for shared responsibility in order to meet the needs of children living with HIV. Nonetheless, the majority reported that this was not happening because each group was working in isolation. The three themes had a common concept of ‘Working together’ as most participants emphasized the need for them to work together to break down the barriers to talking about HIV and disclosure, open communication and shared responsibility among the stakeholders. This led to the development of a “Working Together” conceptual framework, which guided the presentation and discussion of the study findings.

Conclusion

The findings of this study demonstrated that the prevalence of HIV non-disclosure among affected children in Malawi is high. Primary caregivers are facing a range of barriers and constraints to effective disclosure. Non-disclosure is associated with several clinical and demographic characteristics. There is a high acceptability of the disclosure story books among primary caregivers. In addition, close to one-third of children living with HIV in this study had high SDQ scores indicative of mental health problems. Mental health problems in children living with HIV are associated with family demographic and psychosocial factors. The study has also revealed that A significant proportion of healthcare workers are not involved in the disclosure of HIV status to children because of lack of disclosure knowledge and training. There is also a great need and acceptability of the HIV disclosure story books among healthcare workers in Malawi. Furthemore, in addition to needing the disclosure story books, primarycaregivers, healthcare workers, teachers and community leaders have an agreement about the need to work together to disclose HIV status to children living with HIV through talking about HIV, open communication and shared responsibility. The study identified the need for developing guidelines and materials that have been rigorously evaluated prior to dissemination. The involvement of all stakeholders from planning to implementation is important in this process. Based on the results of this study, it is anticipated that the proposed children books will be accepted by the majority of stakeholders. The children’s books will be an important resource for children to understand about their diagnosis and to develop resilience to HIV diagnosis. The material will also help to simplify and standardise the disclosure process as well as promote collaborative HIV status disclosure among primary caregivers, healthcare workers, teachers and community leaders. While the proposal to develop and pilot the disclosure story books may seem to be a relatively straightforward goal, it will be a challenging task in Malawi where healthcare budgets are already stretched and have to cater to numerous competing health priorities. A multi-lateral consortium of governments and international aid organisations will be asked to provide resources and expertise to better support these children living with HIV and their families.

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LIST OF ABBREVIATIONS

AIDS	Acquired Immuno-Deficiency Syndrome
aHR	Adjusted Hazard Ratio
aOR	Adjusted Odds Ratio
ART	Antiretroviral Therapy
DVD	Digital Video Disc
HIV	Human Immunodeficiency Virus
MDHS	Malawi Demographic Health Survey
MOH	Ministry of Health
NGO	Non-Governmental Organizations
SDQ	Strengths and Difficulties Questionnaire
SPSS	Statistical Package for the Social Sciences
STI	Sexually Transmitted Infection
UK	United Kingdom
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations International Children's Emergency Fund
uOR:	Unadjusted Odds Ratio
US	United States of America
WHO	World Health Organization

1. CHAPTER 1: INTRODUCTION

1.1 INTRODUCTION

Malawi, a small landlocked country in Southern Africa, has been ravaged by the Human Immunodeficiency Virus/Acquired/Immunodeficiency syndrome (HIV/AIDS) epidemic. In 2015, the United Nations programme for HIV/AIDS (UNAIDS) estimated that one million people of all age groups, which is 6.7 per cent of the total population, were living with HIV in Malawi (United Nations programme for HIV/AIDS Malawi, 2016). The preliminary results of the first national representative survey to measure the prevalence of HIV among children reported that 1.6 per cent (numbering 84,000) of children under the age of 15 years were living with the HIV in Malawi in 2016 (Government of Malawi, 2016). This estimate is likely to be an underestimate due to the low survey response rate of 62 per cent (Government of Malawi, 2016). In the same year it was estimated that 530,000 children living in Malawi were orphaned due to the HIV-related deaths of both parents (United Nations programme for HIV/AIDS Malawi, 2016). The magnitude of these numbers underscores the huge burden that HIV places on families and healthcare resources in Malawi.

The increase in coverage of antiretroviral therapy (ART) among infected women in Malawi has led to a 71 per cent decline in new infections among children, from 16,000 cases in 2009 to 4,800 cases in 2015 (United Nations programme for HIV/AIDS, Malawi, 2016). Moreover, with the widespread provision of ART to children with HIV at no direct cost to families, they are living longer than ever before (UNAIDS, 2014). Despite these improvements, Malawi and other Sub-Saharan African countries fall well short of the survival rates now being achieved in resource rich countries, such as the Netherlands and Australia (McManus et al., 2012; Mills, Bakanda, Birungi, & et al., 2011; Mutevedzi & Newell, 2014; Nsanzimana et al., 2015). In Australia, it is now expected that young adults living with HIV will have a normal lifespan if they take ART routinely and lead a healthy lifestyle (McManus et al., 2012). On this basis, it is expected that many children living with HIV in Malawi and other sub-Saharan countries could also achieve a longer lifespan (Bakanda et al., 2011). These children have the potential to lead fulfilling lives and contribute significantly to the economic development of Malawi (Save the Children, 2009). For this reason, as well as for moral and ethical reasons, it is critically important that children living with HIV are afforded the same opportunity as other children for achieving optimal health and normal lifespan (Anabwani, Karugaba, & Gabaitiri, 2016). One of the greatest problems is that many children in Malawi are unaware that they have HIV, because they have not been told by their caregivers and healthcare workers.

This chapter provides an overview of the thesis. Background information about children living with HIV in Malawi is provided so readers can appreciate the burden HIV paces on children as well as their families, society, and the healthcare system. This is followed by an introduction to the evidence-based literature regarding the disclosure of HIV status to children, the focal topic of the thesis. The importance of HIV disclosure is briefly outlined, before attention is drawn to barriers and facilitators of HIV disclosure and the lack of materials available to help with the disclosure process. The conceptual framework underpinning the study is then explained. This is followed by the aims and research questions, and the significance of the study. A brief explanation of formative evaluation and the mixed methods approach to data collection in the context of health promotion interventions is then provided. Finally, the structure of the thesis is described.

1.2 THE BURDEN OF HIV

Significant problems faced by children living with HIV in Malawi include: high levels of poverty (Nyando, 2014; World Bank, 2013a); stigma, discrimination and bullying (Kim et al., 2015b; Pindani, Nkondo, Maluwa, & Muheriwa, 2014); and the loss of one or both parents (Schenk, Michaelis, Sapiano, Brown, & Weiss, 2010; Sefasi, 2010). Although these children are at increased risk of developing mental health problems (Kim et al., 2014; Kim et al., 2015b), they are very unlikely to receive appropriate child centred care because of the chronic shortage of material and human resources (Chilemba, 2016; Luke, Hinkle, Schweiger, & Henderson, 2016; World Health Organisation, 2011b). Whereas the World Health Organisation (WHO) recommends one to two doctors, and seven nurses to provide antiretroviral therapy to 1000 people in low-resource settings, Malawi had three healthcare workers per 1000 patients on antiretroviral therapy in 2010 (Aidspan, 2013; World Health Organisation, 2007). In addition to the lack of staff and clear-cut guidelines and resources for HIV disclosure also affects the health and development of children living with HIV (Mandalazi, Bandawe, & Umar, 2014; Ministry of Health Malawi, 2008).

1.3 HIV DISCLOSURE TO CHILDREN

According to the American Academy of Paediatrics and the World Health Organisation (WHO), the early and progressive disclosure of HIV status to children aged between 6 and 12 years is critically important for their wellbeing (American Academy Paediatrics, 1999; World Health Organisation, 2011a). In 2011, following a systematic review of literature by an international group of academics and HIV experts, the WHO published guidelines for HIV disclosure counselling for children up to 12 years of age (World Health Organisation, 2011a). According to the WHO guideline, disclosure of HIV status to children living with HIV is not an isolated event but rather as a step in the process of adjustment by the child, caregivers, and the community to an illness and the life challenges that it poses. The guidelines recommend that age-appropriate information be given to children as early as possible with full disclosure taking place by the time the child is 12 years of age (World Health Organisation, 2011a).

Despite this recommendation, many children in Sub-Saharan Africa remain unaware of their HIV status (Turissini et al., 2013). To date, rates of HIV disclosure to children living in sub-Saharan African countries remain below 50 per cent (Dachew, Tesfahunegn, & Birhanu, 2014; Madiba & Mokgatle, 2016; Nöstlinger, Bakeera-Kitaka, Buyze, Loos, & Buvé, 2015; Nzota, Matovu, Draper, Kisa, & Kiwanuka, 2015; Vreeman et al., 2014). There are many reasons why HIV status is not disclosed. Studies in both resource-limited and resource-rich settings have identified the following factors as barriers to disclosure among caregivers: HIV/AIDS-related stigma (Hejoaka, 2009; Mweemba et al., 2015); fear that children might inappropriately or accidentally disclose their HIV status to others, which would then lead to gossip, stigmatization, and discrimination towards them and their families (Heeren, Jemmott, Sidloyi, & Ngwane, 2012; Mupambireyi, Bernays, Bwakura-Dangarembizi, & Cowan, 2014); concerns over the child's reactions and potential psychological impact (Mandalazi, Bandawe, & Umar, 2014; Vreeman et al., 2010b); and the caregivers' lack of knowledge about the disclosure process (Demmer, 2011). Studies that have assessed healthcare workers' experiences of disclosure of HIV to children in sub-Saharan Africa have revealed that the following factors are major impediments to effective disclosure: a lack of training and skills about the disclosure process (Madiba & Mokgatle, 2015; McCleary-Sills et al., 2013); a lack of cooperation from caregivers; a lack of time (Kidia et al., 2014; Rujumba, Mbasaalaki-Mwaka, & Ndeezi, 2010b); and a lack of standardised disclosure policies and materials (Madiba & Mokgatle, 2015; McCleary-Sills et al., 2013).

Non-disclosure of HIV status has been associated with children experiencing high levels of depression (Mellins et al., 2002), feelings of loneliness, sadness, and fear (Instone, 2000), and internalising and externalising behaviour problems (Bachanas et al., 2001). The WHO suggests that most of the adverse effects of disclosure previously identified could be minimised if the disclosure process starts early, is age appropriate, and gradual (World Health Organisation, 2011).

On the other hand, several benefits of early HIV disclosure have been reported. These include: good psychosocial adjustment (Vreeman, Gramelspacher, Gisore, Scanlon, & Nyandiko, 2013); better understanding by children of their medical condition; greater involvement in medical care decisions; increased opportunities for peer support; and increased trust of healthcare providers and caregivers (Davis & Shah, 1997). Disclosure of HIV has also been associated with an increase in children's level of honesty in their relationship with their parents (Brackis-Cott, Mellins, Abrams, Reval, & Dolezal, 2003) and early preparation for future life as adolescents and adults (Wiener, Battles, & Heilman, 2000). Perhaps most critically, knowledge of HIV status is known to help children adhere to ARV therapy and a healthy lifestyle (Biadgilign, Deribew, Amberbir, & Deribe, 2008; Mburu et al., 2014a; Toska, Cluver, Hodes, & Kidia, 2015).

The failure to disclose HIV status to children becomes more of a public health risk as they get older (Wiener, Mellins, Marhefka, & Battles, 2007). Once these children reach adolescence many start experimenting with sex which poses a risk of transmitting the infection to other people (Main et al., 1994). In Malawi, one-fifth of male adolescents initiate sex by the age of 15 years and only half of these report using a condom during their first sexual encounter (National Statistical Office Malawi and ICF, 2017). The recent national representative study has shown that 13 per cent of women in Malawi have their first sexual intercourse before the age of 15 years and almost half (47%) of women are married before the age of 18 years (National Statistical Office Malawi and ICF, 2017). Adolescents and young adults who are unaware of their HIV status are at increased risk of experiencing physical and mental health problems because they are unlikely to adhere to medication and this places an additional strain on already stretched healthcare resources (Mialky, Vagnoni, & Rutstein, 2001). There is also evidence that the lack of disclosure is associated with poor school outcomes and a diminished opportunity for employment (Tadesse, Foster, & Berhan, 2015).

1.4 DISCLOSURE MATERIALS

In their 2011 guidelines, the WHO identified the need for health experts to develop materials to help healthcare workers and caregivers with the HIV disclosure process (World Health Organisation, 2011). The WHO guideline recommends that models of HIV status disclosure to children should emphasis on obtaining support for caregivers, dealing with stigma, dealing with institutions such as schools, and on life planning and challenges including bereavement. The authors of recent studies undertaken in Sub-Saharan Africa have reported that healthcare workers and caregivers are asking for standardised materials to guide them through the disclosure process (Madiba & Mokgatle, 2015; McCleary-Sills et al., 2013; Sariah et al., 2016). Health education materials, generally, have been identified as an important resource for helping children with HIV and their families to manage the illness so as to achieve the best possible health and developmental outcomes (Beima-Sofie et al., 2017; Nelms & Zeigler, 2008). The benefits of educational materials and interventions, as reported by authors of various studies, include: guiding the HIV disclosure process (Beima-Sofie et al., 2017; Nelms & Zeigler, 2008; O'Malley et al., 2014); improving the rates of disclosure (Nicastro et al., 2013); improving the efficacy of disclosure (O'Malley et al., 2014); improving drug adherence (Lowenthal et al., 2014); and promoting psychosocial wellbeing (Lowenthal et al., 2014; O'Malley et al., 2014).

Despite the great need for disclosure materials (Beima-Sofie et al., 2014; Sariah et al., 2016), and the recognised benefits of HIV health education materials (Beima-Sofie et al., 2017; Lowenthal et al., 2014; Nelms & Zeigler, 2008), there are few studies that have reported on their development, availability, and use. To date, one study has reported on the development of a brochure to assist primary caregivers with HIV disclosure (Beima-Sofie et al., 2017; Nelms & Zeigler, 2008), one has reported the use of a cartoon book to help healthcare workers and primary caregivers disclose to children (Beima-Sofie et al., 2017), and two have reported on the provision of training sessions for healthcare workers and primary caregivers about how to disclose HIV status to children (Beck-Sagué et al., 2015; Lowenthal et al., 2014). Of the four studies, two were conducted in Sub-Saharan Africa (Beima-Sofie et al., 2017; Lowenthal et al., 2014) while the other two studies were conducted in the United States (US) (Beck-Sagué et al., 2015; Nelms & Zeigler, 2008).

1.5 CONCEPTUAL FRAMEWORK – DEVELOPMENTAL SYSTEMS THEORY

The study was guided by Bronfenbrenner's (1994) bioecological model of early child development, which postulates that development is the result of the child's interaction with persons, objects and symbols in the immediate environment, such as family, school and peers, as well as wider patterns of culture, customs, bodies of knowledge, and economic and political factors (Bronfenbrenner & Ceci, 1994). Within this meta-theory, details of the distribution of family and community resources that influence development are operationalised using the Family and Community Resource Framework (Brooks-Gunn, 1995). The impact of chronic and severe stress in early life on the health and development of children is explained using the concepts of Biological Embedding theories (McEwen, 1998; Shonkoff, Boyce, & McEwen, 2009).

1.6 SIGNIFICANCE OF THE STUDY

Malawi has a large population of children living with HIV, but there is limited knowledge regarding the prevalence and the process of HIV disclosure to seropositive children aged 6 to 12 years. In one of the few studies conducted in Malawi, it was revealed that parents were unwilling to have a conversation about HIV with their child because it was thought to be culturally inappropriate to talk to children about sexual issues (Mandalazi et al., 2014). In other studies, it has been found that parents were concerned that discussing HIV with their child might have a negative impact on the child's wellbeing (Mandalazi et al., 2014; Nyando, 2014). Moreover, despite decades of fairly intensive HIV public health campaigns in Malawi, stigma and discrimination directed at parents and children living with HIV are still common (Nyando, 2014). Furthermore, there is a lack of validated and standardised disclosure materials to guide healthcare workers and caregivers with the disclosure process. As such, current practice is largely driven by clinical judgment and the limited experience and skills of healthcare workers and caregivers. Recognising the importance of disclosure materials, the WHO has urged researchers to develop, implement and evaluate a disclosure model that is culturally acceptable and appropriate for children of different ages and levels of development (WHO, 2011). It is against this background that the author evaluated the current practice of HIV status disclosure to children living with HIV in Malawi and conducted formative evaluation of a proposed disclosure intervention in the form of age appropriate and culturally acceptable story books suitable for children living with HIV in Malawi.

This study will provide an opportunity to inform government and other stakeholders of gaps in the current process of HIV disclosure to children in Malawi and will make recommendations for effective interventions to ensure optimal psychosocial adjustment of children to their HIV condition. Furthermore, it is anticipated that the study findings will inform the development of both policies and guidelines in relation to the disclosure of HIV status to children living with HIV. It is anticipated that when implemented, the findings will lead to the development of community-based interventions that will provide support for children and their families, thus minimising the prevalence of significant mental health morbidity among these children. Most importantly, the development of story books will help children living with HIV to understand their HIV status and improve their psychosocial well-being, medication adherence, and resilience to adapt to the multiple physical, mental and social stressors associated with HIV sero-positivity.

Health promotion is defined by the World Health Organisation (1986) Ottawa Charter for Health Promotion as “the process of enabling people to increase control over, and to improve, their health” (n.d., para. 3). Nutbeam (1998) describes health promotion as an activity that empowers people to take action to improve their health. It involves working with individuals, groups or communities in planning and implementing activities with the purpose of building capacity of the target population to take care of internal and external factors related to their health (Nutbeam, 1998). The principles that guide health promotion include: a) participation of all those involved in the program; b) inter-sectoral collaboration of all organisations and agencies involved in the program; c) capacity building of the individuals or communities to sustain the program even after donors cut funding; and d) use of multiple approaches in a holistic way to achieve the program goals (World Health Organisation Europe, 2001).

Health promotion also deals with changing the determinants of health, both those that are within an individual’s control, such as health behaviour, and those that are beyond an individual’s control such as environmental and socioeconomic factors (Nutbeam, 1998; World Health Organisation Europe, 2001). The current study is guided by Bronfenbrenner and Ceci (1994)’s bioecological theory of child development, which shares many health promotion principles. The theory recognises that an individual’s health is influenced by their interaction with the environment.

1.7 STUDY AIMS AND RESEARCH QUESTIONS

This study was undertaken to: 1) evaluate the current practice of HIV status disclosure to children living with HIV aged 6 to 12 years in Malawi, and 2) to begin to develop an age appropriate and culturally acceptable HIV disclosure resource for such children. This study had three studies, namely: Primary caregiver survey (Study 1), healthcare worker survey (Study 2) and qualitative study (Study 3). To address the aims of the study, each study had specific research question and where appliacable hypotheses:

The primary caregiver survey addressed the following four main research questions: (1) What are the knowledge and practice of primary caregivers in Malawi with regards to HIV status disclosure to their children living with HIV? (2) What are their views regarding the need, acceptability and benefits of the proposed children’s story books for guiding the process of informing their children about their HIV status? (3) How does their decision to disclose HIV status to their children differ by demographics, child and family psychosocial factors, and child health factors? (4) How do their reports of emotional and behavioural problems of their children living with HIV in Malawi differ by demographics, child and family psychosocial factors, and child health factors?

The healthcare worker survey addressed the following three main research questions: (1) What are the healthcare workers’ responses regarding knowledge and practice of HIV status disclosure to children living with HIV in Malawi? (2) What are their views regarding the need, acceptability and benefits of the proposed children story books intended to guide the process of telling children about their HIV status in Malawi? (3) How does their decision to disclose HIV status to children differ by demographics in Malawi?

The qualitative study was guided by the following research questions: (1) What are the thoughts of primary caregivers, healthcare workers, teachers, and community leaders regarding the importance and process of disclosing HIV status to children living with HIV? (2) What are their views regarding their involvement in the process of disclosing HIV status to children? (3) What are barriers and facilitators to their involvement in disclosure of HIV status to children. (4) What are their views regarding the need, acceptability and contents of story books intended to guide the process disclosing HIV status to children.

1.8 EVALUATION OF HEALTH PROMOTION PROGRAMS

The design and implementation of sizable health promotion programs requires the utilisation of a substantial amount of social, human, material, and financial resources. Prior to committing their resources, donors and other partners want to know if the program is likely to yield the intended results. According to the WHO, health promotion program evaluation involves: “the systematic examination and assessment of the features of an initiative and its effects, to produce information that can be used by those who have an interest in its improvement or effectiveness” (World Health Organization, 1998, p. 3).

Evaluation is an important part of running a program. It helps to improve health promotion programs by identifying problems facing a program and finding effective solutions (Wimbush & Watson, 2000). Also, evaluation ensures the accountability of project implementers to donors and beneficiaries regarding the use of resources (Hawe, Degeling, & Hall, 2003). Furthermore, evaluation provides feedback to all stakeholders of health promotion programs on their effectiveness in meeting objectives (Hawe et al., 2003; Nutbeam, 1998).

Evaluation of health promotion programs can be divided into four interconnected levels namely: formative evaluation, process evaluation, impact evaluation, and outcome evaluation (Hawe et al., 2003; O'Connor-Fleming, Parker, Higgins, & Gould, 2006). The evaluation of programs begins with formative evaluation. Formative evaluation is conducted during the design phase of a program with the aim of identifying and refining limitations of the program (Stetler et al., 2006).

1.9 FORMATIVE EVALUATION

It is an evaluative process that is undertaken at the outset of a program with the aim of garnering data for the development and improvement of the program (Dehar, Casswell, & Duignan, 1993). Formative evaluation consists of the following activities: development and refinement of program objectives; literature review; conducting a needs assessment survey; pretesting program materials; piloting of programs; obtaining feedback from program participants; assessing initial program effects; and development of program evaluation system (Dehar et al., 1993).

1.9.1 Use of formative evaluation

The importance of formative evaluation in assessing health promotion interventions has been reported by many researchers. According to Nutbeam (1998) and Stetler et al. (2006), formative evaluation aims to provide best answers to relevant questions releted to identified health problems in order to establish the practicality of different intervention methods and assess program feasibility and efficacy. Answers to these relevant questions should not be obtained through logical thought or conversation with a group of experts, given that those who develop interventions are unlikely to comprehend the specific needs of the prople for whom the intervention is intended (Windsor, Jessell, Lassiter, & Benoit, 2014; Windsor, Boyd, & Orleans, 1998). In light of these, it is critically important that those who develop interventions should explain the proposed intervention to stakeholders and enquire if it is perceived to be beneficial and of worth. The stakeholders' perspective of the intervention is then taken into account by modifying the intervention so that it fits well with the people and context in which it is intended (Stetler et al., 2006; Windsor et al., 2014; Windsor et al., 1998).

1.9.2 Application of formative evaluation to the study

The use of a logic framework model in evaluative mixed methods research is encouraged by scholars (Cooksy, Gill, & Kelly, 2001; Shakman & Rodriguez, 2015). A logic model is a tool used in planning and evaluation of a program. It identifies the resources, activities, outputs and long and short-term outcomes of a program (Anold, 2002). In addition, the logic model integrates data collection and analysis by presenting each program element with its related input and output; as a result, it simplifies the understanding of complex programs (Cooksy et al., 2001; Shakman & Rodriguez, 2015). In the current research, a logic model for the study was developed to show the resources, activities, outputs and outcomes needed for successful implementation of the study. The logic model applied to this study had three main activities, namely the formation of, and consultation with, a steering committee, consultation with key stakeholders, and the implementation of a needs assessment survey (see Appendix A). The logic model identifies short and long term outcomes for children living with HIV, as well as their caregivers, healthcare providers, teachers, and community leaders. The logic model provided guidance on planning and implementation of the three phases of the current study (preparatory, needs assessment, and development of the HIV disclosure resource). In this study, all important stakeholders were consulted to obtain their views regarding the proposal to develop story books to help with the disclosure process. It was anticipated that formative evaluation would help to elucidate the process of HIV disclosure in Malawi as well as identify the major challenges to this process.

1.10 MIXED METHODS APPROACH

The use of mixed methods in research has been increasing in recent years (Sandelowski, 2014). What determines the use a mixed approach is when the researcher realises that the utilization of a single method, be it qualitative or quantitative, would not give a full understanding of a research problem (Creswell, 2010).

A number of factors influence the quality of mixed methods research. First, it is imperative that the mixed methods researcher gain adequate training in conducting both quantitative and qualitative research, preferably through courses supplemented by field experience (Collins, Onwuegbuzie, & Sutton, 2006). Second, the researcher should endeavour to clearly articulate a detailed explanation of the phases of the quantitative and qualitative components of the study (Bryman, 2014; O'Cathain, Murphy, & Nicholl, 2007). Most researchers have a preference for either one of the methods, and they usually explain in detail the research process of the preferred method while neglecting to provide a full description or articulation of the less preferred method (O'Cathain et al., 2007).

Moreover, the study’s research questions should determine whether a mixed methods approach needs to be employed in the first place (Bryman, 2014). Often researchers use mixed methods in a study, not because the research questions demands it, but because of the potential of mixed methods to attract donors or to have the study results accepted in high-quality journals for publication (Bryman, Becker, & Sempik, 2008).

1.10.1 Differences between quantitative and qualitative methods

Table 3.1 outlines some of the differences between qualitative and quantitative methods. First, quantitative studies usually use larger sample sizes than qualitative studies, with resultant greater generalizability of study results (Creswell, 2010; Heyvaert, Hannes, Maes, & Onghena, 2013). While quantitative methods use large sample sizes to collect data that lend themselves to statistical analysis, qualitative method collect semi-quantifiable or unquantifiable data from a small sample size that can be difficult to generalise to the larger population (Guest, MacQueen, & Namey, 2012). Moreover, researchers who use quantitative methods strive to be objective, while in qualitative research the approach is often subjective (Guest et al., 2012) (see Table 3.1).

Table 3.1: Differences between quantitative and qualitative methods

Quantitative method	Qualitative method
Large sample size	Small sample size
Generalizability of results	Limited generalizability of results
Used for testing hypothesis	Used for generating hypothesis
Sample probabilistic in nature	Sample non-probabilistic in nature
Objective research process	Often subjective research process
Data is quantifiable through statistical analyses	Usually non-quantifiable data
Explanatory in nature	Predictive in nature
	Provide context or depth to some of the quantitative data.

1.10.2 Advantages of using mixed methods

There are several benefits of using both methods in a study. The limitations of one method can be minimised by the strengths of the other, at the same time, the strengths of one method can augment the weaknesses of the other (Creswell, 2009, 2010; Guest et al., 2012). For example, quantitative findings in a mixed methods study can help to validate qualitative findings and to transfer these findings to other areas (Guest et al., 2012; Kelle, 2006). On the other hand, qualitative findings can help to understand incomprehensible statistical findings (Guest et al., 2012; Kelle, 2006). In addition, mixed methods can provide detailed and strong evidence related to the research problem (Guest et al., 2012). The mixed methods approach is also useful in providing answers to a research question that a single method cannot provide (Guest et al., 2012). Furthermore, the use of more than one method draws expertise from different fields and, as such, it promotes a multidisciplinary approach (Guest et al., 2012).

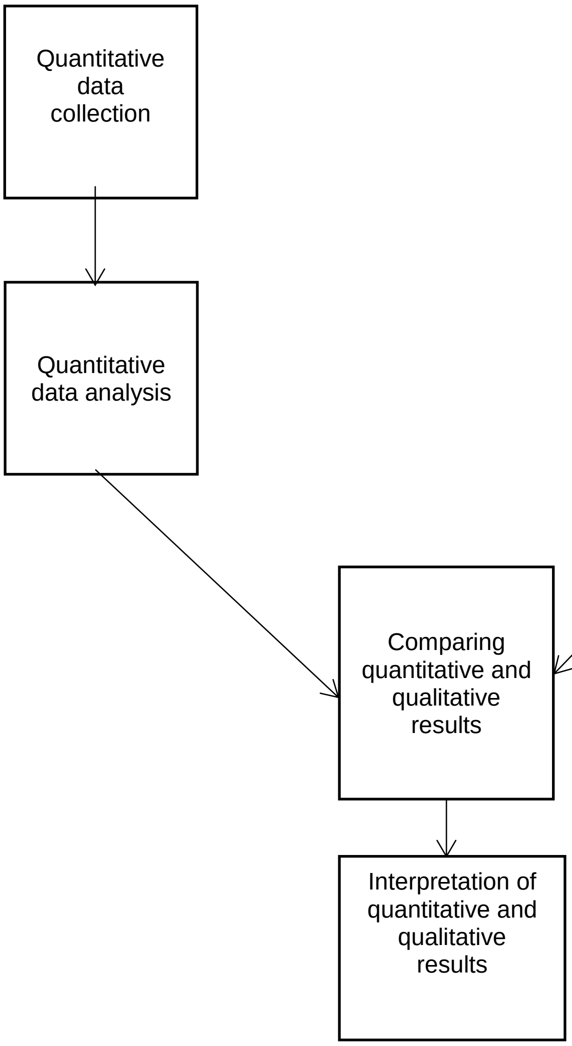
1.10.3 Limitations of using mixed methods

The use of mixed methods necessitates that a researcher should master both methods in terms of designing, implementation and analysis. This can be potentially challenging, as it can be difficult for a person to have the required expertise to carry out rigorous mixed methods research (Collins et al., 2006; Onwuegbuzie & Johnson, 2004; Teddlie & Tashakkori, 2003). However, this can be addressed by bringing together a research team with expertise in both qualitative and quantitative research methods, or by enabling the researchers to take training in both quantitative and qualitative research (Creswell, 2007). In addition, carrying out mixed methods research requires additional time and resources compared to mono-method research (Teddlie & Tashakkori, 2003). This limitation can be addressed by proper planning of the study design to ensure that the study is allocated adequate time and resources.

1.10.4 Concurrent triangulation design

The study used concurrent triangulation design. In this design, quantitative and qualitative data are collected at the same time and phase, analysed separately and then the results of the two methods are compared (Creswell, 2003, 2007) (see Figure 3.1). The design was chosen with the aim of validating the findings of one method with the findings of the other as a means of obtaining comprehensive and credible evidence of the research problem (Bryman, 2006; Creswell, 2007; O'Cathain, Murphy, & Nicholl, 2010). Creswell (2009) refers to this validation of findings from the two methods as confirmation or corroboration. The comparision or integration of the findings is normally done in the discussion section of the study (Creswell, 2009). This design is recommended because it is efficient, as qualitative and quantitative data can be collected at the same time (Creswell, 2009; Creswell & Plano Clark, 2011). In addition, the design promotes teamwork by bringing together experts from qualitative and quantitative disciplines (Creswell, 2007). The major challenge of this design is that sometimes the results of the two methods do not agree, which necessitates the researcher to collect additional data or to re-examine the existing data, a process requiring extra time and resources (Creswell, 2007; Creswell, 2009).

Figure 3.1: Concurrent triangulation design



Concurrent triangulation design adapted from Creswell (2003), Creswell (2007)

1.10.5 Application of mixed methods to the current study

The use of mixed method research depends on the purpose of the study (Collins et al., 2006). The aims of the current study were to evaluate the current status of disclosure of HIV status to children living with HIV and to begin to develop a disclosure resource. The use of mixed methods was considered the best fit for the study for the following reasons. The quantitative methods helped the researcher to estimate the prevalence of HIV disclosure to children living with HIV in Malawi, as well as to identify the potential association between a wide range of child, family, and healthcare system factors and the act of disclosure. On the other hand, the qualitative approach helped the researcher to have a much deeper understanding of the disclosure process. The attitudes of primary caregivers, healthcare workers, teachers, and community leaders on disclosure of HIV status to children were best assessed using qualitative methods. The qualitative approach was also invaluable in assesing the level of participant support for a HIV disclosure resource for children.

By using both methods, the researcher was able to gain an understanding of the current practice of HIV disclosure to children in Malawi and the need for, and acceptability of, the proposed disclosure resource.

1.11 PRESENTATION OF THE THESIS

This thesis is presented in six chapters, followed by the list of references and appendices. Chapter one is the introduction of the thesis, Chapter two contains a detailed literature review, Chapter three describes the primary caregiver survey, Chapter four presents the healthcare worker survey, Chapter five describes the qualitative study, and Chapter six contains a detailed discussion of the findings.

In Chapter two, literature related to the aim and objectives of the study is presented in order to put the current study into context. Following an overview of relevant information about the historical, sociodemographic and cultural background of Malawi, and the conceptual framework that has guided the study, detailed evidence-based literature specific to the disclosure of HIV to children in Sub-Saharan Africa and elsewhere is presented and critically evaluated.

In Chapter three, detailed information of the primary caregiver survey is provided. The Chapter starts with an introduction of the study which is followed by a description of the research questions and hypotheses. The activities that were undertaken prior to data collection, such as the translation and piloting of the study instruments are then described. Thereafter, the sample, procedure, instrumentation, data analysis and ethical consideration are outlined. The findings of the pilot study are presented first, this is followed by response rate, characteristics of participants, bivariate and multivariate findings.

Chapter four provides information about the healthcare worker survey. The Chapter begins with an introduction of the study which is followed by a description of the research questions and hypotheses. Thereafter, the participants recruitment criteria and study setting are provided. The next section describes, sample, procedure, instrumentation, and data analysis. This is followed by an explanation of the study findings that include response rate, characteristics of participants, bivariate and multivariate findings.

Chapter five provides an account of the qualitative study. The Chapter provides information about the methodology and findings of a qualitative study. The chapter starts with an abstract, which is followed by a brief background information of the study. A description of the research questions is then provided. This is followed by an outline of the participants recruitment criteria and study setting. The next sections describe sample, procedure, instrumentation, and data analysis. The findings from the interviews and focus group discussion data are then highlighted. First, the characteristics of the participants are explained. This is followed by a description of the themes and the emerging “Working Together” framework.

Chapter six provides a detailed discussion of the study findings in the light of the published literature. Following a summary of the key findings and a sub-section about the experience of psychological and social problems, the Chapter is organised into three sub-sections that correspond to the “Working Together” model for HIV disclosure that emerged from the findings. These are “Talking about HIV”, “Open Communication”, and “Shared Responsibility”. The strengths and limitations of the study are presented next, and then the Chapter concludes with recommendations that focus on the further development of the proposed intervention, the story books.

Following the list of references section are the Appendices that contain participant information sheets, participant consent forms, survey questionnaires, interview and focus group discussion guides, and ethics approval letters.

2 CHAPTER 2: LITERATURE REVIEW

2.1 INTRODUCTION

This chapter provides a critical review of literature relevant to the current study. Overall, the review seeks to provide an understanding of disclosure of HIV status to children in Malawi and the potential impact of disclosure on their health and development. In order to address these subjects, the review is organised in the following four sections, namely: 1) the history and social demography of Malawi; 2) the epidemiology of HIV/AIDS: 3) the conceptual frameworks used to guide the study; and 4) the disclosure of a diagnosis of HIV to children.

First, background information about Malawi will be provided in order to help readers understand how the physical and social environment impacts on the health and developmental outcomes of children living with HIV. The geographical position, climate, population, government, culture, human development and economy, and healthcare delivery system in Malawi will be discussed.

Second, in order to appreciate the successes and challenges in the fight against HIV over the past three decades, the disease and the history of HIV/AIDS in sub-Saharan Africa and Malawi, will be briefly outlined.

Third, the bioecological model of human development (Bronfenbrenner, 1994) will be introduced. This will help readers appreciate how the developmental trajectories of children living with HIV are impacted when they interact with the physical and social environment over time. Within this overarching theoretical framework, the family and community resource framework will be presented to explain in more detail how resource distribution in the family and community affects the development of children living with HIV. Furthermore, the mechanisms of biological embedding will be described briefly. These are the causal pathways by which the physical and social environments that children living with HIV experience influence gene expression, brain development and stress responsiveness. The section will conclude with an explanation on the application of the models to a child living with HIV in Malawi.

The fourth section presents an overview of the disclosure of a diagnosis of serious illness to children. The section is focused on paediatric cancer because this is the most common serious illness that children experience worldwide, and it has been the subject of most academic inquiry. The processes developed for the disclosure of serious illness to children have been adapted to the current process of HIV disclosure.

Fifth and lastly, literature regarding the process of HIV disclosure, the factors that impact on HIV disclosure to children, and the materials which are available to guide the disclosure process will be reviewed in detail. This will be followed by an examination of:

rates of HIV disclosure; the importance of, and ethical issues in, disclosure of HIV; the HIV disclosure process; barriers and facilitators to HIV disclosure; and the impact of HIV disclosure on children and their families. The literature review will conclude with an overview of disclosure materials available for children that have been published in peer-reviewed journals, as well as materials that can be accessed from grey literature.

2.1 SEARCH STRATEGY

A systematic approach was used to identify relevant literature and place the current study in context. Peer reviewed journal articles were searched from the following databases EMBASE, PubMED, Medline, PyscINFO, AMED, Web of Science, WHO global index medicus library, Cochrane, ProQuest, Google scholar, and DOAJ. Mesh terms such as AIDS virus, Acquired Immune Deficiency Syndrome Virus, Human Immunodeficiency Virus, Human T Cell Lymphotropic Virus Type III, and Human T-Lymphotropic Virus Type III and disclosure were used to identify relevant articles. In addition, other relevant key search terms using a Boolean operators; “OR” and “AND” were also used. The following were some of the main key search terms HIV OR hiv OR hiv1 OR hiv 2 OR human immunodeficiency virus OR AIDS OR acquired immunodeficiency syndrome AND disclosure OR communication OR literacy OR dissemination AND child OR school children OR adolescent AND mental health, OR behavioural problems OR conduct problems OR psychological problems OR child health OR child development AND Malawi OR Sub-Saharan Africa OR Africa.

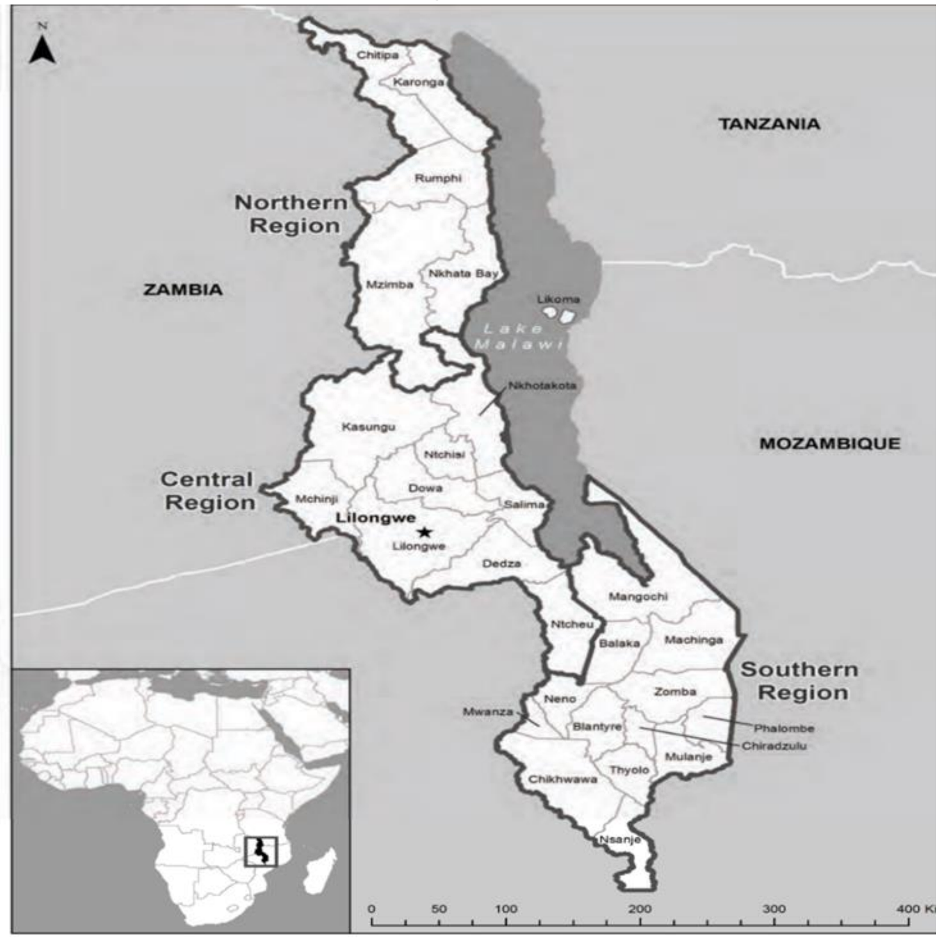
In addition, articles from the grey literature were searched from databases or libraries of Governments and reputable international organisations including the World Health Organization, UNICEF, UNDP, UNAIDS, Save the Children, and the World Bank. Additional searches for articles were made in conference proceeding databases such as the International AIDS Conference, The IAS Conference on HIV Science and the Annual Conference on Rotaviruses and Opportunistic Infections. Titles and/or abstracts of studies from the initial search were reviewed first and only those that were related to the aims of the study were retrieved and tabulated. The studies were organised using the following headings author, year of study, type of participants, age, setting, country, sample size, study design, methods, study purpose, study objectives, and study outcome measures. Only studies that were published in English were included in the review. All suitable literature was included regardless of the year of publication and study design. Individual searches in the databases yielded a total of 3663 pieces of literature. A total of 416 pieces of literature were included in this thesis after excluding duplicates and articles not directly related to the aims and research questions of the study.

2.2 HISTORY AND SOCIAL DEMOGRAPHY OF MALAWI

2.2.1 Geographical position and climate

Malawi is a landlocked country located in the south-eastern part of Africa with a total land area of 118, 484 square kilometres. It shares borders with Zambia to the west, Tanzania to the north and east, and Mozambique to the south and east. One-fifth of the country is covered by Lake Malawi (see Figure 2.1). Malawi has a tropical continental climate with two different seasons; a wet season and a dry season. The wet season runs from November to April while the dry season runs from May to October. The mean annual minimum and maximum temperatures range from 12℃ to 32℃. The two seasons have variations in terms of temperature and rainfall (Malawi Government, 2006).

Figure 3.2: Map of Malawi



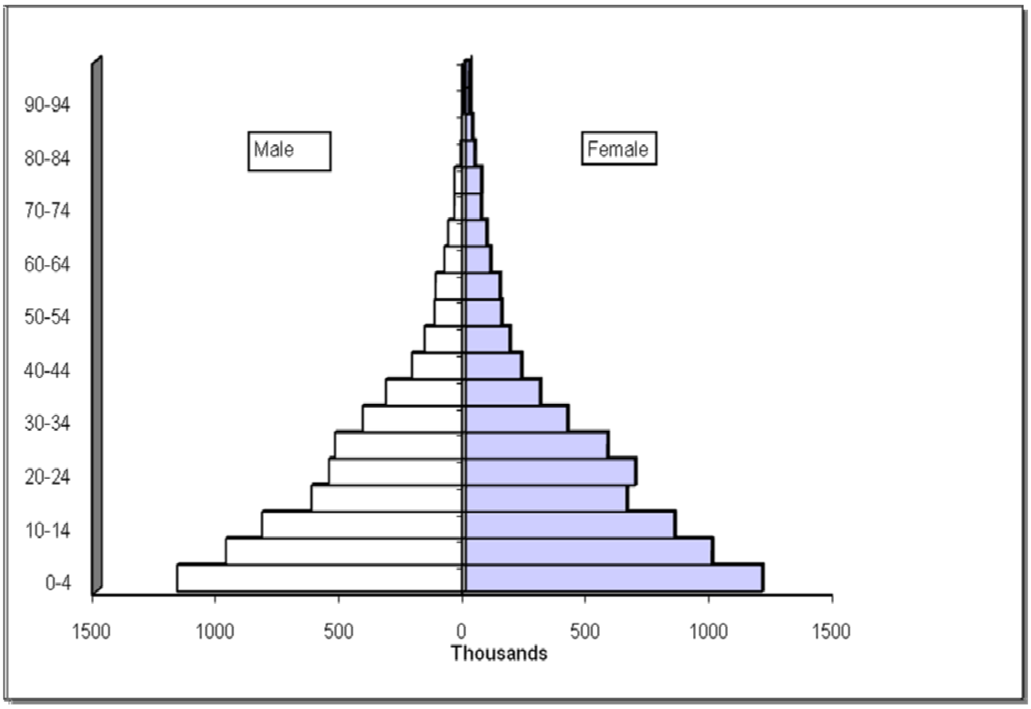
Source: (National Statistical Office, 2011)

2.2.2 Population

The World Bank estimated that the population of Malawi in 2016 was 18.2 million (The World Bank, 2016). The annual population growth is at 2.8 per cent (Icelandic International Development Agency, 2012). It is projected that if the population continues to grow at this rate, the population of Malawi will reach approximately 40.6 million by 2040 (Government of Malawi, 2010). The total fertility rate is at 5.7 children per woman

(NSO and ICF Macro, 2011). Data from the last national population census in Malawi show that Malawi has a youthful population (Republic of Malawi, 2008) (See figure 2.2). Fifty-four per cent of the population in Malawi are under the age of 18 years and the median age is 17 years (Republic of Malawi, 2008). Children under the age of five years account for one-fifth of the total population while adults aged 65 years or older account for only 4 percent of the total population (Republic of Malawi, 2008).

Figure 3.3: Population pyramid of Malawi



2.2.3 History of Malawi

Malawi was founded by a group of Banthu speaking people in 1480 (Kalinga & Pike, 2000). In 1891 the country was taken over as a protectorate under British colonial power until 1964 when it gained independence (Baker, 2006). Malawi was ruled by a single party from independence until 1993 when it became a multi-party democracy (Kalinga, 2012). As an ex-British colony, most Malawians who are formally educated speak English and the government follows the English education system (Kalinga, 2012). The unofficial language, Chichewa, is spoken by most people (Kalinga, 2012).

2.2.4 Government

Malawi has a democratically elected Government. The Government has three independent branches namely the executive, the legislature and the judiciary (International Bar Association's Human Rights Institute, 2012). The executive consists of the president, vice president and the cabinet (International Bar Association's Human Rights Institute, 2012). The president is the head of the government. The role of the executive is to implement laws in line with the provisions of the constitution. The legislative power belongs to parliament which is headed by the speaker. The judiciary is responsible for protecting, interpreting and enforcing all laws in Malawi and is headed by the chief justice (International Bar Association's Human Rights Institute, 2012).

Unlike some of its immediate neighbours, Malawi is a peaceful country. Since independence, it has experienced five presidential regimes: Kamuzu Banda’s regime (1964-1994), Bakili Muluzi’s regime (1994-2004), Bingu wa Mutharika’s regime (2004-2012), Joyce Banda’s regime (2012-14) and Peter Mutharika’s regime (2014 to date) (De Gobbi & Anang, 2013; World Bank, 2013b). Poor governance, during the second term of office of Bingu wa Mutharika led international donors to suspend financial support over a period of two years. The consequences were grave considering the fact that international donors finance 40% of the Malawi’s national budget (Oversees Development Institute, 2011). During this period, there were electricity cuts, high rates of unemployment, and a shortage of medications in the hospitals.

Malawi has three administrative regions namely the Northern, Southern and Central regions (Malawi National Statistical Office & ICF International, 2017). The Southern region has the highest population seconded by the Central region which harbours the administrative capital, Lilongwe. (Malawi National Statistical Office & ICF International, 2017; Oversees Development Institute, 2011). For administrative purposes, the country is divided into districts (Malawi National Statistical Office & ICF International, 2017). There are 13 districts in the Southern region, nine in the Central region and six in the Northern region (Icelandic International Development Agency, 2012). The districts are subdivided into traditional authorities presided over by chiefs who play an important role in customary custodianship (Icelandic International Development Agency, 2012). Each traditional authority has smaller administrative units, villages, that are presided over by village headmen (Icelandic International Development Agency, 2012).

2.2.5 Culture and society specific to the transmission of HIV

Patrilineal and matrilineal are two lineage patterns practised in Malawi depending on geographical location, with those residing in the north practising the former and those in the south and central practicing the latter (White, 2007). Patrilineality descent is through males and a woman resides at her husband ‘s village while under matrilineality descent is through females and the husband leaves his village and resides at the wife’s village. In both matrilineal and patrilineal societies women assume an inferior position to male members and decisions are made by men with women on the receiving end (White, 2007). White (2007) argues that patrilineality provides more social security than the matrilineal system since men feel obliged to take care of their families, unlike in the matrilineal system where men do not feel obliged to make investments as they feel that they will not live in the village forever. In the matrilineal system, culture gives the responsibility of taking care of the family to the maternal uncle. This has resulted in differences in poverty levels between the two systems; the areas that practice matrilineality are poorer than those that practice patrilineality (White, 2007).

The inferior position that culture places on women makes them least able to negotiate safe sex, to prevent sexual violence, and to have adequate access to quality healthcare. (Malawi Government, 2012a; White, 2007). In Malawi, cultural norms and values define masculinity in terms of sexual prowess and sexual activity (Poulin, 2007; White, 2007). The society encourages women not to refuse sex to their husbands or to ask for use of condoms during sex even if they are aware of their husbands' promiscuous behaviour (Poulin, 2007). Moreover, men in Malawi have a negative attitude towards the use of condoms (Poulin, 2007; White, 2007). In one study the author found that men described using condoms during sex as not enjoyable and they compared it to eating a sweet while it is inside the wrapper (Poulin, 2007). The authors of another study revealed that women who were enrolled in the study about the prevention of mother to child transmission of HIV dropped out because their husbands refused to engage in protective behaviour and many felt unable to negotiate condom use (Chinkonde, Sundby, & Martinson, 2009). Due to the risk of HIV transmission from the mother to a newborn, HIV testing for pregnant women is mandatory in Malawi. Some of the women who test positive, experience divorce when they reveal their HIV status results to their male partners because they are accused of infidelity and bringing the infection in the house (Kasenga, Hurtig, & Emmelin, 2010).

Polygamy is accepted amongst certain tribes and religions in Malawi. The recent national representative study in Malawi has revealed that 13 per cent of women are in polygynous unions (Malawi National Statistical Office & ICF International, 2017). While it is common for a man to marry several women without he or his partners being tested for HIV (Malawi Ministry of Health, 2002), in the 2010 Malawi Demographic and Health Survey no difference was found in HIV prevalence between polygamous and non-polygamous participants (National Statistical Office, 2011). There are, however, several traditional beliefs and customary practices associated with sex that do promote the transmission of HIV (Malawi Government, 2012a). These include the "hyena" practice where a couple who are having difficulties conceiving hire a man to come in the house and have sex with the woman with the consent of the husband, with the aim of conceiving a baby (Muula & Mfutso-Bengo, 2004). This happens when it is strongly suspected that the husband is infertile. This practice has ethical challenges similar to sperm donation and surrogate parenthood practised in the West. In the "hyena" practice, the sperm is provided through a sexual encounter unlike in the West, where it is provided in a test-tube. Another difference is that in the "Hyena" practice the donor is known to the family, whereas in

Western culture the sperm donor is not known to the recipient (Muula & Mfutso-Bengo, 2004).

Another practice is the widow inheritance. This practice is followed when a husband dies, and his young brother inherits the widow. He marries her in order to ensure that she and her children are taken care of (Muula & Mfutso-Bengo, 2004). The practice exposes the brother and the widow to the risk of contracting HIV (Muula & Mfutso-Bengo, 2004). Another practice is “funeral cleansing” where a widow is supposed to have sex with a man identified by elders following the death of her husband (Muula & Mfutso-Bengo, 2004). It is believed that the practice helps to remove all misfortune associated with the death of the spouse (Muula & Mfutso-Bengo, 2004). Once the practice is completed the woman is ready to remarry. Yet another cultural practice is known as “removing the dust and putting on body oil” (Muula & Mfutso-Bengo, 2004). In this cultural practice, males and females are encouraged to have sexual intercourse after being initiated into adulthood (Muula & Mfutso-Bengo, 2004). Initiation ceremonies are practised by several tribes after boys and girls reach puberty (Muula & Mfutso-Bengo, 2004). The initiates are forced to “remove the dust” because of the belief of the elders that if they do not do it, a curse may fall on their family (Muula & Mfutso-Bengo, 2004). While such traditional practices have been declining since the the advent of HIV, they continue to be performed.

2.2.6 Human development and economy

The Human Development Index value for Malawi in 2015 was 0.476. This is in the low development category, ranking it at position 170 out of 188 countries and territories (UNDP, 2016b).The Human Development Index is a summary for assessing long-term progress in three basic dimensions of human development namely: access to knowledge, a decent living, and a long and healthy life (UNDP, 2016b). Malawi has an annual gross national per capita income of United States (US) $320 and more than 50 per cent of the population lives below the poverty level (World Bank, 2013a).

Agriculture is the main stem of the country’s economy contributing to 36 per cent of the country’s Gross Domestic Product (The World Bank, 2009). It is also the main source of livelihood for the majority of the rural people. Tobacco, tea and agricultural products account for 80 per cent of the all agricultural exports (Malawi Government, 2006). Approximately 88 per cent of the Malawians live in rural areas and a large majority of them depend on Agriculture for their living. More than 90 per cent of farmers grow maize which is the country’s main crop and more than half of the household grow no other crop (The World Bank, 2009). The soil in Malawi has lost fertility over the years and people now depend on artificial fertiliser which is very expensive for ordinary Malawians (Chisinga, 2008). Because of a lack of fertiliser 70-80 per cent of rural households experienced food insecurity from 1990 to 2004 (Chisinga, 2008). Malnutrition during this period exacerbated the, already, poor health outcomes experienced by people living with HIV (Chisinga, 2008) . In 2005 the government introduced a subsidy program for farm inputs, including fertilizer, where farmers pay less than 10 per cent of the price and the rest is paid by Government (Chisinga, 2008). Since the introduction of the subsidy program, Malawi has produced more food, with the prevalence of growth stunting in children failing from 6.4 per cent in 2005 to 4.9 per cent in 2007 (Dorward & Chirwa, 2011; Waage et al., 2010).

From Table 2.1, it can be observed that life expectancy in Malawi decreased from 1990 to 2004 and started increasing from 2005 to 2015. The period between 1990 and 2004 was the time when Malawi was severely hit by HIV/AIDS and there was no free ART. Many people died due to HIV related diseases. This was also the period when many people experienced famine.

Table 3.2: Malawi's Human Development Index

	Life expectancy at birth	**Expected years of schooling**	**Mean years of schooling**		**GNI per capita (2005 PPP$)**	**Human development index value**
1980	44.4	4.8	1.8		0,628	0.272
1985	46.1	4.6	2.1		0,617	0.283
1990	47.1	5.2	2.5		0,554	0.295
1995	46.7	7.5	2.7		0,602	0.322
2000	46	11	3		0,654	0.352
2005	49	9.7	3.4		0,640	0.363
2010	53.5	10.4	4.2		0,775	0.413
2011	54.2	10.4	4.2		0,763	0.415
2012	54.8	10.4	4.2		0,774	0.418
2013	61.5	10.7	4.4		1.055	0.446
2014	62.8	10.8	4.4		1.085	0.473
2015	63.9	10.8	4.4		1.073	0.476

Source: (UNDP, 2016a)

2.2.7 Education

Education is the key to formal employment in Malawi and it leads to higher hourly earnings (Castel, Phiri, & M., 2010). In a study conducted in Malawi it was revealed that within regular wage employment, secondary education and university education were associated with 123 per cent and 234 per cent wage premiums respectively (Castel et al., 2010). In the same study it was revealed that men were three times more likely to finish secondary education than women (Castel et al., 2010). Empowering women through education can help to improve health and wellbeing since education can improve their economic status as well as participation in decision making related to their health (Castel et al., 2010). Women with higher education and socioeconomic status have a higher likelihood of using modern contraception (C-Change and USAID, 2012). In a survey conducted by the National Statistics Office in Malawi it was revealed that use of modern contraception was higher in women in the wealthiest quintile (48.4%) as compared to those in the least wealth quintile (34.9%) (NSO and ICF Macro, 2011).

2.2.8 Healthcare delivery system

Healthcare in Malawi is primarily delivered by three sectors, namely Government, the Christian Health Association (CHAM) and other private providers (World Health Organisation, 2014). The Government provide 63 per cent, the CHAM 26 per cent and other private providers the remaining 11 per cent (World Health Organisation, 2014). Healthcare facilities in the country are organized under three tiers: primary, secondary, and tertiary (Chirwa, 2013). The levels are linked through a referral system (Chirwa, 2013).

At the primary level, healthcare is provided through community-based outreach programs, dispensaries, health posts, healthcare centres and community hospitals. The primary level facilities refer obstetric emergencies and patients requiring in-patient medical, surgical or paediatric care to secondary level facilities. Secondary level care is provided through district hospitals (for the public sector) and CHAM hospitals (church owned health facilities). Patients who require specialist care are referred to tertiary level facilities (Chirwa, 2013). The tertiary health care service is provided by four central hospitals with two in the Southern Region, one in the Central and another in the Northern Region (World Health Organisation, 2009). People living with HIV have access to ART at no cost in health centres, community, district, and central hospitals (Harries et al., 2016). In addition, the government provides essential health care services known as the Essential Health Package (EHP) free of charge to all citizens. The use of CHAM facilities incurs a small fee (Mangham, 2007).

This section of the literature review has provided a brief overview of political, social, economic, cultural, and healthcare system factors in Malawi that impact on HIV transmission and the experience of people living with HIV. The following section outlines the aetiology and prevalence of the disease and the history of the spread of HIV/AIDS globally and regionally.

2.3 HIV/AIDS AND IT’S SPREAD GLOBALLY AND REGIONALLY

2.3.1 Aetiology of HIV/AIDS

HIV stands for Human Immunodeficiency Virus (Nye & Parkin, 1994). It is a virus that once acquired, destroys the immune system of the host thereby predisposing the person to a group of infections (Healey, 2011). HIV gains entry into the blood cells by attaching itself to the CD4 receptor (Klatt, 2016; Pope & Haase, 2003). Once in the cell it is known as retrovirus and it encodes the enzyme transcriptase (Klatt, 2016). This results in the viral RNA making DNA copies which consequently lead to high rate of HIV mutation (Gupta, Hill, Sawyer, & Pillay, 2008a; Klatt, 2016). Once inside the DNA cell, the virus can be dormant for a long period of time or it can use the processes within the human cell to replicate itself (Klatt, 2016). Within a few weeks viral replication can exceed 10 million viral copies per microliter of plasma (Morris & Cilliers, 2005). This process leads to depletion of the CD4-T cells which eventually lead to a decrease in body immunity, thereby making the body susceptible to opportunistic infections (Klatt, 2016; Morris & Cilliers, 2005). While the risk of heterosexual transmission is lower than homosexual infection, the risk increases in the presence of ulcerative sexually transmitted infections, high viral load in the host, and a lack of ART (Pope & Haase, 2003; Varghese, Maher, Peterman, Branson, & Steketee, 2002). The group of infections that develop due to HIV is known as Acquired Immunodeficiency Syndrome (AIDS) (Healey, 2011). Globally, the main mode of HIV transmission in adults is heterosexual intercourse while in children perinatal transmission (at birth and through breast feeding) accounts for 90 per cent of HIV infections (Alrajhi, Halim, & Al-Abdely, 2004; Brewer, 2012; Shattock & Moore, 2003). Other modes of transmission include blood transfusion, men having sex with men, contact with infected blood, and by sharing injection needles or razor blades with an infected person (Brewer, 2012; Case et al., 2012; Gouws, White, Stover, & Brown, 2006).

There are two types of HIV namely, HIV-1 and HIV-2 (Nye & Parkin, 1994). HIV-1 was discovered first in 1981 in the USA (Makroo, 2010), while HIV-2 was discovered in 1985 in West Africa (Witvrouw et al., 1999). HIV -1 and HIV-2 are both lentiviruses which are believed to have evolved from Simian Immunodeficiency Virus (SIV) commonly found in primates. HIV-1 is related to SIV isolated from wild Chimpanzees, while HIV-2 is related to SIV isolated from Macaques and Sooty Mongabeys (Bailes et al., 2003; Witvrouw et al., 1999). The consumption of uncooked, contaminated meat and contact with the blood of infected animals during meat preparation provide a possible explanation of the cross-species transmission of SIV to become HIV (Hahn, Shaw, De Cock, & Sharp, 2000; Sharp et al., 2001). While HIV-1 infection is common globally, HIV-2 is confined to West Africa (Travers et al., 1995). HIV-1 has four groups namely N, O, P, and M. Group M is the most common and it is responsible for 98 per cent of HIV infections worldwide (Sharp & Hahn, 2010). Group M is further classified into nine subtypes; A-D, F-H, J and K (Maartens, Celum, & Lewin, 2014). Subtype C is more common in Africa and India while subtype B is more common in western Europe, America and Australia (Hemelaar et al., 2011). Despite HIV-1 and HIV-2 having similar biological properties, they differ in many ways (Witvrouw et al., 1999). HIV-1 has higher rates of sexual and perinatal transmission than HIV-2 (Travers et al., 1995). In addition, HIV-1 has higher infectivity compared to HIV-2, and the disease free survival time for HIV-1 is significantly shorter (Kanki et al., 1994).

2.3.2 Global and local prevalence and incidence of HIV

The United Nations estimated that, globally, there were 36.7 million people living with HIV in 2016 and three quarters of these were living in Sub-Saharan Africa (UNAIDS, 2016). The availability of free ART has resulted in an increase in the global prevalence of HIV from 31.0 million in 2002 to 36.7 million in 2016 (UNAIDS, 2016; Zaidi, Grapsa, Tanser, Newell, & Barnighausen, 2013). Provision of free ART has increased accessibility of the medicine to people living with HIV, which has consequently decreased their mortality, at the same time there are new HIV infections recorded yearly resulting in increase in the prevalence of HIV (UNAIDS, 2016; Zaidi et al., 2013). On the other hand, the global annual incidence of new HIV cases decreased from 3.3 million in 2002 to 1.8 million in 2016, largely due to reductions in heterosexual transmission (Maartens et al., 2014; UNAIDS, 2016). In 2016, globally, there were 2.1 million children aged below 15 years living with HIV, with Sub-Saharan Africa accounting for 1.5 million (UNAIDS, 2016). In the same year there was a 47 per cent decline in new infections among children under the age of 15 compared to 2010 (UNAIDS, 2016). Nevertheless, despite the decline in new infections in 2016, there were 160,000 children newly infected with the virus (UNAIDS, 2016; WHO, 2013). The majority of the new infections among children under the age of 15 are from Eastern, Southern, and West Africa, followed by South Asia and the Pacific (UNAIDS, 2016; UNICEF, 2013).

In Malawi, the first case of HIV was diagnosed in 1985. Since then the prevalence of HIV increased to a peak of 16.4 per cent among people aged 15 to 49 in 1999. Thereafter, the prevalence has declined to 12 per cent in 2004 and 10.6 per cent in 2010. By the end of 2015, UNAIDS estimated that there were one million Malawians living with HIV, which is 6.7 per cent of the total population (United Nations programme for HIV/AIDS Malawi, 2016). The findings of the first national representative survey to measure the prevalence of HIV among children in Malawi has shown that 1.6 per cent of children under the age of 15 years (84,000) were living with the virus in 2016 (Government of Malawi, 2016). This estimate is likely to be an underestimate due to the low survey response rate of 62 per cent (Government of Malawi, 2016). Great progress has been made in reducing new infections among children, as evidenced by a 50 per cent reduction in new HIV infections within the period of 2009 to 2012 (UNICEF, 2013). UNAIDS further estimated that new HIV infections in children aged 0-14 years declined by 88 per cent between 2009 and 2015 (UNICEF, 2011).

2.3.3 History of HIV in sub-Saharan Africa

The history of HIV in sub-Saharan African can be traced back to the early 1900s through evidence from genetic molecular studies (Kagaayi & Serwadda, 2016). However, it was not until the early 1980’s the first clinical cases were reported. Although the first case of

HIV was first reported in the United States in 1981 among the African community (Makroo, 2010), it was not until 1983 that an alarm was raised in Africa about the epidemic (Kagaayi & Serwadda, 2016). This was after several cases of HIV were reported among African immigrants to European countries (Kagaayi & Serwadda, 2016). Between 1984 and 1987, many cases of HIV were reported in Sub-Saharan African countries, with a high prevalence among truck drivers (Carswell, Lloyd, & Howells, 1989). Unfortunately, the Governments of many African countries were in state of denial and they did little to respond to the epidemic (Carswell & Lloyd, 1987). Political instability and the lack of resources for HIV testing were two of the key factors that escalated the transmission of HIV in many Sub-Saharan African countries (Premkumar & Tebandeke, 2011).

In the early 1990s HIV had a severe impact on many African countries (Rigby, 1995). HIV related mortality and morbidity increased significantly (Lange, 1993; Zwi & Bachmayer, 1990). More than 50 per cent of all adult deaths were associated with HIV (Borgdorff et al., 1995; Gregson, Garnett, & Anderson, 1994; Lange, 1993; Zwi & Bachmayer, 1990). Hospitals and healthcare systems were severely burdened (Tembo et al., 1994). Many healthcare workers were infected which reduced the human capital available to control the epidemic (Lange, 1993). More than half of the beds in medical wards were occupied by patients with HIV related diseases (Lange, 1993; Tembo et al., 1994). The death of parents dramatically increased the number of orphans in many countries (Kamali et al., 1996; Makumbi et al., 2005). Parental death also increased the number of households headed by children (Collins et al., 2016). The number of children acquiring HIV from their mother increased tremendously with rates between 19 and 26 per cent by 6 to 12 weeks of breastfeeding (Coutsoudis et al., 1999; Guay et al., 1999). The survival rate of infants born to women living with HIV was very low with more than 50 per cent of children dying before their second birthday (Bobat, Coovadia, Moodley, & Coutsoudis, 1999; Newell et al., 2004b). It was not until 1996 that hope for those living with HIV was found when research showed that triple ART was effective in reducing the number of viruses present in the body (Kagaayi & Serwadda, 2016). Nonetheless, the price of the new ARV medication was very high and very few people could afford it (Kagaayi & Serwadda, 2016). The annual estimated cost of medication for one person was between US$25,000 and US$31,000 (Kagaayi & Serwadda, 2016). Most African Governments could not afford to buy ARV medication (Kagaayi & Serwadda, 2016).

In 2000, many activists and “the civil society” globally advocated for free ARV, by the year 2002. The United States President’s Emergency Plan for AIDS relief (PEPFAR) and the Global Fund started a program of providing free ARVs in Sub-Saharan countries (Kagaayi & Serwadda, 2016). The number of Sub-Saharan African people who were able to access ARV medication increased from 100,000 in 2000 to approximately 11 million in 2014, accounting for 41 per cent of all people living with HIV in the region (UNAIDS, 2015a). The availability of free ARVs has resulted in a remarkable reduction in mortality and morbidity among people living with the virus (April et al., 2013; Bor, Herbst, Newell, & Bärnighausen, 2013). ARVs have also helped to prevent the transmission of HIV from mother to child by 48 per cent and among heterosexual adults by 90 per cent (Bor et al., 2013; Fasawe et al., 2013; VanDeusen, Paintsil, Agyarko-Poku, & Long, 2015).

Having outlined the history and social context of HIV in Malawi and briefly described the aetiology and prevalence of HIV/AIDS the history of its spread, the following section will introduce developmental systems theory and explain how the developmental trajectories of children living with HIV are impacted when they interact with the physical and social environment over time.

2.4 THE POTENTIAL IMPACT OF HIV ON THE DEVELOPMENT OF CHILDREN LIVING WITH HIV IN MALAWI

2.4.1 Bioecological model of human development

The bioecological model of human development was popularised by Uri Bronfenbrenner, a psychologist whose model was inspired by the work of other psychologists, such as Lev Vygotsky and Kurt Lewin (Bronfenbrenner, 1977; Bronfenbrenner & Ceci, 1994; Thompson, Hogan, & Clark, 2011). Bronfenbrenner proposed that human development takes place through a dynamic reciprocal interaction between the biological material of an individual and the persons, objects, and symbols in his or her environment (Bronfenbrenner & Ceci, 1994). In this model, the environment is described as a system of nested layers of influence, each inside the other and all acting at the same time on the individual (Bronfenbrenner, 2009; Bronfenbrenner & Ceci, 1994; Bronfenbrenner & Morris, 2006). Bronfenbrenner describes the nested layers as microsystem, mesosystem, exosystem, microsystem and the chronosystem(Bronfenbrenner, 2009; Bronfenbrenner & Ceci, 1994).

The microsystem is described as the pattern of interactions or processes taking place between the developing person and his or her immediate environment such as family, school, peer group and work environment (Bronfenbrenner, 2009; Bronfenbrenner & Ceci, 1994). These processes may include patterns of activities, roles, and relationship (Bronfenbrenner & Ceci, 1994). Any disruptive rather than supportive behaviour in the environment can disrupt the developmental process of the developing individual (Bronfenbrenner, 2009; Bronfenbrenner & Morris, 2006). The mesosystem involves interaction processes that take place in two or more immediate environments of the developing person (Bronfenbrenner, 2009; Bronfenbrenner & Ceci, 1994;

Bronfenbrenner & Morris, 2006). For example, the interactions that take place between home and school or home and the working environment (Bronfenbrenner, 2009). The exosystem refers to the relationships and interactions that take place in two or more environment of which one of them does not contain the developing person but does influence his or her immediate environment (Bronfenbrenner, 2009; Bronfenbrenner & Ceci, 1994). A good example is the parent's workplace, where if the parent is made redundant, the resulting economic challenges can affect his or her child at home. The macrosystem involves interaction between the proximal environments of the microsystem, mesosystem and exosystem and the broader social, cultural, economic and political environment (Bronfenbrenner & Ceci, 1994; Bronfenbrenner & Morris, 2006; Kendall, van Eekelen, Mattes, & Li, 2009).

The final system, the chronosystem, describes the changes or consistency in the environment and characteristics of people over time. For example, transitions occurring in one's lifespan such as entering school, marriage, divorce, death, chronic illness can have an influence on the individual's health and developmental outcomes (Hosek, Harper, Lemos, & Martinez, 2008). The success of each setting regarding the provision of a favourable environment for development depends on the interconnectedness between the settings (Bronfenbrenner, 2009). For example, readiness for child entry into school is dependent on the information or communications provided to the child about the school environment at home.

Furthermore, the bioecological model posits that the developmental outcomes of an individual are a result of the interaction between the environmental experience and the biological processes of the individual that begin early in life during conception (Bronfenbrenner & Ceci, 1994). Optimal functioning results from the two-way interaction between the biopsychological human being and the environment over a period of time (Bronfenbrenner & Ceci, 1994; Bronfenbrenner & Morris, 2006). These interactions can be in the form of a child to parent, child to child, playing, reading, learning new skills, problem-solving, and conducting complex activities. These interactions enable the translation of the person's biological potential to effective psychosocial functioning and healthy development (Bronfenbrenner & Morris, 2006). The likelihood of positive developmental outcomes is higher for individuals who are in an environment where there is strong interaction compared to those who are in an environment where interaction is weaker (Bronfenbrenner & Ceci, 1994; Bronfenbrenner & Morris, 2006). In addition, exposure to a disadvantaged environment is more likely to lead to an exhibition of poorer developmental outcomes such as externalised and internalised problems (Bronfenbrenner, 2009). Conversely, exposure to a stable and advantaged environment is more likely to result in positive developmental outcomes, such as good academic achievement, emotional well-being and social skills (Bronfenbrenner & Ceci, 1994) (Bronfenbrenner, 2009; Bronfenbrenner & Morris, 2006).

The bioecological model, or developmental systems theory as it has become known, is regarded by most scholars of human development to be the most appropriate metatheory with which to understand processes at the macro level (Belsky & Pluess, 2013). The family and community resource framework which is outlined next is widely used internationally for describing in more detail than the bioecological model, processes within the family and community that impact children's health and developmental outcomes (Kendall & Li, 2005).

2.4.2 The family and community resource framework

The main concepts of the family and community resource framework are rooted in the bioecological model of human development (Brooks-Gunn, 1995). The model was proposed by Brooks-Gunn and her colleagues in 1995 to describe how the availability and distribution of resources in the family and community impact on child development (Brooks-Gunn, 1995). The framework identifies time, income, human, and psychological resources as important resources in the family (Brooks-Gunn, 1995). It focuses on decisions made in families regarding the allocation of these resources, constraints in resources allocation and the impact of parental resources on child development (Brooks-Gunn, 1995; Kendall, 2003). The settings of the environment in this framework include childcare institutions, schools, and peer and community groups. Brooks-Gunn identifies information, norms and sanctions, opportunity, stability, and relationships, and social networks, as valuable resources in the community (Brooks-Gunn, 1995).

A simplification of the resource framework categorises family and community resources into four groups, namely: human capital, social capital, financial capital and physical capital. Children accrue human capital from the time of conception in the form of knowledge and skills as well as the inheritance of their parents biological characteristics (Coleman, 1988; Kendall, 2003). Accumulated human capital is evaluated in terms of years of study or education, informal skills and experience, motivation and physical appearance, and other characteristics (Coleman, 1988; Kendall, 2003). According to the resource framework, children who are born into families whose parents are rich in human capital in terms of their level of education, health, and parenting skills, have many advantages over those who are not. This is manifested in the differences seen in developmental outcomes, such as mental health, literacy and numeracy, and school achievement, between children from families with abundant human capital resources and those from families with few human capital resources (Brooks-Gunn, 1995; Kendall, 2003).

Social capital is a resource that resides in both families and communities. Like the human capital of parents, social capital is used in the creation of the human capital of children (Brooks-Gunn, 1995; Kendall, 2003). Human capital is necessary for the formation of social capital which emanates from connections between individuals, and groups of people, through trusting, sharing, reciprocal relationships (Kendall, 2003). Social capital is formed in families when parents and other caregivers work co-operatively to care for and nature their children (Coleman, 1988). Social capital is formed in communities when individuals and groups of people work together and look after one another. This can involve providing goods and services free of charge on a reciprocal basis (Coleman, 1988). Sharing the care of children is a very good example (Kendall, 2003, p. 4). When families are constantly relocating or experiencing disruptions, there is little opportunity to create social capital and this can impact negatively on children's health and development (Zubrick & Zubrick, 2000).

While financial capital is described in terms of family's income and wealth, physical capital is described as the translation of the financial capital and human capital into physical resources to be used on behalf of the child (Brooks-Gunn, 1995; Coleman, 1988; Kendall, 2003). Physical capital is evaluated by the quality of physical assets that can promote healthy developmental outcomes in children, goods such as books and other educational materials (Kendall, 2003). Overall, the family and community resource framework takes into consideration decision making in way resources are allocated (Brooks-Gunn, 1995). Children's developmental outcomes are determined by the choices made by society, families, and children, themselves, in the allocation and utilisation of resources (Kendall, 2003, p. 9).

In his description of the bioecological model, Bronfenbrenner and Ceci (1994) wrote about genes as the sole biological process whereby the individual interacts with the environment. Bronfenbrenner's conception of biological development has been extended more recently to include psycho-neuro-endocrine-immune pathways and brain plasticity in addition to gene expression and epigenetics (Nelson, Kendall, & Shields, 2014). Nutrition and toxic environmental exposures are two more processes of what has become known as biological embedding (Nelson et al., 2014). This concept that was first described by Clyde Hertzman, an epidemiologist who wrote about early child development (Hertzman, 1999). A very brief description of the concept of biological embedding follows because it will help readers to understand the impact of living with HIV has on children's health and development in Malawi.

2.4.3 Biological embedding

Because human beings are in constant interaction with the environments that they experience, as Bronfenbrenner explained, biological processes of development are very much influenced by physical and psychosocial factors in those environments (Bronfenbrenner & Ceci, 1994). There is now a great deal of evidence that during pre-conception, conception, embryonic development, foetal development, birth and the earliest years of life there are critical and sensitive periods when these environmental factors play a significant role in determining health and developmental outcomes across the life course of the individual (Danese, 2013; Hertzman, 1999; Nelson, 2013; Nelson et al., 2014; Shonkoff et al., 2009). Children living with HIV in Malawi are especially vulnerable to poor outcomes because of the many adversities they experience.

2.4.4 Gene expression and epigenetics

There is a growing body of knowledge in human development regarding epigenetics and gene expression (Egger, Liang, Aparicio, & Jones, 2004; Kanherkar, Bhatia-Dey, & Csoka, 2014; Zoghbi & Beaudet, 2016). Epigenetics in its simplest description, is the change in gene expression that does not involve any changes to the underlying DNA sequence (alteration of the phenotype type without changes in the genotype). Specifically epigenetics involves three processes namely; histone modification, DNA methylation expression, and RNA-associated silencing (Egger et al., 2004; Zoghbi & Beaudet, 2016). Epigenetics mechanisms control the normal function of the cells and organs by regulating gene expression and noncoding RNA expression (Simmons, 2008). Moreover, epigenetic processes control how certain genes are turn on and off to regulate normal growth and development of the body (Simmons, 2008). While epigenetics occurrence is a natural process, any disturbance to the three processes of epigenetics, may lead to lifelong developmental, metabolic and health problems including cancer, mental retardation, learning disabilities and other chromosomal alteration related conditions (Egger et al., 2004; Zoghbi & Beaudet, 2016). Research has shown that exposure to substances, stress, disease and individual factors such as age may play a role in disturbance of the three process of epigenetics conditions (Egger et al., 2004; Kanherkar et al., 2014). Children living with HIV in Malawi are at risk of developing epigenetics related disorders because of the influence of their infection as well as adverse environmental factors.

2.4.5 Psycho-neuro-endocrine-immune pathways

Although children experience both physical and psychosocial stressors in their everyday life, the body has its mechanism known as allostasis that helps to buffer the effects of such stressors (Danese & McEwen, 2012; Hertzman, 2012; Nelson et al., 2014). This process protects children from negative experiences that can be harmful (McEwen, 1998). This adaptive physiological process is made up of the nervous, immune and endocrine systems (Danese & McEwen, 2012). These systems are integrated into their work towards allostasis such that an activation of one system results in the activation of the other systems (Danese & McEwen, 2012). While this mechanism is protective in nature, it can be potentially harmful if the person is exposed to chronic or repeated physical or psychosocial stressors (Shonkoff et al., 2009; Shonkoff et al., 2012). Chronic exposure to physical and psychosocial stressors results in a condition known as an allostatic load which has negative physiological effects (Danese & McEwen, 2012; Hertzman, 2012; Nelson et al., 2014). Allostatic load can also happen if a child is exposed to a number of major stressors over a relatively shorter period of time. For example, a child who is seriously ill and loses a parent is likely to experience allostatic load (McEwen, 1998). There is also evidence that social determinants of health also affect how a person adapts to a stressful event by reducing the availability of resources (Danese & McEwen, 2012; McEwen, 1998). For example, people with lower levels of income, education and social class are susceptible to allostatic load.

2.4.6 Brain plasticity

Biological embedding is also believed to take place when the developing brain is exposed to positive or negative stimuli during sensitive periods of development (Nelson et al., 2014; Shonkoff et al., 2009). At birth, the nerve cells in the cortex of the human brain are largely in place, however there is an extensive overproduction and pruning of synapses that takes place (Andersen, 2003). Put very simply, children's brains are "wired-up" as a direct result of the interactions they experience with their primary caregivers. During sensitive periods, the brain is most vulnerable to harmful physical and psychosocial stimuli, such as toxic substances that are ingested and the experience of stress. For example, there is evidence that there is a sensitive period for depression later in life and this is likely to occur when children aged three to five years are exposed to sexual abuse (Andersen & Teicher, 2008).

2.4.7 Nutrition

Maternal nutrition during pregnancy is very important as it has an impact on the physiological and metabolic changes of the foetus throughout the lifespan (Morrison & Regnault, 2016). Poor nutrition during preconception and pregnancy may negatively affect the growth of the foetus which may lead to intrauterine foetal growth restriction (Morrison & Regnault, 2016; Zhang et al., 2015). When malnutrition occurs during late stages of pregnancy, the foetus activates an adaptive process that divert oxygenated blood from other organs to the brain and this results in asymmetrical growth (Indrio et al., 2017). In addition, this process affects the growth of the liver leading to dysregulation of cholesterol, blood clotting and blood glucose that lead to type 2 diabetes mellitus and cardiovascular diseases later in life (Musumeci et al., 2015). Furthermore, maternal malnutrition leads to neural tube defects (Musumeci et al., 2015; Prado & Dewey, 2014). Malnutrition in early childhood may lead to poor physical and cognitive development and low body immunity (Indrio et al., 2017; Prado & Dewey, 2014). A significant proportion of women and children in Malawi are undernourished and this is likely to have devastating effect to a child living with HIV born to an undernourished mother.

2.4.8 Toxic environmental exposure

Maternal exposure to toxic substances during pregnancy has detrimental lifelong negative impact on the child's health and development (Kendall et al., 2009; Mattison, 2010). For example, maternal exposure to alcohol, smoking pollutants, pesticides, heavy metal during pregnancy affect foetal development (World Health Organization, 2011). Alcohol intake during pregnancy can cross the placenta to the foetus leading to neurological, brain functioning impairment, behavioural problems later in life known as foetal alcohol syndrome (Murray et al., 2016; Nomura, Gilman, & Buka, 2011). Similarly, smoking during pregnancy may lead to impaired foetal growth, low birth weight, emotional and child's behavioural development and behaviour (Knopik, 2009; Muraro, Gonçalves-Silva, Ferreira, Silva, & Sichieri, 2015; Wehby, Prater, McCarthy, Castilla, & Murray, 2011). Children are susceptible to toxic substances during early life which may affect their emotional, social and attentional development (Abbasi, 2016). A good example of toxic exposure in Malawi, is the transmission of HIV from mother to the child during birth or breastfeeding (Flax et al., 2017). While there is increased coverage of prevention of mother to child transmission of HIV and ART provision programmes to women living with HIV in Malawi (Kim et al., 2015a), close to 20% of the women are lost to follow up during breastfeeding period (Tweya et al., 2014). Approximately half of the women who are lost to follow up, stop taking ART, consequently increasing the risk of transmitting the virus to the child (Tenthani et al., 2014). According to UNAIDS, the MTCT rate in Malawi in 2014 was 17% (UNAIDS, 2015b). In addition, the majority of people in Malawi uses firewood as a source of energy for cooking and this is likely to affect pregnant women and the foetus through passive smoking. In addition, children may also be exposed to passive smoking when food is being cooked.

Having outlined developmental systems theory and associated concepts relevant to child development, the next section will demonstrate their application to an understanding of the development of children living with HIV in Malawi.

2.4.9 Application of bioecological theory to children living with HIV in Malawi

The health and developmental outcomes of children living with HIV in Malawi are influenced by many factors which are nested within: individuals, families, communities, cultures, healthcare systems, and political systems. These will be discussed in the following paragraphs.

2.4.9.1 Individual factors

The experience of HIV is a major stressor for many children living in Malawi (Kim et al., 2015b). Feeling unwell, the burden of taking medications every day, dealing with side effects of medication, the death of parents and other loved-ones, facing stigma and discrimination, poverty, and hunger are some of the stressful factors faced by children living with HIV in Malawi (Kim et al., 2015b). In addition, children who are aware of their HIV status are likely to worry about the outcome of the disease (Schenk et al., 2010). Children tend to be worried about how they got the disease, the longevity of their life, the reaction of their peers and other people to their HIV status and the need to take medication for the rest of their lives (Schenk et al., 2010; Vranda & Mothi, 2013). In addition, there is evidence that HIV affects the neurocognitive development of children (Ravindran, Rani, & Priya, 2014; Sherr et al., 2014). The stressful live events experienced by children living with HIV compound the already existing problem of delayed or compromised neurocognitive development. Moreover, exposure to such stressors activates the allostasis systems which result in lowering the body's immune system. This might reduce the effect of ART thereby predisposing the children to infections. In addition, the chronic stressors experienced by children living with HIV can activate the allostasis load which may affect the memory, emotional and attentional regulation in the brain that can lead to learning and behaviour problems later in life.

2.4.9.2 Family factors

A greater proportion of children living with HIV have lost one or both parents and they live either with a single parent, or with their relations (Short & Goldberg, 2015). Losing parents has a great psychosocial and economic impact on the child. By losing a parent the children, loose a variable human and social capital resource that has a great role to play in the promotion of children's health and wellbeing (Short & Goldberg, 2015) . Moreover, a great proportion of primary caregivers of children living with HIV in Malawi are unemployed, and they depend on subsistence farming as such they have low incomes to support their children (Short & Goldberg, 2015). According to the World Bank Half of the population in Malawi are poor and a quarter of the population live in extreme poverty (World Bank, 2016). Unemployment and low income in families are associated with lack of drug adherence (Yakob & Ncama, 2016). Many children in Malawi who have lost both parents stay with their grandparents who are also likely to be unemployed, poor, and often too weak to take care of them (Jonasi, 2007; Sefasi, 2010). These children are more likely to drop out of school and have poor medication adherence due to lack of supervision, and they are at greater risk of developing emotional and behavioural problems (Guo, Li, & Sherr, 2012).

In addition, the mothers of children living with HIV in Malawi are also likely to have HIV, considering that a large proportion of children with HIV got the virus from their mother (Luzuriaga & Mofenson, 2016). Women living with HIV are likely to experience significant stress and anxiety because of the poor outcomes associated with HIV (Grant, 2008; Kuo, Cluver, Casale, & Lane, 2014; Murphy, Marelich, Armistead, Herbeck, & Payne, 2010); Ji, Li, Ding, Xiao, and Tian (2012). Maternal stress related to HIV is associated with poor mother-child communication and poor parenting discipline which result in the child having poor emotional and behavioural outcomes (Murphy et al., 2010). Moreover, many pregnant women living with HIV struggle to have adequate nutrition and are therefore malnourished (Ramlal et al., 2015). For example, the recent national representative survey conducted in Malawi has shown that 45 per cent of pregnant women are anaemic (Malawi National Statistical Office & ICF International, 2017). This is compounded by exposure to HIV infection which reduces the women's body immunity thereby exposing them to other diseases (Ramlal et al., 2015). These factors may have created stressful environment for the child while in utero and become biologically embedded with a potential negative impact on the growth and development of the child throughout the life span (McEwen, 1998; McEwen & Gianaros, 2011).

2.4.9.3 Community factors

Practices of stigma and discrimination against people living with HIV remain very common in Malawi (Kamen et al., 2015; Pindani et al., 2014). The authors of a recent study found that children living with HIV who were stigmatised for taking HIV medication were more likely to develop depression than those who were not (Kim et al., 2015b). In addition, children who are stigmatized are less likely to adhere to medications or to remain in treatment (Yakob & Ncama, 2016). The experience of stigma and discrimination, therefore, has repercussions for these children's health and developmental outcomes (Kamen et al., 2015).

The extended type of family is embedded in Malawian culture and it provides the needed social capital to support the growth and development of children (Mathambo & Gibbs, 2009). Members of the extended family and community share resources in caring for children (Heymann & Kidman, 2009). Members of the extended family and parents take turns to care for the children without an attached cost (Cox, Tice, & Long, 2015). More than three quarters of families with children in Malawi receive financial support from their social network averaging US 81$ a year (Heymann & Kidman, 2009). Moreover, communities are divided into villages, which are headed by chiefs who organise social support for children orphaned by HIV (Beard, 2005; Bryceson & Fonseca, 2006). The villages have support groups that provide care to orphans and children living with HIV (Beard, 2005). Heymann and Kidman (2009) estimates that 40 per cent of orphans in

Malawi live in communities with support groups for chronically ill children and adults (Kidman & Heymann, 2009). While the Malawian culture promotes the availability of social capital, stigma and discrimination make it harder for children and their families to seek or receive such support (Anglewicz & Chintsanya, 2011; Nyando, 2014; Pindani et al., 2014).

2.4.9.4 Cultural factors

As described previously, several cultural practices, influence the developmental trajectories of children living with HIV in Malawi. The impact of three of the most troublesome practices are described here very briefly. First, Malawi has one of the highest child marriage rates in the world with 50 per cent of girls marrying before the age of 18 years (Mkali, 2016; UNFPA, 2012). The Government has set the marriage age at 18 years, but the policy is not enforced (Vibeke Wang, 2016). There is evidence that women who are married at a young age are likely to drop out of school, to be unemployed, to be at high risk of complications during pregnancy and birth, and to be at greater risk of contracting HIV (Naveed & Butt, 2015; Nour, 2006). Second, the matrilineal marriage system practiced in some parts of the country, especially in the central and southern regions, makes the father of the child powerless, because traditionally in such cultures children are the responsibility of the maternal uncle (White, 2007). The biological fathers of children living with HIV are less likely to be able to organise for their children to attend school and since the maternal uncle does not live with the child, he is unlikely to support the child (White, 2007).

Third, there has been an increase in the practice of some church ministers praying for people living with HIV and telling them that they are healed (McKinney, Modeste, Lee, Gleason, & Maynard-Tucker, 2014). Worse still, people are advised to stop taking their HIV medication without consulting the relevant health professionals (Kim et al., 2015b). This has resulted in treatment default and a lack of medication adherence by some children and their families (McKinney et al., 2014). Furthermore, some primary caregivers visit a herbalist for treatments because they believe that the herbal medicine is stronger than the western medicine. When this happens, ARV medication adherence is negatively affected (McKinney et al., 2014).

2.4.9.5 Healthcare system factors (institutional factors)

Malawi has critical shortage of staff in ART clinics and healthcare professionals have limited time to assist with disclosure of HIV to children or to support primary caregivers in providing appropriate care for their children (Ron Levey & Jasmine Baleva, 2010). Whereas the World Health Organisation recommends one to two doctors and seven nurses to provide ART to 1000 people in low-resource settings, Malawi had three healthcare workers per 1000 patients on ART in 2010 (Aidspan, 2013; World Health Organisation, 2007). In addition, to the lack of staff, a lack of clear cut guidelines and resources for HIV disclosure also affects the health and development of children living with HIV (Mandalazi et al., 2014; Ministry of Health Malawi, 2008). The extensive literature regarding HIV disclosure to children will be reviewed in detail in a following section.

On the positive side, the Government of Malawi, with support from donors, has been successful in providing free ARV medications to almost all children and adults living with HIV. The Government has made ART accessible to children in remote areas by providing ART in health centres in the community (Ministry of Health Malawi, 2008). This has helped to reduce the transport costs that some primary caregivers used to incur when taking their child to a secondary or tertiary hospital. Overall, this has led to a considerable increase in the lifespan of many children (Makwiza et al., 2009; Muula, 2006; Ntata, 2007). However, while substantial resources have been channelled to the provision of ART, very few resources, if any, have been allocated to providing psychological and social support for children and their families (Kim et al., 2015b). There are few programs to support children to know their HIV status and to help them live positively with the disease (Kim et al., 2015b).

2.4.9.6 Political factors

As mentioned previously, Malawi has a reasonably stable democratic Government and it is a peaceful country. However, it has one of the highest rates of Government corruption in the world (De Gobbi & Anang, 2013). Because of corrupt Government practices, in recent years donors have withdrawn their level of financial support (World Bank, 2015). The high inflation rate of almost 24 per cent in 2014 is indicative of the very poor performance of the economy (World Bank, 2015). Therefore, these corrupt practices have worsened the poverty levels of people in the country, including those living with HIV (Dionne & Dulani, 2013; World Bank, 2016). Furthermore, Malawi has recently experienced a drought which has resulted in food insufficiency and increases in food prices (World Bank, 2016). Higher prices for food have resulted in many parents being unable to afford to purchase adequate and appropriate food for their children who are living with HIV. The lack of adequate food due to drought and increases in food prices has resulted in increased rates of malnutrition among children living with HIV. Given the double impact of malnutrition and stress on the immune system, children living with HIV are at increased risk of poor health and developmental outcomes. Moreover, food insecurity has been identified as one of the barriers to ARV adherence among people living with HIV in studies conducted in Malawi and Ethiopia (Hadgu, Worku, Tetemke, & Berhe, 2013; McKinney et al., 2014).

Although the Government has a policy of providing free ARV medication to people living with HIV, almost three-quarters of the funding for the program comes from donors (Dionne & Dulani, 2013). The sustainability of the program is unknown because if the donors decide to withdraw funding, the Government has no capacity in its budget to be able to buy them (Dionne & Dulani, 2013; Donnelly, 2011). An example of the precarious financial situation of the Government can be seen in a previously successful program of providing children living with HIV with free peanut butter to supplement their nutrition. Due to “donor fatigue” and a lack of funding from the Government, this program has ceased (Manary, Ndkeha, Ashorn, Maleta, & Briend, 2004; Ndekha, Manary, Ashorn, & Briend, 2005; UNICEF, 2016).

2.5 DISCLOSURE OF SERIOUS ILLNESS TO CHILDREN

2.5.1 Introduction

This section reviews literature regarding the disclosure of serious illness to children because it is closely associated with HIV disclosure (Instone, 2000; Lee & Johann-Liang, 1999; Lipson, 1993, 1994; Mellins et al., 2002; Meyers & Weitzman, 1991). It is anticipated that this review will begin the process of understanding of how best HIV status disclosure can be effectively conducted. The section will focus on the extensive literature surrounding the disclosure of a cancer diagnosis to children, including: the importance of disclosure, patterns of disclosure, factors associated with disclosure, and the lived experiences of disclosure among children.

2.5.2 Overview of paediatric cancer diagnosis disclosure to children

There is extensive literature on how the diagnosis of cancer is disclosed to a child (Chesler, Paris, & Barbarin, 1986; Parsons et al., 2007). The accurate diagnosis of cancer has not been possible until recently, perhaps the last four to five decades (Sisk, Bluebond-Langner, Wiener, Mack, & Wolfe, 2016). Even with the advent of accurate diagnosis, the prognosis for individuals is far from an exact science (Sisk et al., 2016). Prior to the 1970s there was little academic literature that discussed the disclosure of cancer diagnosis to adults or children (Sisk et al., 2016). The book “Death and Dying” written by Elizabeth Kubler Ross, published in 1969, brought the issue of the lack of support children who were dying of cancer were given by their parents and health professionals to the public’s attention for the first time (Kubler-Ross, 1969). Kubler Ross described in detail a number of scenarios in which children who were hospitalised with cancer were painting pictures that forecast their own death. Despite their reaching out for help in this way, most were not able to communicate their fear to their parents and healthcare staff because these people simply could not bear to talk about it (Kubler-Ross, 1969). Prior to the 1970s, children with cancer were given little information about their condition (Chesler et al., 1986; Meiring, 2011; Sisk et al., 2016). Parents thought that it was better not tell children of their condition in order to protect them from the negative psychological impact of knowing their diagnosis (Eiser, 1979; Meiring, 2011; Sisk et al., 2016). With the reluctance of primary caregivers and healthcare professionals to tell children about their diagnosis, studies conducted during the time revealed that non-disclosure of cancer diagnosis to children was associated with emotional distress and anxiety (Eiser, 1979; Kidia et al., 2014; Spinetta & Maloney, 1975).

With time the treatment of cancer improved, and this led to increased survival rates. This, along with advocacy for children's rights, led to a higher proportion of children being informed of their cancer diagnosis (Bibace & Walsh, 1980; Wiener et al., 2007). In the 1980s and 1990s researchers and healthcare workers recognised the need for disclosure of cancer to children (Bibace & Walsh, 1980). Researchers started looking for ways to effectively disclose; including the appropriate person and time to disclose the illness to the child. Although many healthcare workers supported telling children their diagnosis and outcome, they raised some issues to consider before beginning the process of disclosure (Bluebond-Langner, Perkel, Goertzel, Nelson, & McGeary, 1990; Claflin & Barbarin, 1991; Gupta, Willert, Pian, & Stein, 2008b). These included: the age of the child, the level of the child's cognitive and emotional development, and the availability of disclosure resources. These issues will be discussed in some detail following an outline of the importance of disclosure to children and the current pattern of disclosure.

2.5.3 Importance of disclosure of diagnosis in paediatric cancer

There is evidence that most children living with terminal cancer do want to know about their disease and prognosis (Wolfe, Friebert, & Hilden, 2002). Moreover, the literature supports that telling children about their illness may help to build trust with primary caregivers and healthcare workers and that such children are more likely to comply with the treatment regimen (Clarke, Davies, Jenney, Glaser, & Eiser, 2005; Kunin, 1997). In addition, there is evidence that early disclosure of diagnosis as opposed to delayed disclosure promotes the long-term social and emotional wellbeing of children (Kunin, 1997). A longitudinal study conducted in the Netherlands among caregivers of children aged 0-18 years living with cancer demonstrated that the disclosure of diagnosis decreased caregiving stress, depressive symptoms, and anxiety among primary caregivers within one year following disclosure (Sulkers et al., 2015). Furthermore, early studies in cancer have shown that disclosure of the illness to a child helps to improve his or her self-esteem, emotional well-being, and their relationship with the primary caregiver (Chesler et al., 1986; Claflin & Barbarin, 1991; Van Dongen-Melman & Sanders-Woudstra, 1986). Also, literature has shown that disclosure of illness to the child facilitates communication among children, parents and healthcare workers and protects children from potential worries of accidental disclosure (Watanabe, Nunes, & de Abreu, 2014).

2.5.4 Patterns of disclosure of diagnosis

Different patterns of disclosure of illness to children with cancer have been reported in the literature. The first type of disclosure consists of the provision of minimal information about the illness to the child. In this type of disclosure, parents tell children that they have a blood disease without giving further details of the disease (Clarke et al., 2005). In a second type, some parents provide ambiguous information to the child by telling the child the type of cancer that he or she has while concealing the word cancer (Kessel et al., 2013; Mack et al., 2006). In the third type of disclosure, parents inform their child that he or she has cancer but do not talk about the seriousness of the disease and the possibility of death (Clarke et al., 2005). In this pattern of disclosure, the child is given full information about the disease and their prognosis (Clarke et al., 2005). While some sort of disclosure is now very common, a small minority group of parents, or primary caregivers, totally avoid disclosing the diagnosis to their child (Arabiat, Alqaissi, & Hamdan-Mansour, 2011).

Although some parents avoid telling children about the prognosis of their illness for fear of psychologically burdening the child, research has revealed that some parents regret taking this decision. A retrospective cohort study of 368 Swedish children with malignant cancer, who were told about their diagnosis before the age of 17, showed that many parents who failed to discuss death with a child with terminal cancer regretted having made such a decision while none of those who discussed death with their child regretted doing so (Kreicbergs, Valdimarsdóttir, Onelöv, Henter, and Steineck, 2004). With regard to who should disclose to the child, the following people have been identified as best placed to disclose the diagnosis to the child: parents, psychologists, social workers, nurses, physician assistants, oncologists and palliative care specialists (Arabiat, Alqaissi, & Hamdan-Mansour, 2011; Beale, Baile, & Aaron, 2005; Stenmarker, Hallberg, Palmérus, & Márky, 2010; Yin & Twinn, 2004).

2.5.5 Barriers and facilitators associated with disclosure of paediatric cancer diagnosis

A number of factors have been identified as barriers to telling children with cancer about their condition and prognosis. These include the perceived psychological impact of disclosure (Badarau et al., 2015; Beale, Baile, & Aaron, 2005; Kim & Yi, 2014; Nóia et al., 2015), age of the child(Last & Van Veldhuizen, 1996) (Claflin & Barbarin, 1991; Clarke et al., 2005), lack of knowledge about the disclosure process (Badarau et al., 2015; Kessel, Roth, Moody, & Levy, 2013; Mack, Wolfe, Grier, Cleary, & Weeks, 2006;

Turner et al., 2007), lack of shared responsibility (Wiener et al., 2007) (Badarau et al., 2015; Noble, Price, & Porter, 2015) and culture (Liben, Papadatou, & Wolfe, 2008; Parsons et al., 2007; Trill & Kovalcik, 1997).

Research has shown that the primary caregivers of children with cancer struggle to cope with the diagnosis of their children (Nóia et al., 2015). The frequent hospitalization and invasive procedures that the child undergoes predispose them to psychological problems, such as anxiety and depression which make disclosure more difficult (Nóia et al., 2015). Authors of a cross-sectional study conducted in South Korea among the parents of childhood cancer survivors reported that disclosure of the diagnosis helped to reduce psychological distress while perceived public stigma resulted in psychological distress by increasing internalised shame (Kim & Yi, 2014). In another study, fear of the child's negative emotional reaction to disclosure was identified as a barrier to telling children about their illness (Badarau et al., 2015).

The age of the child often determines whether the child is told about the disease, or not, as well as the level of information to be given to the child (Last & Van Veldhuizen, 1996) (Parsons et al., 2007). Younger children are likely not to be told of their illness or to be given little information about their illness compared to older children (Last & Van Veldhuizen, 1996) (Parsons et al., 2007). A cross sectional study conducted by Claflin and Barbarin (1991) among 43 children diagnosed with cancer in the US revealed that children younger than nine years were less likely to be given information about their disease compared to children who were nine years or older. In addition, studies conducted in the United Kingdom (UK) and US have revealed that younger children were being given minimal information compared to older children (Clarke et al., 2005; Parsons et al., 2007). In another study, the term cancer was concealed from one-third of the children aged 8-12 years compared to one-fifth of those aged 13 to 16 years (Last & Van Veldhuizen, 1996). Although parents are less likely to disclose to younger children, there is evidence that children can understand cause and effect relationships by the time they are between six and eight years of age (Gary, 1992).

Knowledge about the disclosure process is an important element of the management of paediatric cancer, given the psychological impact associated with a diagnosis of the disease (Clarke et al., 2005; Kunin, 1997). However, a qualitative study conducted in Romania identified that a lack of knowledge about disclosure was given as a reason for non-disclosure (Badarau et al., 2015). Another qualitative study conducted in Australia among 27 nurses of children with cancer revealed that parents received little information about how to disclose advanced cancer to their children (Turner et al., 2007). In a cross-sectional study among 194 parents of children with cancer in the US, parents reported wanting more information about the child's prognosis (Mack, Wolfe, Grier, Cleary, and

Weeks, 2006). In another cross-sectional study conducted in the US, some parents wanted more information about the cure rate as well as the long and short-term treatment plan (Kessel et al., 2013). Thus, for the disclosure process to be effective, there is a need for an open flow of information among all those involved in the process in terms of what issues to include in telling children about their illness.

A lack of shared responsibility among healthcare workers and primary caregivers has an influence on disclosure of illness to the child. Primary caregivers' grief and lack of acceptance of the child's diagnosis stifle openness in sharing information about the disease with the child (Beale et al., 2005). Moreover, in a study conducted in Romania, physicians reported that disclosure was the primary caregiver's responsibility (Badarau et al., 2015). In Taiwan, nurses were not willing to disclose the cancer diagnosis to the family or child because they thought that it was the physician's responsibility (Huang et al., 2014). Such lack of shared responsibility is likely to affect the collaborative care and communication among the child's healthcare team (Pirie, 2012). The lack of willingness by primary caregivers to be involved in an open disclosure process can lead to health professionals feeling helpless in providing quality care to children (Noble et al., 2015).

Research has also shown that culture plays a substantial role in the disclosure of serious illness (Liben et al., 2008; Mayer et al., 2005; Trill & Kovalcik, 1997). While in Western cultures, open communication about the child's illness is promoted (Parsons et al., 2007; Trill & Kovalcik, 1997), in other cultures such as the Japanese, Chinese, and Indian cultures, telling a child about life threatening illness and the potential for death is discouraged (Gupta et al., 2008b; Kato et al., 2004; Martinson, Bi-Hui, & Yi-Hua, 1994; Sagara & Pickett, 1998). In Asian culture telling children about their illness is thought to increase the parental burden as well as subject the family to stigma and discrimination (Parsons et al., 2007). Moreover, there is a belief in Asian culture that telling a person about his/her disease may expedite his/her death (Gupta et al., 2008b). A comparison cross-sectional study conducted among physicians in the US and Japan showed that 65 per cent of the US physicians consistently told children their diagnosis and less than one per cent rarely or never communicated to the children about their diagnosis, while in Japan only 9.5 per cent consistently communicated to the children about their condition and 35 per cent rarely or never informed children of their condition (Parsons et al., 2007). A study conducted among patients of Chinese ethnicity in Singapore revealed that a strategy of secrecy about chronic illness in the family and community was adopted with the aim of saving the reputation of the family, protecting the family from disharmony, and honouring the family's cultural beliefs (Ow & Katz, 1999). These cultural variations on the disclosure of illness call for the cultural competence of healthcare workers in controlling their own prejudice and beliefs when dealing with disclosure (Wiener, McConnell, Latella, & Ludi, 2013).

2.5.6 Children's lived experience of disclosure

Literature has also shown that children with cancer react differently to knowledge about their condition. Findings of a mixed methods study conducted in Hong Kong showed that children who knew about their cancer diagnosis had low self-esteem, weakened bonds with friends and struggled academically. (Li, Lopez, Joyce Chung, Ho, & Chiu, 2013). In a related cross-sectional study conducted in the UK, 84 per cent of children with leukaemia, who knew their diagnosis showed negative behavioural or mood changes, such as anxiety , withdrawal, difficult temperament, and lack of cooperation (Clarke et al., 2005). The authors of a qualitative study that enrolled 16 children with cancer from France, Italy, South Africa, the US, the Netherlands and Ukraine reported that those who knew about their prognosis reacted differently: some anticipated meeting their loved ones who died; some reported being tired with the disease and wanting to rest; some were angry at the tumour because of the pain it caused; some did not want to talk about it; and some were angry and refused to be comforted (Jankovic et al., 2008). Children who survived cancer for seven years in Sweden thought that other people could not understand what they had gone through and preferred to share their experiences with fellow cancer survivors (Sundler, Hallström, Hammarlund, & Björk, 2013).

Having reviewed literature regarding the process of disclosure of a serious illness to children and the factors that promote or deter disclosure, the next section will build on the information presented in this section and discuss the disclosure of HIV status to children living with HIV.

2.6 DISCLOSURE OF HIV STATUS TO CHILDREN LIVING WITH HIV

2.6.1 Introduction

In 2011, the World Health Organisation published a guideline for HIV disclosure to children aged between 6 and 12 years (WHO, 2011). The guideline presents recommendations that followed from the findings of a systematic review conducted by a WHO task force (WHO, 2011). The guideline was developed with the overall goal of promoting the emotional, physical, cognitive and social wellbeing of children living with HIV. It was intended to help healthcare workers to support children living with HIV, and their primary caregivers, with the process of HIV disclosure. Before the development of the guideline, the WHO noted that healthcare workers were having problems disclosing and assisting primary caregivers to disclose HIV to children because of lack of evidence based policies and guidelines (WHO, 2011). The WHO observed that HIV disclosure to children was a complicated issue because of: the stigma associated with HIV; concerns about the availability of social support for children and their families; a perceived lack of parenting skills specific to disclosure; and concerns about children's emotional and cognitive capacity to cope with the news of the diagnosis (WHO, 2011). The review concluded that disclosure has many health benefits, rather than a negative impact on long term psychological health, and that disclosure is part of the process whereby the child, family, and community members can adjust to the illness and its impact (WHO, 2011).

The guideline highlights important considerations for promoting disclosure of HIV to children living with HIV. First, the guideline recognises the impact of stigma on disclosure of HIV to children. Given that HIV is highly stigmatised, many primary caregivers are reluctant to disclose to their children. The WHO, therefore, recommends that interventions to reduce stigma in families, communities and schools should be implemented to promote disclosure. Second, it is important to provide adequate social support and increase community tolerance to children living with HIV. In addition, since disclosure is a gradual process, and requires multiple conversations, in different settings, it is important to garner both individual support (from peers and siblings) and institutional support (from schools and hospitals). Such support will help reduce stigma and discrimination and to help children cope with the infection. Third, the WHO identified the need for developing materials to help with the disclosure process and the need to adapt such materials to suit the environments for which they are intended.

The following sections will review literature about disclosure of HIV status to children. Most of the literature presented in the first subsections is from the US because that is where a great deal of research on HIV was conducted during the early years of the epidemic (1980s to early 2000s). As the review moves on more literature from the sub-Saharan region will be presented.

2.6.2 Differences between disclosure of paediatric cancer and HIV status to children

Notwithstanding the rationale of HIV disclosure having its roots in paediatric cancer, it is important to take into consideration the differences between the two diseases when planning HIV disclosure interventions. Unlike a diagnosis of cancer in most cultures, HIV is associated with a great deal of stigma because of its mode of transmission (Lipson, 1994). HIV is associated with risky sexual behaviours that make it difficult for primary caregivers to discuss the condition with their children. Moreover, the majority of children living with HIV got the infection from their mother. This leads to feelings of guilt among primary caregivers and makes disclosure more difficult compared to paediatric cancer disclosure (Hardy, Armstrong, Routh, Albrecht, & Davis, 1994; Meyers & Weitzman, 1991). Furthermore, because of the stigma and discrimination associated with HIV, parents are often reluctant to disclose to their children because they feel children may end up telling others who may, in turn, treat them badly (Wiener et al., 2007) . These differences make the disclosure of HIV more complicated compared to cancer.

2.6.3 Historical background of disclosure of HIV status to children

Vertical transmission, which is the transmission of HIV from an HIV-infected mother to her child during pregnancy, labour and delivery, or breastfeeding (through breast milk), has been the major mode of transmission of HIV among children since the first cases of HIV were reported in the United States in 1981 (Mofenson & McIntyre, 2000; Townsend et al., 2008). During the 1980s and early 1990s, many children with HIV were dying before their fifth birthday (Dabis & Ekpini, 2002; Scott et al., 1989; Walker, Schwartländer, & Bryce, 2002). Of those who survived most were unaware of their condition (Forsyth, 2003; Newell, Brahmbhatt, & Ghys, 2004a), because of the poor prognosis associated with the disease and primary caregivers' fear of the negative consequences of disclosure (Butler et al., 2009; Forsyth, 2003; Wiener et al., 2007).

The introduction of ARV therapy in the 1990s in the US brought hope to many primary caregivers and healthcare worker (Palmisano & Vella, 2011; Wiener et al., 2007). The availability of ARV medications increased the lifespan of children living with HIV (Palmisano & Vella, 2011; Wiener et al., 2007). Fears surrounding the development of drug-resistant strains of HIV due to a lack of medication adherence and the potential of children to unknowingly transmitting the virus to others once they reach adolescence, prompted healthcare workers and researchers to find effective ways of telling children about their condition (Saunders, 2012; Wiener et al., 2007). The disclosure of HIV to children was identified as the best strategy to help children adhere to treatment and protect others from the infection (Lee & Johann-Liang, 1999) (Saunders, 2012).

Despite the recognition of the importance of the disclosure of HIV status to children, many parents in the US were unwilling to disclose to their children (Wiener et al., 2007) (Instone, 2000). Even among researchers, two different schools of thought emerged: those who advocated for the immediate disclosure of HIV status to children and those who were concerned about the timing and consequences of HIV disclosure (Lee & Johann-Liang, 1999). Primary caregivers who did not want their children to be told about their HIV status, thought that the children's cognitive functioning was not sufficiently well developed to enable them to process and react positively to the news about their condition (Lee & Johann-Liang, 1999; Waugh, 2003; Wiener, Battles, Heilman, Sigelman, & Pizzo, 1996).

The US was the first country to formally advocate for disclosure of HIV status to children in 1999 when the American Academy of Paediatrics developed recommendations for

HIV disclosure to children (American Academy Paediatrics, 1999). Although the Academy recommended the disclosure of HIV to all children, recommendations about the best time to disclose and the impact of disclosure were unclear (American Academy Paediatrics, 1999; Lester et al., 2002). Moreover, the lack of guidelines for HIV disclosure globally acted as a barrier. It was not until 2011 that the World Health Organisation addressed this gap and developed guidelines for HIV disclosure to children that could be used globally (World Health Organisation, 2011a).

The following sections will review global and regional literature related to HIV disclosure to children. However, the majority will be from the Sub-Saharan African region.

2.6.4 Importance of HIV disclosure to children living with HIV

There are many benefits of disclosure that have been reported in the literature. These include: good mental health and reduced likelihood of emotional and behavioural problems; improving the relationship between children, primary caregivers and healthcare workers; increasing access to HIV treatment and care among children living with HIV; improving medication adherence among children living with HIV; encouraging continuity of care in the community; and helping to prepare children for their future as adolescents and adults living with HIV. These benefits will be discussed in detail in the following paragraphs.

2.6.4.1 Good mental health and reduced likelihood of emotional and behavioural problems

There is evidence from Sub-Saharan African countries that has demonstrated that disclosure of HIV status to children has a positive impact on the emotional well-being of children (Lowenthal et al., 2014; Menon, Glazebrook, Campain, & Ngoma, 2007). For example, a Zambian cross sectional study of 127 adolescents living with HIV aged between 11-15 years, found that children who were unaware of their HIV status were twice as likely to experience concerning levels of emotional difficulties compared to those who were disclosed (Menon et al., 2007). Similar findings were reported by authors of two cross sectional studies and one prospective study conducted in resource-rich countries among children living with HIV and their families who reported that disclosure of HIV status promotes emotional well-being of children (Butler et al., 2009; Mellins et al., 2002; Wiener, Battles, & Heilman, 1998). In a cross sectional study of 77 primary caregivers and children living with HIV conducted in the US children who knew their HIV status had a lower score of children depression inventory of 6.1 compared to a score of 8.9 among those who did not know (Mellins et al., 2002). In another cross-sectional study with a small sample size of 17 parents-child dyads conducted by Wiener et al. (1998), in the US, children who had been disclosed their HIV status had less depressive symptoms compared to those who had not been disclosed. In a prospective study conducted in the

US among children living with HIV, disclosure of HIV was associated with a decline in symptoms of distress (Butler et al., 2009). In addition, in a prospective cohort study conducted among 438 Thai children aged between 7 and 18 years who were living with HIV, children identified as ready for HIV disclosure were offered disclosure sessions for six months and a baseline and follow up evaluation was conducted to assess children's psychosocial wellbeing (Boon-yasidhi et al., 2016). The median Children's Depression Inventory score decreased significantly from 11 at baseline to eight at six months follow up. Moreover, the median children's quality of life score increased from 78 at baseline to 80 at six months follow up (Boon-yasidhi et al., 2016). Furthermore, qualitative and cross-sectional studies conducted in the US and Uganda have shown that disclosure brings hope to children living with HIV (Bakeera-Kitaka, Nabukeera-Barungi, Nostlinger, Addy, & Colebunders, 2008; Mellins et al., 2002).

On the other hand, there is literature that has shown that some children have the following negative emotional reactions to disclosure of HIV status: crying, sadness, and worrying (Mellins et al., 2002; Vreeman et al., 2010b); shock, sorrow, hurt, anxiety, worries, disbelief, depression, and nervousness (Santamaria et al., 2011; Vaz et al., 2008; Vaz, Eng, Maman, Tshikandu, & Behets, 2010); shame, hatred, blame, hopelessness, unhappiness, social withdraw, self-harm, and suicide (Blasini et al., 2004; Gachanja, Burkholder, & Ferraro, 2014; Kiwanuka, Mulogo, & Haberer, 2014; Mutwa et al., 2013; Vaz et al., 2011a); as well as distress, and disturbed self-esteem (Instone, 2000) . Nonetheless, there is evidence that the psychological problems that children face are normally short lived if managed properly (Blasini et al., 2004; Mellins et al., 2002) and are replaced with a sense of satisfaction, responsibility on drug adherence and participation in their own care (Mellins et al., 2002; Menon et al., 2007; Vaz et al., 2010). For example, in a Kenyan qualitative study among children living with HIV and their parents, recovery time from emotional problems following disclosure lasted for few hours to four months, and most of the children ultimately experienced relief and self-acceptance after recovery (Gachanja et al., 2014), while in a quasi-experimental study conducted in Puerto Rico among children living with HIV and their parents, the recovery time of psychological problems to disclosure of HIV averaged six months post-HIV disclosure (Blasini et al., 2004).

2.6.4.2 Improvement of the relationship between the child, the primary caregiver and the healthcare workers

Providing honest and truthful information to children about their illness improves the relationship between the primary caregivers, healthcare workers and the child (Dematteo et al., 2002; Kiwanuka et al., 2014). When children are not told about their HIV status, they often harbour suspicions about their illness, given their frequency of hospital visits

(Instone, 2000; Lee & Johann-Liang, 1999). In addition, such children may inadvertently learn about their HIV status from peers or other patients at the clinic (Lee & Johann-Liang, 1999). Children who learn about their HIV infection from sources other than their parents or healthcare workers are at increased risk of emotional and psychological problems and dysfunctional relationships with their parents (Mehta, Ekstrand, Heylen, Sanjeeva, & Shet, 2016; Mutwa et al., 2013).

2.6.4.3 Increased access to HIV treatment and care

Children living with HIV need to periodically attend ART clinics for routine collection of medications (Haberer et al., 2011; Merzel, VanDevanter, & Irvine, 2008). Those with symptoms of health problems are assessed and given treatment on the appointment day (Merzel et al., 2008; Mutwa et al., 2013). Authors of a retrospective cohort study conducted in Romania among 325 children living with HIV reported that children who know their HIV status are more compliant than those who do not know in attending their clinic appointments, because they are aware of the importance of such appointments (Ferris et al., 2007). During disclosure, children are given information that promotes their independence in managing the disease (Bikaako-Kajura et al., 2006; Vreeman et al., 2010b). When they are not feeling well, these children are keen to attend hospital and to receive treatment without waiting to be told by their caregivers (Mutwa et al., 2013; Mweemba et al., 2015). Moreover, there is a great deal of evidence that shows that children who are unaware of their HIV status often refuse to go to the hospital for their periodic medical examinations and the collection of medications (Kallem, Renner, Ghebremichael, & Paintsil, 2011) (Blasini et al., 2004; Mutwa et al., 2013; Sanjeeva, Pavithra, Chaitanya, Sunil Kumar, & Rewari, 2016). There is also evidence that disclosure increases understanding and knowledge of HIV among children (Corneli et al., 2009; Vreeman et al., 2013). For example, the authors of qualitative studies in Namibia that assessed the impact of HIV disclosure to children reported that children's understanding of HIV/AIDS significantly increased following disclosure (O'Malley et al., 2014). Knowledge and understanding of HIV enables children to make informed decisions about their treatment and care (Corneli et al., 2009; O'Malley et al., 2014). In addition, Wiener et al. (2000) argue that children with knowledge about their HIV status find a feeling of satisfaction in teaching others about HIV. Moreover, a cross-sectional study conducted in the US reported that youths who were told about their HIV status were willing to disclose to their potential sex partners (Santamaria et al., 2011).

Studies have shown that the disclosure of HIV status can help to improve retention in HIV treatment and care (Arrive et al., 2012) as well as physical health outcomes (Ferris et al., 2007). In a retrospective study conducted among 650 children living with HIV aged between 10 and 21 years in three Sub-Saharan countries (Ivory Coast, Mali and

Senegal) it was found that those who were knew their HIV status were less likely to be lost to follow up compare to those who were not aware [adjusted hazard ratio (aHR) =0.23, p, 0.0001] (Arrive et al., 2012).

2.6.4.4 Promotion of adherence to treatment

When children are very young, the responsibility of ensuring that they are taking the prescribed HIV medications lies with their parents or primary caregivers. As they grow older they are expected to take over the responsibility of complying with the treatment regimen, which without disclosure of HIV can be difficult to accomplish (Gyamfi, Okyere, Appiah-Brempong, Adjei, & Mensah, 2015; Lee & Johann-Liang, 1999). Disclosure has been found to increase children's adherence to ARV medication (Brown et al., 2011; Hejoaka, 2009; Vreeman et al., 2010b). In qualitative studies conducted in Kenya and Uganda many children who knew their HIV status reported good medication adherence (Bikaako-Kajura et al., 2006; Mehta et al., 2016; Vreeman et al., 2010b). A study conducted in Ethiopia found that disclosure of HIV status was a protective factor for medication adherence among children living with HIV [adjusted odds ratio (aOR) = 0.27, 95% CI: 0.24, 0.32] (Dachew et al., 2014).

There is evidence that children who adhere to ART have more positive health and developmental outcomes (Mehta et al., 2016; Merzel et al., 2008; Mutwa et al., 2013). Recent evidence shows that children who adhere to ART treatment are likely to achieve and maintain undetactable viral load which improves their health and reduces the likelihood of sexually tramsmitting the virus to other children especially when they reach adolescence (Cohen et al., 2016; Hoenigl et al., 2016; The Centers for Disease Control and Prevention, 2017). Although children living with HIV need to take medication every day for the rest of their lives (Bikaako-Kajura et al., 2006; Kunapareddy et al., 2014; Merzel et al., 2008), it is difficult to convince them to do so if they are unaware of their HIV status (Bikaako-Kajura et al., 2006; Kunapareddy et al., 2014; Vreeman et al., 2010b).

2.6.4.5 Continuity of care in the community for children living with HIV

Support from community organisations increases the likelihood that children living with HIV will have positive health outcomes (Mupambireyi et al., 2014; Vreeman et al., 2010b). Schools, community organisations, church groups and HIV support groups have been identified as playing a significant role in providing supportive care to children (Chokephaibulkit et al., 2015; Lowenthal et al., 2014; Mupambireyi et al., 2014; Vreeman et al., 2010b). Children living with HIV should ideally communicate to their teachers about their HIV status so that they can be exempted from class during hospital appointments (Kunapareddy et al., 2014). In addition, teachers can provide remedial classes to children who miss school because of sickness or hospital appointments (Kunapareddy et al., 2014). Hence, disclosure has the potential to optimise children's academic performance (Blasini et al., 2004). Furthermore, children are more likely to seek and receive emotional support from their teachers with regards to their condition if they are aware of their HIV status. (Bikaako-Kajura et al., 2006; Kunapareddy et al., 2014). Besides schools, there are support groups for children living with HIV in many countries that promote healthy behaviours, such as treatament adherence, exercise, and the consumption of nutritious food (Blasini et al., 2004; Chokephaibulkit et al., 2015; Lowenthal et al., 2014). In order for children to receive this community support they must be aware of their HIV status (Lowenthal et al., 2014).

2.6.4.6 Protection from re-infection and infecting others

It is important for children to know their HIV status before they reach adolescence, before they begin to engage in sexual activity (Lee & Johann-Liang, 1999; O'Malley et al., 2014). When they are unaware of their HIV status, adolescents can more easily transmit the infection to their partners (Brogly et al., 2007). HIV disclosure can equip adolescents with knowledge on how to prevent re-infection and transmission of HIV to others (Dematteo et al., 2002; Gyamfi et al., 2015; Lee & Johann-Liang, 1999). Through effective HIV disclosure adolescents living with HIV can appreciate the importance of ART adherence in supressing viral load and preventing transmission of HIV to their sexual partners (Cohen et al., 2016; Hoenigl et al., 2016; The Centers for Disease Control and Prevention, 2017). Moreover, there is evidence suggesting that adolescents living with HIV are significantly more likely to experience sexually transmitted infections and unplanned pregnancies (Brogly et al., 2007). For example, in a cohort study conducted in the US among 638 HIV-infected female adolescents aged 13 to 19 years, 23 per cent were known to be sexually active, on the basis of self-disclosure (Brogly et al., 2007). The overall incidence of pregnancy was 18.8 per 1000 person years (95% CI 13.3-25.7), while the cumulative incidence of condyloma, a sexually transmitted infection, was 8.2 per cent (Brogly et al., 2007). The engagement of adolescents in risky sexual behaviours is not limited to Western countries alone, authors of a qualitative study conducted among 75 adolescents aged between 11 and 21 years who were living with HIV in Uganda reported that some female adolescents living with HIV were exchanging sex for money (Bakeera-Kitaka et al., 2008). In addition to this, the authors of a mixed methods study conducted among 740 adolescents aged between 15-19 years who were living with HIV in Uganda found that a-third of the study participants reported having had sex while 41 per cent reported having a girlfriend or boyfriend. Only 37 per cent of adolescents who reported having had sex used any protective method (Birungi, Obare, Mugisha, Evelia, & Nyombi, 2009).

2.6.4.7 Planning for children’s future

When children are aware of their HIV status, their parents are able to support them to plan for their future as adolescents and adults living with HIV (Bakeera-Kitaka et al., 2008). As children grow up, they need information on how they can live positively with the HIV (Abubakar et al., 2016; Hejoaka, 2009; Mutwa et al., 2013). Disclosure of HIV enables parents to freely discuss with their children ways of independently managing their condition (Gyamfi et al., 2015) (Hejoaka, 2009). In addition, disclosure of HIV status prepares children for the challenges that they may have as they grow up with HIV (Abubakar et al., 2016).

2.6.5 Rates of HIV disclosure to children living with HIV

There is a great variation between low and resource rich countries in the disclosure rates of HIV status to children living with HIV (Vreeman et al., 2010a; Wiener et al., 2007). The following section describes the rates of HIV disclosure to children in Western countries, Asian countries and sub-Saharan Africa.

2.6.5.1 Rates of HIV disclosure to children in Western countries

Authors of nine studies conducted in 10 Western countries from 1996 to 2011 found that HIV disclosure rate among children ranged from 17 per cent to 75 per cent (see Table 2.3). The mean age of the children ranged from 7.6 years to 12.7 years. The highest disclosure rate was found in a study with a mean child age of 10.2 years (Wiener et al., 1996).

Table 3.3: Rate of HIV disclosure to children in Western countries

Author(s) and year	Country	Study design	Number of participants	Disclosure rate	Children's mean age /age range
(Bachanas et al., 2001)	USA	Cross-sectional	36	67.0%%	9.6
(Ferris et al., 2007)	Romania	Retrospective study	325	69.2%	13.5
(Funck-Brentano et al., 1997)	France	Qualitative	35	17.0%	7.6
(Murphy et al., 2010)	USA	Qualitative	12	66.6%	6 to 12
(Lester et al., 2002)	USA	Cross-sectional	51	43.1%	4-13
(Mellins et al., 2002)	USA	Cross-sectional	77	30%	3-13
(Santamaria et al., 2011)	USA	Cross-sectional	196	70%	12.71
(Thorne, Newell, & Peckham, 2000)	Italy, Germany, Portugal, Spain, Switzerland, The Netherlands and the UK	Cross-sectional	140	18%	10 years
(Wiener et al., 1996)	USA	Cross sectional	99	75%	10.2

2.6.5.2 Rates of HIV disclosure to children in Asian countries

Authors of six studies conducted in two Asian countries from 2005 to 2016, described the disclosure rates among children as ranging from 14 per cent to 70 per cent (see Table 2.4). The mean age of children ranged from 8.6 years to 14.8 years. The highest disclosure rate was found in a study with the highest mean child age of 14.8 years (Sirikum et al., 2014)

Table 3.4: Rate of HIV disclosure to children in Asian countries

Author (s) and year	Country	Study design	Number of participants	Disclosure rate	Children's mean age /age range
(Arun, Singh, Lodha, & Kabra, 2009)	India	Cross sectional	50	14%	8.98
(Bhattacharya, Dubey, & Sharma, 2011)	India	Cross sectional	145	41.1%	9.1
(Boon-Yasidhi et al., 2005)	Thailand	Cross-sectional	93	19.8%	8.6
(Sirikum et al., 2014)	Thailand	Prospective cohort study	260	70%	14.8
(Oberdorfer et al., 2006)	Thailand	Cross-sectional	103	30.1%	9.2
(Sanjeeva et al., 2016)	India	Cross-sectional	362	36.7%	13.7

2.6.5.3 Rates of HIV disclosure for children in sub-Saharan Africa

Rates of HIV disclosure for children living with HIV in 18 studies conducted in sub-Saharan countries from 2007 to 2017 ranged from three per cent to 56.7 per cent (see Table 2.2). The mean age range of the children who participated in the studies ranged from 6.8 years to 12.1 years. The study with the highest disclosure rate had also the highest child mean age of 12.1 years (Kajubi, Whyte, Muhumuza, Kyaddondo, & Katahoire, 2014).

Table 3.5: Rate of HIV disclosure to children in sub-Saharan Africa

Author (s) and year	Country	Study design	Number of participants	Disclosure rate	Children's mean age /age range (in years)
(Kajubi et al., 2014)	Uganda	Cross-sectional	394	50.8%	12.1
(Vreeman et al., 2014)	Kenya	Cross sectional	792	26%	9.7
(Dachew et al., 2014)	Ethiopia	Cross-sectional	342	42.1%	0-15
(Skeen et al., 2014)	South Africa	Cross-sectional	979	31.9%	8.9
(Turissini et al., 2013)	Kenya	Cross-sectional	270	11.1%	9.3
(Biadgilign, Deribew, Amberbir, Escudero, & Deribe, 2011)	Ethiopia	Cross-sectional	390	17.4 %	8.52
(Brown et al., 2011)	Nigeria	Cross-sectional	96	13.5%	8.7
(Kallem et al., 2011)	Ghana	Cross-sectional	71	21.0%	10.4
(Vaz et al., 2011a)	The Democratic Republic of Congo	Cross-sectional	259	3%	Age range 8-17
(Vreeman et al., 2010b)	Kenya	Qualitative	120	3.2%	6.8
(Moodley, Myer, Michaels, & Cotton, 2006)	South Africa	Cross sectional	176	9%	Age range 5 to 11
(Menon et al., 2007)	Zambia	Cross sectional	127	37.8%	12.4
(Bikaako-Kajura et al., 2006)	Uganda	Qualitative	42	29%	12
(Namasopo-Oleja M, Bagenda, & Ekirapa-Kiracho, 2015)	Uganda	Cross-sectional	174	56%	9.9
(Nzota et al., 2015)	Tanzania	Cross-sectional	334	32.6%	9.4
(Mweemba et al., 2015)	Zambia	Qualitative	30	56.7%	Age range 10-15
(Gyamfi, Okyere, Enoch, & Appiah-Brempong, 2017)	Ghana	Cross-sectional	118	32.3%	11
(Ubesie et al., 2016)	Nigeria	Cross-sectional	107	29%	10

Comparing the disclosure rate of HIV among the three regions, Western countries had the highest disclosure rate, followed by Asian countries and then sub-Saharan countries. In terms of mean age of children who were disclosed their HIV status, the Asian countries had the highest mean age, followed by Western countries and then the sub-Saharan African countries. The disclosure rates for Western, Asian and sub-Saharan countries identified in the three tables reviewed should be interpreted with caution as many of the studies had small sample sizes.

2.6.6 Ethical issues in disclosure of HIV to children

Children’s immature cognitive and executive functioning render them less competent to make decisions regarding their health (Hein et al., 2015). Since children are under the custody of parents, parents are legally considered to have the best interests of the child in mind and are given the right to make health-related decisions on behalf of the child (De santis & Collins, 2005). In view of this, parents have the right to decide whether to disclose HIV status to the child or not and if they choose to disclose, they have the right to make decisions regarding when, where and how to disclose to the child, as well as who is the best person to disclose (Moodley et al., 2006) . Children also have rights and ethically, it is argued, that they have a right to know about their illness (Lee & Johann-Liang, 1999; Moodley et al., 2006). In sub-Saharan African countries, such as Malawi and Republic of South Africa, guidelines for HIV testing recommend that children who are 12 years of age or older can independently give consent for HIV testing and can be given the results (Malawi Government, 2007; Roux-Kemp, 2013). The same guidelines give a mandate to both the primary caregiver and the healthcare worker to decide when and how to disclose to the child (Malawi Government, 2007; Roux-Kemp, 2013).

In this regard, it may be argued that parents, who choose not to disclose HIV status to the child in order to protect them from the negative psychological impact of disclosure, are still practicing within the boundaries of their legal and ethical rights (De santis & Collins, 2005; Klitzman, Marhefka, Mellins, & Wiener, 2008). While legally parents have the right to make health-related decisions for their child, virtue-based ethics has two schools of thought. On the one hand, objectivism proposes that every individual has the right to make independent decisions regarding their health, and on the other hand, paternalism proposes that those in positions of power, such as healthcare workers, have the right to make decisions for vulnerable people because of their superior knowledge and skills (Burris, 2001; Klitzman et al., 2008). While paternalistic attitudes in decision making have decreased in resource rich countries in recent decades, they remain a dominant force in resource limited countries. When healthcare workers make a decision on behalf of the child, they violate the rights of parents to make decisions for their children (Burris, 2001).

While parents have the right to make decisions for their children, it has been argued that those who fail to tell their child about their HIV status at the right time, violate ethical principles of autonomy, beneficence, and veracity (Bartholome, 1995; De santis & Collins, 2005). The principle of autonomy encourages the independence of individuals to take part in issues related to their health (Bartholome, 1995; Klitzman et al., 2008). If the primary caregiver decides to conceal the HIV status from the child this can be construed as a violation of this principle since the child can fail to develop independence in HIV treatment and care (De santis & Collins, 2005). The child will not know why they have to take medications daily or why they have to periodically go to the hospital for assessment. They may eventually decide to stop taking the medications without realising the consequences of this behaviour (Klitzman et al., 2008; Mitchell, Armstrong, Goodman, & Cava, 2008). This would result in the violation of the principle of non-maleficence (Burris, 2001; De santis & Collins, 2005; Klitzman et al., 2008). By avoiding timely HIV status disclosure, the primary caregiver may be doing harm to the child rather than good since his or her condition may deteriorate (Klitzman et al., 2008). In addition, the caregiver may indirectly cause harm to others, if the child unknowingly transmits the infection to others once he or she becomes sexually active (American Academy Paediatrics, 1999). Furthermore, some primary caregivers lie to their child, telling them that they are suffering from a less stigmatised disease such as pneumonia, malaria, or heart disease instead of HIV (Kiwanuka et al., 2014; Ledlie, 1999; Vaz et al., 2010). The principle of veracity advocates for telling the truth. By failing to disclose HIV status, the primary caregivers hides the truth about the disease from the child (De santis & Collins, 2005; Fry, Veatch, & Taylor, 2010).

On the other hand, it has been argued that disclosure may also result in a violation of the ethical principles of avoiding harm and doing good (non-maleficence and beneficence), especially if it is inappropriately conducted (Klitzman et al., 2008). Children who are aware of their HIV status while they are still very young may not be cognitively and emotionally ready to understand the implications of HIV infection (World Health Organisation, 2011a). Some children divulge information about their HIV status to others, who may discriminate against them or stigmatise them (Sterken, 1995). Moreover, for some children, the burden of keeping their HIV status secret causes emotional or behavioural problems, since they see themselves as different from others who do not have HIV (Wiener et al., 2000). In addition, if disclosure is conducted as a one-off event rather than a gradual process, some children have difficulties in accepting and adapting to their condition, which results in emotional or behavioural problems, and in the worst case scenarios, suicide (Crepaz & Marks, 2002). In Western countries, disclosure may foster further marginalisation of people already in marginalised groups due to race and socioeconomic status (Klitzman et al., 2008).

While inappropriate disclosure may cause more harm than good, the literature shows that, overall, if disclosure is appropriately conducted the benefits outweigh the disadvantages (Klitzman et al., 2008; Mitchell et al., 2008).

2.6.7 The disclosure process

The World Health Organisation recommends that the disclosure of HIV should be conducted gradually as a process rather than as a one-off event (World Health Organisation, 2011a). It should take place gradually starting from the day the child's diagnosis has been confirmed and should continue throughout the child's early life (Lester et al., 2002; Melvin, Donaghy, & Conway, 2008). When disclosure is gradual, children are given time to process the information and to cognitively and psychologically adapt to the illness (Lesch et al., 2007; Saunders, 2012). The process should start with healthcare workers providing information to the primary caregivers about the need to disclose to children before they reach adolescence (De santis & Collins, 2005). Disclosure should be planned in line with the children's age and cognitive development (Lesch et al., 2007; Saunders, 2012). The process should start with giving the child partial information in simple terms about his or her disease and continue by providing more complex information depending on the child's level of development (Koopman, Baars, Chaplin, & Zwinderman, 2004; Lesch et al., 2007).

In order to provide an age appropriate disclosure process to a child living with HIV it is recommended that adults understand the stages of the child's cognitive development (Lesch et al., 2007) as well as the phases of HIV disclosure (Tasker, 1992).

2.6.7.1 Cognitive development in relation to disclosure of HIV status

According to Lesch et al. (2007) and Saunders (2012), a child's level of understanding of a disease can be explained according to Piaget's three stages of cognitive development namely: preoperational, concrete operational, and formal operational.

2.6.7.1.1 Preoperational stage (2-6 years)

During this stage, children are able to understand issues using pictures and their ability to use language increases (Smith & Watkins, 2005; Smith, Cowie, & Blades, 2015) . They can explain the illness based on perceived relationships with other things or events in life, such as object or person (Koopman et al., 2004; Lesch et al., 2007). The ability to explain the relationship between the cause and the illness is also uncommon during this period (Walsh & Bibace, 1991). Children in this stage need to be given a simple explanation about their illness (Miah, 2004; Saunders, 2012).

2.6.7.1.2 Concrete operational stage (7-10 years)

Children in this stage show a greater understanding of illness than those in the preoperational stage. Children can provide an explanation of the disease based on sequence (Lesch et al., 2007), and they understand the different pathways of disease transmission (Koopman et al., 2004; Walsh & Bibace, 1991). During this time it is recommended that children are told about blood, the virus, the body's defence system and health, and the relationships between these characteristics (Melvin et al., 2008; Saunders, 2012). Full disclosure can also take place during this stage (Melvin et al., 2008; Saunders, 2012).

2.6.7.1.3 Formal operational stage (11 years and older)

Children develop abstract reasoning and thinking, and they are able to give an explanation of their illness based on the interactions of several factors, in addition to viewing their body as a system (Lesch et al., 2007; Smith, Cowie, & Blades, 1998; Smith et al., 2015). Children understand illness as an interaction between the host and agent that causes the organs to malfunction (Koopman et al., 2004; Walsh & Bibace, 1991). Children start to be attracted to the opposite sex (Melvin et al., 2008). Arrangements should be made to disclose to all children who are unaware of their HIV status during this stage (Miah, 2004; Saunders, 2012).

2.6.7.2 Phases of HIV disclosure to children

Tasker (1992), described four phases of HIV disclosure that families affected with HIV typically go through in order to disclose HIV status to children. These phases include secrecy, exploration, readiness, and disclosure.

2.6.7.2.1 Secrecy phase

This is the phase that occurs when a primary caregiver has just learnt the diagnosis of the child and vows not to tell anyone about it (Gerson et al., 2001; Instone, 2000; Tasker, 1992). The caregiver attempts to cope with both the shocking news of the diagnosis and living with the secret (Tasker, 1992). During this phase, the healthcare worker has the responsibility of providing a trusting and safe environment for the caregiver to be free to discuss the implications of keeping the diagnosis secret (Stutterheim et al., 2011; Vaz et al., 2008). Once the caregiver develops trust in the healthcare worker, a strong relationship with openness and honesty develops between the two which is fundamental to open discussion about disclosure of HIV to the child (Instone, 2000).

2.6.7.2.2 Exploratory phase

During this phase, the parent still keeps a secret, however, the extent to which he or she protects the secret is less compared to the secrecy phase (Tasker, 1992). During this phase, the caregiver is ready to share the secret with other trustworthy people; mostly members of their immediate and extended family (Instone, 2000). The caregiver discusses with the child the treatment and hospital procedure with an aim of supporting the child to cope with stressful hospital visits or procedures (Gerson et al., 2001; Instone, 2000). This is the best time for the healthcare worker to start educating the caregiver on how to disclose the diagnosis; this should be done in small steps over time while assessing the readiness of the caregiver to disclose HIV to the child (Gerson et al., 2001).

2.6.7.2.3 Readiness phase

By this time the caregiver does not want to keep the secret from the child anymore (Ledlie, 1999). He or she starts thinking of ways to tell the child about their HIV diagnosis (Ledlie, 1999). The primary caregiver may decide to disclose to the child because of: the frequent questions children ask about their condition; changes in the physical or emotional development of the child; need for the child to participate in treatment or care; or the child is becoming sexually active (Gerson et al., 2001; Ledlie, 1999). During this time the caregiver needs assistance from the healthcare worker to appropriately disclose the diagnosis to the child (Vaz et al., 2008). The caregiver needs to be empowered with: knowledge of HIV infection and its management; the child's potential life expectancy; and the likelihood of the child leading a normal life if he or she is adherent to the treatment regimen (Eisenhut, 2012).

2.6.7.2.4 Disclosure phase

This is the phase when the caregiver decides to finally tell the child about his or her HIV diagnosis (Tasker, 1992). Some caregivers decide to disclose HIV status to the child at their home without the assistance of a healthcare worker, while others may seek help from healthcare workers, or other people they trust to assist them with the process (Gerson et al., 2001). It is important at this stage for the healthcare worker and the caregiver to plan together: who should disclosure the HIV status to the child; how the disclosure process should be conducted; and where the disclosure process should be conducted (Gerson et al., 2001; Hazra, Siberry, & Mofenson, 2010). The child's age and level of development should be considered when making such plans (Lipson, 1993). The disclosure process should be systematic, documented and reviewed regularly (Eisenhut, 2012; Gerson et al., 2001). The healthcare worker needs to assist the caregiver in identifying sources of support from significant others (Blasini et al., 2004). Rehearsing every stage of the disclosure process with the caregiver prior to implementation with the child can ensure an effective disclosure (Blasini et al., 2004). The caregiver should be prepared to respond to the possible reactions of the child, such as anger, isolation and quietness (Blasini et al., 2004; Gerson et al., 2001).

After full disclosure, healthcare workers are supposed to assist the child with information in order for him or her to adjust positively to the diagnosis. The child should be told that others may have misunderstandings or different beliefs about the diagnosis, and that may lead to mistreatment (Eisenhut, 2012). When children reach later adolescence (13 to 17 years) they need to be prepared to manage adherence to medication and their conduct of sexual relationships, including safe sex behaviours and condom use (Eisenhut, 2012). Counselling sessions for adolescence should be directed towards their: school success, career, marriage plans, and transition to adult medical care (Hazra et al., 2010).

2.6.7.3 Mode of disclosure to children living with HIV

Vaz et al. (2011a), conducted a qualitative study of children living with HIV aged between 8 and 17 years and their primary caregivers in order to explore events before, during and after disclosure of HIV status to children in the Democratic Republic of Congo. The majority of children who were told their HIV status described their experience of disclosure as a one-off event rather than a process, with half reporting that they were not prepared prior to disclosure. On the other hand, the authors of a qualitative study of 6 - 13 years old children and their primary caregivers conducted in the US (Instone, 2000) , and the authors of an article describing how disclosure is conducted at one of the large centres of paediatric HIV care in Botswana (Lowenthal et al., 2014), have reported that disclosure of HIV to children was gradual starting with the avoidance of certain words such as 'HIV' and 'AIDS', then giving more information to children on a number of occasions. Surprisingly, the authors of two qualitative study studies conducted in Uganda and the Democratic Republic of Congo among children aged between 5-18 years reported that some caregivers lied to children by telling them that they were suffering from asthma, tuberculosis, or other diseases in order to conceal the diagnosis from the child (Kiwanuka et al., 2014; Vaz et al., 2010). In the same studies, those who disclosed reported that they waited for a cue from the child to know more about his or condition for them to disclose. Such cues included children asking questions about their illness or medications.

Although most of the guidelines for HIV testing and counselling for children mandate both the primary caregiver and the healthcare worker to disclose HIV, the authors of studies conducted in Sub-Saharan Africa, as well as resource rich countries, indicate that primary caregivers are considered to be the best people to disclose (Vaz et al., 2011a) (Brown et al., 2011; Dematteo et al., 2002; Mellins et al., 2002; Moodley et al., 2006). In a Nigerian cross-sectional study conducted among 96 primary caregivers of children living with HIV, for example, 64 per cent of the participants said that the primary caregiver should disclose compared to 15 per cent who said that a healthcare worker should disclose (Brown et al., 2011). The findings of this study are limited because of the small sample size. In addition, authors of a South African cross-sectional study of 174 caregivers of children aged between 5 to 11 years, reported that three-quarters of participants preferred primary caregivers to disclose HIV to the child (Moodley et al., 2006). Apart from being a relatively old study, the findings of this study are also limited by the small sample size. Likewise, authors of a cross-sectional study conducted in the Democratic Republic of Congo among 259 primary caregivers of children living with HIV reported that half of the primary caregivers reported that they were better placed to disclose to the child, 36 per cent thought that healthcare workers were the right people to disclose to the child while 10 per cent felt that family members should disclose to the child (Vaz et al., 2011a). In West Africa, researchers conducted a cross-sectional study of 71 caregiver-child (aged 8-14 years) dyads and nine health care workers conducted in Ghana, primary caregivers were thought to be the right people to disclose to the child by 65 per cent of participants followed by 19 per cent who thought that primary caregiver and health care workers should disclose together to the child (Kallem et al., 2011). The findings of this study were limited by the small sample size and the small number of healthcare workers in the sample.

Authors of a cross sectional study involving 64 healthcare workers 131 community members in Zimbabwe that investigated the pattern of HIV disclosure to children revealed that more than three-quarters of the primary caregivers reported wanting to disclose to their children (De Baets, Sifovo, Parsons, & Pazvakavambwa, 2008). However, more than half of them reported needing help from healthcare workers to effectively disclose to the child (De Baets et al., 2008). Likewise, authors of two cross sectional studies conducted in Western countries have also revealed that disclosure was mostly conducted by primary caregivers of children living with HIV. In an American (US) cross sectional study involving 77 caregivers of children living with HIV aged three to 13, 70 per cent of disclosure of HIV to children was conducted by primary caregivers, with the remaining being conducted by healthcare workers and family members (Mellins et al., 2002). Similarly, in a Canadian mixed methods study with a total sample of 105 children and their primary caregivers, 69 per cent of disclosure to children was conducted by parents (Dematteo et al., 2002).

2.6.8 Barriers and facilitators of HIV status disclosure to children

Although the WHO recommends six to 12 years as the appropriate age range for disclosure of HIV status to children (WHO, 2011), the literature shows that demographic, psychosocial, cultural, and health-related factors play a big role in determining whether children living with HIV are told about their HIV status or not (Amuyunzu-Nyamongo, Biddlecom, Ouedraogo, & Woog, 2005; Bastien, Kajula, & Muhwezi, 2011; Mbugua, 2007). The following section will discuss how these factors influence or hinder disclosure of HIV status to children. The barriers and facilitators of HIV disclosure will be presented concurrently.

2.6.8.1 Demographic factors

Demographic factors such as child’s age, and educational level, have been identified in the literature as either facilitating or hindering the practice of HIV disclosure to children living with HIV (Arrive et al., 2012; Atwiine, Kiwanuka, Musinguzi, Atwine, & Haberer, 2015; Bhattacharya et al., 2011; Biadgilign et al., 2011; Domek, 2010; Kallem et al., 2011; Mburu et al., 2014a; Vreeman et al., 2013). These are described in greater detail below.

2.6.8.1.1 Child’s age

Several studies conducted in both resource limited and resource rich settings have shown that older children are more likely to be told about their HIV status than younger ones (Arrive et al., 2012; Atwiine et al., 2015; Bhattacharya et al., 2011; Dematteo et al., 2002; Kajubi et al., 2014; Ledlie, 1999; Mburu et al., 2014a; Meless et al., 2013; Mellins et al., 2002; Turissini et al., 2013; Waugh, 2003). For example, contrary to the WHO recommendation of six to 12 years of age being the optimal age for disclosure of HIV status to children, seven studies conducted in resource limited countries have shown that children 12 years or older are more likely to be disclosed their HIV status than those who are younger (Sirikum et al., 2014; Turissini et al., 2013; Vreeman et al., 2014). For example, the authors of a cross-sectional study conducted among 792 primary caregivers of children in Kenya revealed that the prevalence of disclosure of HIV status to children was nine per cent among six to seven year-olds, 33 per cent among 10 to 11 year olds and 56 per cent among 13 to 14 year-olds (Vreeman et al., 2014). Still in Kenya, Turissini et al. (2013), conducted a cross-sectional study of 270 children-caregiver dyads to assess the prevalence of HIV disclosure to children. The findings revealed that disclosure was 3.3 per cent among children younger than 10 years, 9.2 per cent among the 10-12 year olds and 39.5 per cent among 13-14 year olds. Elsewhere, in Thailand, Sirikum et al. (2014) conducted a prospective cohort study of 260 children to assess the pattern of HIV disclosure and they found that the prevalence of disclosure among children was 21 per cent among the six to 12 year olds and 84 per cent after six months follow-up period.

2.6.8.1.2 Caregiver’s educational level

The authors of a cross sectional study in India who assessed the pattern and correlates of HIV disclosure to children among 145 primary caregivers found that primary caregivers who had higher than fifth grade education were almost 2.7 times more likely to disclosure compared to those with fifth grade or lower level education (Bhattacharya et al., 2011) . In contrast, a Rwandan cross-sectional study with a large sample of 1034 children living with HIV aged between seven and 15 years revealed that children whose parents were illiterate were twice as likely to know about their HIV status compared to those whose parents had high school educational level (Binagwaho et al., 2012).

2.6.8.2 Children’s psychological wellbeing and family social factors

There is evidence that concern about a negative impact on children’s psychological functioning is a barrier to HIV disclosure (WHO, 2011). Furthermore, a great deal of literature shows that social factors can also be barriers to the disclosure of HIV status to children. Factors, such as: fear of stigma and discrimination, fear that the child will not keep their HIV status secret; and the primary caregiver’s feelings of guilt for transmitting the infection to the child (Kiwanuka et al., 2014; Mandalazi et al., 2014; Mburu et al., 2014b; Menon et al., 2007; Vreeman et al., 2014; Wiener & Battles, 2006; Wiener et al., 1998).

2.6.8.2.1 Fear of emotional and behavioural problems

Studies conducted in both resource limited and resource rich countries indicate that some primary caregivers do not disclose HIV status to their child because they want to protect them from the psychological impact of HIV disclosure, such as hopelessness, anxiety, depression and grief (Domek, 2010; Kiwanuka et al., 2014; Kouyoumdjian, Meyers, & Mtshizana, 2005; Madiba, 2013; Moodley et al., 2006; O'Malley et al., 2014; Ostrom, Serovich, Lim, & Mason, 2006; Vaz et al., 2010; Vreeman et al., 2014), In a focus group of 26 parents of children living with HIV in South Africa and a cross sectional studies of 71 caregiver-dyads in Ghana, primary caregivers felt that the message about HIV as disseminated in the media portrays an HIV diagnosis as tantamount to telling someone that he or she is dying (Kallem et al., 2011; Madiba, 2013).

While some primary caregivers think that HIV disclosure might lead to psychological or behavioural problems, this is not backed up by the evidence-based literature (Santamaria et al., 2011; WHO, 2011). For example, the authors of a study that enrolled 99 African American primary caregivers and their children aged between six and 11 years in the US showed that there was no significant difference in children’s own reports about externalising and internalising behaviours pre and post HIV disclosure, while primary caregivers reported that there were significant negative behavioural outcomes for children after disclosure (Shaffer, Jones, Kotchick, Forehand, & Group, 2001). High-quality studies are required to investigate whether it is children, their parents, or both who are really distressed about the diagnosis of HIV (WHO, 2011).

2.6.8.2.2 The impact of stigma and discrimination on disclosure of HIV status to children

HIV/AIDS is a disease that is associated with inappropriate sexual behaviour, therefore many people in African countries living with HIV are stigmatised (Airhihenbuwa et al., 2009; Kyaddondo, Wanyenze, Kinsman, & Hardon, 2013; Rankin, Brennan, Schell, Laviwa, & Rankin, 2005). More recent, integrative reviews on stigma have revealed that people living with HIV in developing countries like Malawi are stigmatised by the community because of the following reasons: 1) perceived infectious nature of the infection; 2) life threatening nature of the disease and its association with death; 3) the perception that people living with HIV are responsible for the onset of the infection; and 4) associating HIV infection with norm violating behaviour such as prostitution and homosexuality (Bos, Pryor, Reeder, & Stutterheim, 2013; Bos, Schaalma, & Pryor, 2008). The stigma and shame that are associated with HIV/AIDS disease compels primary caregivers to keep their HIV condition and that of their child secret (Bos et al., 2013; Vranda & Mothi, 2013). In five qualitative studies conducted in South Africa, Uganda, Zambia, Burkina Faso, and Namibia, primary caregivers have reported failing to disclose HIV status to their child because they were afraid that the child would not be able to keep their HIV status secret, which might, in turn, result in the family being stigmatised (Hejoaka, 2009; Kouyoumdjian et al., 2005; Mburu et al., 2014a; McCleary-Sills et al., 2013; O'Malley et al., 2014). In addition, the authors of a qualitative study conducted in South Africa have reported that primary caregivers think the only way to protect the child and the family from stigma and discrimination is to conceal the diagnosis from the child (Demmer, 2011). Similar findings have been reported in qualitative study conducted in the UK where parents failed to disclose HIV status to the child because of fear of the that the child will not keep secret, fear of stigma, discrimination and prejudice (Waugh, 2003).

2.6.8.2.3 Primary caregiver’s feeling of guilty of transmitting the infection to the child

Parental guilt is another barrier to HIV disclosure to children (Domek, 2010). Authors of an integrative review conducted during the early years of the HIV epidemic, report that some parents are afraid that disclosure may reveal how the child contracted HIV from his or her mother, and this may result in the parents being blamed (Lee & Johann-Liang, 1999). This is supported by findings of a recent qualitative study conducted among 40 primary caregivers of children aged five to 15 years living with HIV in Uganda, where the parents of children reported that they felt responsible for transmitting the virus to the child and reported not wanting to disclose to the child for fear of damaging their relationship with their child (Kiwanuka et al., 2014). Authors of a recent qualitative study conducted among 42 adolescents living with HIV in Rwanda reported that adolescents who knew their HIV status blamed their parents for giving them the infection (Mutwa et al., 2013).

According to Lipson (1993), parents of children living with HIV find it hard to disclose HIV status to their children because they think that discussing the child's infection would mean parental HIV disclosure as well, which might negatively affect the child (Lipson, 1993). This is supported by the authors of cross sectional studies conducted among primary caregivers of children living with HIV in Thailand and Ghana who reported that children who stayed with biological parents were less likely to know about their HIV status (Kallem et al., 2011; Oberdorfer et al., 2006). Similar findings were also reported by authors of a cross sectional study of 250 primary caregivers in seven European countries (Germany, Italy, France, The Netherlands, Portugal, Spain, Switzerland, and the UK) where more than half of the children living with HIV who were told about their HIV status were not living with their parents (Thorne et al., 2000).

2.6.8.2.4 Promoting honesty and trust

In a Canadian mixed method study, parents disclosed HIV status to their children because they wanted to maintain family trust (Dematteo et al., 2002). In addition, authors of two cross-sectional studies conducted in the US and South Africa found that primary caregivers wanted the child to hear about their diagnosis from the primary caregiver first, and they also felt that the child had the right to know about their disease (Moodley et al., 2006; Ostrom et al., 2006).

2.6.8.2.5 Social support

In a Zimbabwean qualitative study of 15 primary caregivers of children living with HIV and eight community leaders, openness within the family and community support promoted safe and effective disclosure of HIV status to children (Busza, Dauya, Bandason, Mujuru, & Ferrand, 2014). Moreover, the authors of a Kenyan qualitative study who enrolled 120 primary caregivers of 0 to 14 year old children living with HIV, reported that parents were more likely to to tell the child about his or her HIV status if they felt that disclosure would enhance shared care for the child and community support (Vreeman et al., 2010b).

2.6.8.3 Cultural factors

Culture also plays an important role in the disclosure of HIV to children (Gerson et al., 2001; Kyaddondo et al., 2013). HIV is normally related to sexual behaviour, and the process of disclosing HIV involves talking about the mode of transmission (Kouyoumdjian et al., 2005). Literature has shown that in the African culture, it is normally considered a taboo for parents or adults to discuss sexual issues with their children (Amuyunzu-Nyamongo et al., 2005; Kyaddondo et al., 2013; Mbugua, 2007; Paruk, Petersen, Bhana, Bell, & McKay, 2005). For example, Mburu et al. (2014a) enrolled 111 adolescents (10-19 years), 14 healthcare workers and 24 primary caregivers in a study that explored barriers of HIV disclosure to adolescents. The findings revealed that parents were reluctant to disclose to adolescents because of cultural taboos related to sex (Mburu et al., 2014a). Likewise, in Kenya, authors of qualitative study of children living with HIV reported that many children reported having at least one question following disclosure such as wanting to know more about the source of infection. However, their parents ignored the questions because they were uncomfortable to discuss HIV infection openly with their children because it was related to sexuality (Vaz et al., 2010). Thus, as highlighted by literature in this section, cultural taboos related to sexuality impede disclosure of HIV status to children living with HIV.

2.6.8.4 Healthcare-related factors

Factors identified as facilitators and barriers to HIV disclosure to children include the following: children wanting to know more about their condition (Binagwaho et al., 2012; Mburu et al., 2014a; Ostrom et al., 2006), promotion of child's independence in treatment (Dematteo et al., 2002; Vaz et al., 2010; Vreeman et al., 2010a), healthcare workers' lack of knowledge on disclosure (Domek, 2010; Kouyoumdjian et al., 2005; Madiba, 2013), distance to the clinic (Biadgilign et al., 2011; Vreeman et al., 2014), and being on ART treatment (Arrive et al., 2012; Bhattacharya et al., 2011; Kallem et al., 2011).

2.6.8.4.1 Child asking about his condition

Some primary caregivers are compelled to disclose HIV status to their children when the child asks about their illness (Ledlie, 1999). For instance, a qualitative study conducted in Zambia and the US among children living with HIV found that primary caregivers were forced to disclose to their child because of the child's persistence in wanting to know more about their condition (Ledlie, 1999; Mburu et al., 2014a). In a related qualitative study conducted in Rwanda, children who engaged in conversation with their primary caregivers about their condition were 15 times more likely to be told about their HIV status compared to those who did not (Binagwaho et al., 2012). On the other hand, authors of a descriptive qualitative study of 20 primary caregivers of children who had HIV, study conducted in Burkina Faso found that despite the children's persistent questions about their illness, primary caregivers opted for dishonesty and threatening the children that they will die if they stop taking the medication (Hejoaka, 2009).

2.6.8.4.2 Promoting child's independence in treatment and protecting other children

Authors of cross-sectional studies conducted in South Africa, the Democratic Republic of Congo, and Ghana have found that a proportion of caregivers disclosed HIV status to children in the hope that the children would protect others and take responsibility of the treatment regimen (Moodley et al., 2006; Vaz et al., 2008; Vaz et al., 2011a; Vreeman et al., 2010b). In addition, in a Ghanaian cross-sectional study, 21 per cent of primary caregivers disclosed HIV status to children because they wanted their child not to miss hospital appointments (Kallem et al., 2011). Similar findings were also reported in cross sectional studies conducted in Canada and the US, where disclosure was conducted in order to prepare the child for healthy living with HIV status (Dematteo et al., 2002; Ostrom et al., 2006).

2.6.8.4.3 Primary caregiver's lack of knowledge

Lack of knowledge and skills on how to disclose HIV to children is another barrier to HIV disclosure to children (Domek, 2010; Kouyoumdjian et al., 2005; O'Malley et al., 2014; Thorne et al., 2000). In a prospective cohort study conducted in Thailand and cross-sectional studies in South Africa and the Democratic Republic of Congo, primary caregivers of children living with HIV asked healthcare workers to support them during disclosure of HIV to their children, since they felt unprepared to do so (Kouyoumdjian et al., 2005; Madiba, 2013; Sirikum et al., 2014; Vaz et al., 2008). This underscores the importance of having simple resources that guide caregivers in the disclosure of HIV to children as well as the need for healthcare workers to provide support and guidance to the caregivers about disclosure (Myer, Moodley, Hendricks, & Cotton, 2006; Nostlinger et al., 2004).

2.6.8.4.4 Health facility related factors

In a cross-sectional study conducted in Kenya, children receiving ART at a rural clinic were 3.5 times more likely to know about their HIV status than those who were receiving their medication at an urban clinic (Vreeman et al., 2014) . On the other hand, authors of another cross sectional study of 340 primary caregivers conducted in Ethiopia, reported that primary caregivers who were referred from a community clinic for HIV screening were approximately three times more likely to have children who knew their HIV status compared to those who were referred from the hospital (Biadgilign et al., 2011).

2.6.8.4.5 Being on ART treatment

The authors of cross sectional Kenyan study conducted among 792 children living with HIV and their primary caregivers, showed that children who are on treatment are two times more likely to be told about their HIV status compared to those who are not (Vreeman et al., 2014). According to the authors of cross-sectional and qualitative studies conducted in the Democratic Republic of Congo, Ethiopia, and Ghana, the need to adhere to ART treatment prompted the primary caregivers to disclose to their children

(Biadgilign, Deribew, Amberbir, & Deribe, 2009; Kallem et al., 2011; Vaz et al., 2008; Vaz et al., 2010; Vaz et al., 2011a; Vreeman et al., 2010b).

2.6.9 Health education materials for children

2.6.9.1 Introduction

Educational materials for children and their families are important in the management of children with chronic, acute and surgical conditions (Mahat, Scoloveno, & Donnelly, 2007). There is evidence that children who receive more information about their illness and treatment have a more positive adjustment to their condition with a greater sense of control over their lives, even if they do not know the outcome of their illness (Mahat et al., 2007). There are many health education resources globally that have been developed for patients and their families to impart relevant health related knowledge and skills (Bufton, 2005). These include story books, booklets, pamphlets, posters, billboards, DVDs, television and radio campaigns, and online materials (Bufton, 2005; Crawley, Ditzel, & Walton, 2012; New Zealand Ministry of Health, 2012).

2.6.9.2 Importance of health education materials

There are many benefits of health educational materials as reported in the literature (see Table 2.5). The use of booklets containing information about chronic diseases and their management has been reported to help children and their families to develop a positive attitude towards care and treatment and to adopt healthy behaviours in the UK (Absolom, Eiser, Greco, & Davies, 2004); increase the level of knowledge about minor illnesses and their involvement in the care process in the UK and Japan (Robbins, Hundley, & Osman, 2003; Sakamoto et al., 2014); reduce worries and anxiety related to the disease in Japan (Sakamoto et al., 2014); and increase confidence in providing home care in the UK (Martins, Soler, Batigalia, & Moore, 2009; Robbins et al., 2003). Also, authors of a study in the UK reported that the use of workbooks helped children who had a loved one in hospice to interact and build a relationship with hospice workers, in addition to preparing nurses to answer questions that the children had (Macpherson & Cooke, 2003). Furthermore, the use of cartoon books was associated with improved compliance to treatment of an eye problem, amblyopia in the Netherlands (Tjiam et al., 2016) and ability among children to identify early symptoms of stroke in Japan (Sakamoto et al., 2014).

The use of story books in relaying health information to children has been supported by studies from different disciplines including psychology, social science and nursing (Greenhalgh, 2001; Hartling et al., 2010). Story books can be both reflective and interactive in nature and enable parents and children to discuss thoughts, characters and feelings at the developmental level of children (Dyer, Shatz, & Wellman, 2000).

Storybooks are an attractive teaching resource for children because they are short, colourful, interesting and easy to read (Crawley et al., 2012).

Table 3.6: Health education materials for children

Author and year	Country	Description of interventions	Outcomes/Evaluation
Absolom et al. (2004)	United Kingdom	A booklet containing information about cancer treatment, health risks linked to cancer treatment and importance of adopting healthy lifestyle was given to 48 childhood survivors of cancer aged 10-16 years. The children were asked to complete a questionnaire after reading the booklet	Participants had a positive attitude toward the cancer clinic and were more ready to change health behaviours
Sakamoto et al. (2014)	Japan	A total of 219 children aged between 10 to 11years were given a 30 minutes lesson per week using a teaching material that consisted of a cartoon and manga. Questionnaires on stroke knowledge and identification of stroke symptoms were administered to participants before onset and 3 months immediately after completion of the lesson	Stroke knowledge increased significantly after lessons compared with before (<0.001). The number of children calling emergency medical service on identifying stroke symptoms was higher immediately after the lesson than baseline (P 0.007)
Hartling et al. (2010)	Canada	Parents of children with Croup were asked to evaluate story books containing information about croup	Participants felt the books were more complex to comprehend and asked for more character development and information of the disease. Feedback from participants improved the quality of the story books
Badarudeen and Sabharwal (2008)	The United States of America	A total of 77orthopaedic education materials were assessed for readability	Only 2% of the materials had the suitable readability for the audience
Gleason-Morgan (1992)	The United States of America	An HIV booklet was developed by nurses for families of children diagnosed with HIV. The book contained general information about HIV transmission, prevention, treatment and psychosocial care	Families of children overwhelmingly received the hand book and felt that it had comprehensive information which was easier to understand
Bufton (2005)	United Kingdom	An informational booklet for children of liver transplant recipient parents was developed to prepare them for the psychosocial implication of the procedure. The book was developed through review of literature	The booklet helped children to be involved in the care process
Arora et al. (2012)	Australia	To assess how parents, cope with dental education materials (leaflets) for their children	Parents reported that the materials were easier to read but had technical words which were difficult to understand
Naumann, Huss, Calabrese, and Smith (2004)	The United States of America	Asthma colouring book for children aged between 6 and 12 years was developed to assist children in rural areas understand about their disease, treatment and prevention	Was widely accepted by children in pilot study. Further evaluation to test the effectiveness of the resource is not yet conducted
Fernandes, Arriaga, and Esteves (2014)	Portugal	Three education materials for preparing children for surgery were evaluated. A total of 125 children aged between 8 and 12 years were recruited. The children were assigned into three groups; the intervention group received the booklet containing preoperative information, the comparison group received entertainment material with the same format and the third group, the control group received no intervention	The materials helped to reduced preoperative worries among children in the intervention group compared to those in the comparison and control group

Continuation of Table 2.5

Author and year	Country	Description of interventions	Outcomes/Evaluation
Robbins et al. (2003)	The United Kingdom	Parents of children were given a booklet on how to identify and manage minor childhood illnesses at home	Participants showed greater certainty about the home care options they would choose, and a reduction in intention to consult a doctor. But they also reported that they had reduced confidence and knowledge
Macpherson and Cooke (2003)	The United Kingdom	A workbook for use by children aged 5 to 14 years visiting a loved one in a hospice. Children, parents and hospice staff were asked for their views regarding the importance of the workbook. The book was developed through synthesis of ideas found in the literature, other children's books and experience	The book provided an opportunity for children to interact and build a relationship with healthcare workers, helped children to become involved in the visit to the hospice, prepare nurses to answer questions that children had. Nonetheless, nurses asked for training to empower them with knowledge and skills on how to use the books
Tjiam et al. (2016)	The Netherlands	Use of an educational cartoon to improve compliance with occlusion therapy for amblyopia among children. Children were given the books after their parents were educated about the procedure	The cartoon books improved compliance among the participants by more than 70%
Mahat et al. (2007)	The United States of America	Evaluation of children written educational materials for children with Sickle Cell Disease. Parents of children were asked about the usefulness of the material	Caregivers were knowledgeable about the cause, signs and symptoms, and what to do during A sickle crisis. More than half of the caregivers reported having confidence in managing their child's problems
Joubert and Githinji (2014)	South Africa	Twenty-one information pamphlets on hearing and hearing loss for children were evaluated to determine the quality and readability levels	About 95% of the materials assessed were found to be of low quality with a higher readability level compared to the recommended one
Martins et al. (2009)	Brazil	Caregivers of children requiring clean Intermittent catheterization was given health education session using an illustrated booklet on how to perform clean intermittent catheters. upon completion of the education session, participants were given a questionnaire to evaluate the booklet	All participants reported that they were able to perform clean intermittent catheterisation A proportion of 61% evaluated the booklet as excellent and 39% as good

2.6.9.3 Process of developing an education material

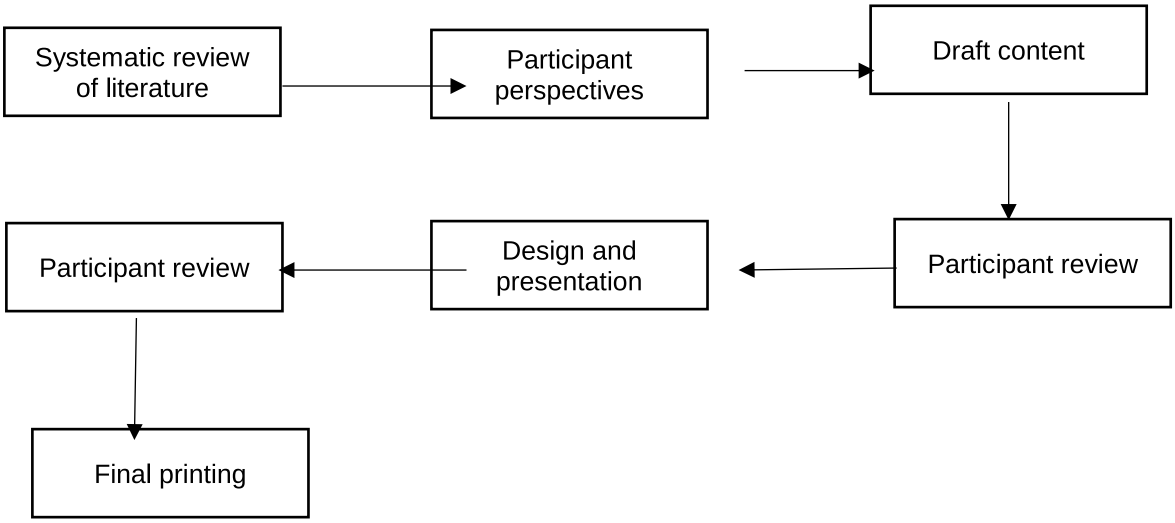
The ideal health education material for children should be age and developmentally appropriate (Badarudeen & Sabharwal, 2008; Dyer et al., 2000; Joubert & Githinji, 2014), based on the best evidence which is obtained through a rigorous process (Jensen, Moreno, & Rice, 2014; Kennedy, Robinson, Thompson, & Wilkin, 1999), and the content and design should be adaptable in a variety of settings (Berger, Inkelas, Myhre, & Mishler, 1994). The authors of previous studies have also emphasised the importance of considering the suitability of the education materials and reading grade level (level of understanding of the target population) during the development process (Horner, Surratt, & Juliusson, 2000; Larson, Wong-McLoughlin, & Ferng, 2009).

Doak, Doak, and Jane (1996) developed a tool to assess the suitability of education materials for low literacy populations based on six criteria: content, literacy demand, graphics, layout and typography, learning stimulation, and cultural appropriateness. The content aspect entails that the material has a purpose and that instructional information for the users and time frame for activities are clearly outlined (Absolom et al., 2004; Doak et al., 1996; Feldman-Stewart, Brennenstuhl, & Brundage, 2007). With regards to literacy demand, the researcher should assess whether writing style, reading level, sentence construction and the organisation of topics and the language used are appropriate for the target group. The graphics component refers to how the use of drawings, images and illustrations, and their quality influence learning (Absolom et al., 2004; Doak et al., 1996; Tortolero-Luna et al., 2006). The layout and topography entail that the size of the printed text and information is structured to promote readability and flow of information (Doak et al., 1996). As for learning stimulation, the researcher should assess whether the information provided enables the reader to act and apply it (Absolom et al., 2004; Doak et al., 1996). Lastly, cultural appropriateness assesses whether the information in the material is in line with the language and experience of the targeted audience (Absolom et al., 2004; Doak et al., 1996; Oetzel, De Vargas, Ginossar, & Sanchez, 2007).

Furthermore, four principles of developing health education materials have been identified in the literature. These are: 1) patients should be involved in deciding the content and presentation of the material; 2) the material to be developed should be based on the best scientific evidence available and best practice (Jensen et al., 2014); 3) patients should be involved in decision-making regarding the health material (Rudd, 2011); and 4) the material should be easy to use and understand (Kennedy et al., 1999; Rudd, 2011). In practice, however, these principles are seldom used, with the literature showing that patients or target groups for health literacy materials are often not involved at the outset of developing the materials (Kools, 2007; Kools, Ruiter, Wiel, & Kok, 2007; Larson et al., 2009). For example, a Canadian study evaluating the quality of 298 educational materials found that more than half of these consisted of low-quality information mainly because the targeted population had not been involved in the development of the materials (Feldman-Stewart et al., 2007).

According to Kennedy et al. (1999) and Rudd (2011), development of educational materials involves seven stages (see Figure 2.3). The first stage is a systematic review of the literature, which involves a thorough and rigorous search of literature related to the topic. The second stage involves obtaining the views of the targeted population regarding the material to be developed through surveys, focus group discussions and/or interviews. The third stage involves drafting the content using information obtained from the first two stages of development. The fourth stage entails the review of the draft content by the targeted population in order to identify deficiencies in the material. The fifth stage is designing and presentation of the material. This stage includes making changes to the content of the material depending on feedback from the target population and structuring the content and outlook of the material. The penultimate stage is the final review by the targeted population prospective users of the designed material, and the final stage is the printing of the material, ready to be used (see Figure 2.3)

Figure 3.4: Process development of printed health education materials



Adapted from Kennedy et al. (2010)

In addition, there is a great deal of literature recommending the use of intervention mapping in planning and development of participatory health promotion interventions such as health education materials (Garba & Gadanya, 2017; Koops van't Jagt, de Winter, Reijneveld, Hoeks, & Jansen, 2016; Rutten et al., 2014). Intervention mapping is defined as as "a planning approach that is based on using theory and evidence as foundations for taking an ecological approach to assessing and intervening in health problems and engendering community participation"(Eldredge, Markham, Ruiter, Kok, & Parcel, 2016, p. 7). This approach is problem solving driven, and is guided by the ecological model (Eldredge et al., 2016). Intervention mapping has six steps namely: 1) development of a logic model through a needs assessment; 2) outlining of program outcomes and objectives; 3) development of the program plan that include scope, structure, change methods and practical applications; 4) Generation of an intervention, including program materials and messages; 5) planning program use, including adoption, implementation and maintenance; and 6) development of an evaluation plan (Eldredge et al., 2016; Highfield et al., 2015). Intervention mapping enables the planning and development of interventions that meet the needs of the target population (Garba & Gadanya, 2017; Highfield et al., 2015).

2.6.9.4 Resources to guide and promote disclosure of HIV status to children

Globally, there are only a limited number of interventions that promote and guide disclosure of HIV status to children (McCleary-Sills et al., 2013). Recognising the importance of evidence-based interventions to guide and promote disclosure of HIV status to children, the WHO in 2011 recommended the need for the development of interventions that can guide the disclosure process (WHO, 2011).

Table 2.6 outlines interventions across a range of countries that have been trialled to promote or guide disclosure of HIV status to children living with HIV. Three interventions were conducted in the US (Blasini et al., 2004; Nelms & Zeigler, 2008; Nicastro et al., 2013), one in the Caribbean region (Beck-Sagué et al., 2015), three in sub-Saharan Africa (Lowenthal et al., 2014; O'Malley et al., 2014; Rochat, Arteche, Stein, Mitchell, & Bland, 2015) and one in Asia (Simoni et al., 2015). Of these eight interventional studies, two were on disclosure of maternal HIV status to children (Rochat et al., 2015; Simoni et al., 2015) while the remainder were on disclosure of HIV status to children living with HIV. Six interventions involved providing training sessions to primary caregivers or/and healthcare workers on how to disclose HIV status to children (Beck-Sagué et al., 2015; Blasini et al., 2004; Lowenthal et al., 2014; Nicastro et al., 2013; Rochat, Arteche, Stein, Mkwanazi, & Bland, 2014; Simoni et al., 2015), one involved the development of a brochure to assist primary caregivers with disclosure to children (Nelms & Zeigler, 2008), another involved the use of a cartoon book to help healthcare workers to disclose to children and to assist primary caregivers on how to disclose HIV to children (O'Malley et al., 2014).

Overall, the interventions had a positive impact on guiding the disclosure process (Nelms & Zeigler, 2008; O'Malley et al., 2014; Simoni et al., 2015), improving the rates of HIV disclosure (Beck-Sagué et al., 2015; Nicastro et al., 2013), improving drug adherence (Blasini et al., 2004; Lowenthal et al., 2014), improving the psychosocial well-being of children (Blasini et al., 2004; Lowenthal et al., 2014; Nicastro et al., 2013; O'Malley et al., 2014; Rochat et al., 2015; Simoni et al., 2015) as well as improving efficacy of disclosure of HIV status to children (Nelms & Zeigler, 2008; O'Malley et al., 2014; Simoni et al., 2015). Refer to Table 2.6 for more information about the interventions and outcomes.

Table 3.7: Interventions that promote and guide disclosure of HIV status to children

Author and year	Country	Description of intervention	Outcomes
(Nicastro et al., 2013)	USA	Implemented an intervention to promote disclosure of HIV status among parents to their children and provide psychosocial support to parents. The intervention involved randomly assigning parents with children aged 1 to 17 years living with HIV to two intervention groups. The interventions involved providing psychotherapy to the treatment group while withholding it in the control group. Eight sessions were offered to the treatment group; one session provided every month.	• Disclosure rate was 60% in the treatment group as compared to 14% in the control group. • Psychological well-being improved by 70% in participants in treatment as compared to none in the control group. • Anxiety significantly decreased in 60 % of the participants in the treatment group as compared to none in the control group.
(Nelms & Zeigler, 2008)	USA	Development of a brochure to assist primary caregivers in disclosing HIV to children. Information to develop the brochure was collected from primary caregivers, healthcare workers, experts in psychology and from the body of literature. Children as old as 17 years were targeted.	• Though no scientific evaluation of the intervention was done, caregivers who used the brochure provided positive feedback that the disclosure resource was helpful.
(Blasini et al., 2004)	Puerto Rico	The intervention was aimed at overcoming stigma and helplessness and to empower caregivers with information and support. The interventions involved training of health workers on appropriate HIV Disclosure and promoting family support for disclosure. Interventions included; individual interactive sessions during disclosure, disclosure sessions, and teaching support groups post-disclosure. The mean age for children who were disclosed to was 13.8 years.	• 70% of the youth adjusted to the infection 6 months after disclosure. • Drug adherence increased by 58%. • A total of 85% of the youth and 97% of the caregivers considered disclosure as a positive event.
(Beck-Sagué et al., 2015)	Haiti and the Dominican Republic	Separate pre-disclosure training for caregivers, healthcare workers and youths aged 10 to 17 years. Health care works were given capacity training to handle HIV disclosure; primary caregivers were educated on disclosure, and the youths were given education on chronic illness. Supportive discourse process was conducted by a healthcare worker in the presence of the primary caregiver. The caregivers and children were assessed for emotional problems on four occasions in three months after disclosure by the psychologist	• Prevalence of disclosure was 28.8 in Haiti and 22.6% in the Dominican Republic. • Most of the parents appreciated that talking to the psychologist was very helpful as they could not talk to anyone about the child's HIV status.
(O'Malley et al., 2014)	Namibia	A cartoon book, provided structure, language and guidance for gradual disclosure process to be used by healthcare workers during disclosure as well as helping caregivers to disclose HIV to their children. The targeted children were aged between 7 to 15 years	• Reduced caregiver resistance to disclosure. • The disclosure process was organised and systematic. • Caregivers felt more confident in their ability to engage in the disclosure process.

Continuation of Table 2.6

Author and year	Country	Description of intervention	• Outcomes
(Lowenthal et al., 2014)	Botswana	Children were seen by the healthcare workers once in three months during which they were given disclosure related messages beginning from an early age. Primary caregivers attended a group session at the clinic and were taught basic concepts of HIV, how young people can be taught about HIV as well as how to disclose HIV to children. The target age group for children was 4 to 19 years.	• Improved psychosocial adjustment to HIV diagnosis and improved drug adherence among children.
(Rochat et al., 2015)	South Africa	Provision of education sessions to primary caregivers to prepare them for maternal HIV disclosure to children. Mothers were taught the step by step way of disclosing HIV, how to deal with the child's emotional reaction to disclosure. Materials which were used included printed materials, games and activities for children. Six education sessions were conducted for a period of 6 to 8 weeks The targeted children were HIV-uninfected children aged 6 to 10 years.	• Decreased parenting stress • Decreased internalizing and externalizing behavioural problems in children • Improved child -parent relationship
(Simoni et al., 2015)	China	The nurse offered three sessions of education of 1 hour each to parents on how they could disclose their HIV status to children. Education involved the importance of disclosure, preparations for disclosure, children's emotional, social and cognitive development. Post-intervention assessment was done at 4 and 13 weeks The targeted children were aged 13 to 25 years old.	• Decreased levels of distress • High level of disclosure self-efficacy in the intervention group

2.6.9.5 Non-peer reviewed HIV disclosure resources

A number of resources on HIV disclosure to children were identified from the grey literature, as shown in Table 2.7 below. These include nine print resources and one audio-visual one. The resources provide information about delivering age appropriate HIV information to children; children stories and experiences of living with HIV including worries, stigma and treatment. The resources were developed by Government, non-Government, and research organisations, and individuals. None of the resources were evaluated for effectiveness.

Table 3.8: Non-peer reviewed HIV disclosure resources

Author and year	Title and country	Description of intervention	Source
Anna Forbes (2003)	Myths and facts about HIV and AIDS	Age and developmental appropriate HIV information for children	http://www.amazon.com/s?keywords=myths+and+facts+about+HIV+and+AIDS
Paulina Chiziane	Quero Ser Alguem (Mozambique)	Compilation of stories of children living with HIV. It covers stories about worries, stigma and disclosure	http://www.yahanet.org/resources/i-want-be-somebody-testimonies-children-living-hivaids
South2South	South2South Pediatric HIV Disclosure Series (South Africa)	Booklets containing information that caregivers can use to disclose HIV to children aged between 2 and 6 years	http://www0.sun.ac.za/southtosouth/toolkits/aps/toolsforteaching/Knowing%20about%20Myself_Read%20to%20your%20child.pdf
Rae Simons & Elise DeVore Berlan	AIDS and HIV: The Facts for Kids (Kids' Guide to Disease and Wellness)	Age appropriate information for children	http://www.amazon.com/s?field-keywords=Aids+and+HIV+facts+for+kids
Hijltie Vink	Brenda Has a Dragon in Her Blood	A story about a girl with HIV and how she copes with her condition	http://positivepeople.md/en/istoria-brendi-i-malenikogo-drakona/
Chee Mamuk	A children's storybook about a family's experience with HIV	A family's experience of living with HIV explained through a story book	http://www.theytusbooks.ca/
Health Communication Partnership (HCP) and Joint Clinical Research Centre (JCRC) in Uganda	Lukia's Story	A story about a girl's experience of living with HIV in Uganda is described through a story book	http://www.k4health.org/toolkits/%20Uganda-paediatric-hiv/lukias-story
Thailand Ministry of Public Health	Pediatric HIV Disclosure Manual (Thailand)	Healthcare workers manual used to support caregivers with disclosure of HIV	http://www.cqihiv.com/Final_Pediatric_HIV_Eng.pdf
Baylor International Pediatric AIDS Initiative	Baylor International Pediatric AIDS Initiative (BIPAI) adherence curriculum	A comprehensive resource for Healthcare workers caring for children living with HIV	http://www.bipai.org/
AIDS Map	HIV & Children	A resource provides HIV information to parents related to treatment and care of children living with HIV	http://www.aidsmap.com/
Baylor International Pediatric AIDS Initiative	"Now You Know, Now What?" video program	A video which shows children living with HIV talking to other children with the condition	Bipai.org

The literature in this section has provided detailed information regarding paediatric HIV disclosure including its importance, the process of disclosing HIV status to a child, factors associated with disclosure and the availability of peer reviewed and health education materials that can guide the process of HIV disclosure.

2.7 Summary of the literature review

The review of the literature covered issues related to the study objectives, in order to identify gaps in the knowledge and lead up to the rationale for the study. The overriding themes that emerged from the review were the extraordinary life stress experienced by children living with HIV in Sub-Saharan African countries, the low prevalence of HIV disclosure to these children, the lack of knowledge and challenges faced with regards to disclosure among both primary caregivers and healthcare workers, and the lack of materials to guide the disclosure process.

The next chapter will present the methodology and results of the primary caregivers' survey. The study was conducted to evaluate the current status of HIV disclosure to children living with HIV in Malawi and assess the need and acceptability of children story books that can guide the disclosure process.

3 CHAPTER 3: PRIMARY CAREGIVER SURVEY (STUDY 1)

3.1 INTRODUCTION

This chapter provides detailed information about the methodology and findings of the primary caregivers' survey. The chapter begins with a brief background information of the study. A description of the research questions and hypotheses is then provided. This is followed by an outline of the participants' recruitment criteria and study setting. The next section describes the preparatory activities undertaken prior to data collection, such as translation and piloting of the study instruments. Thereafter, sample, procedure, instrumentation, and data analysis are outlined.

According to the American Academy of Paediatrics and the World Health Organisation (WHO), the early and progressive disclosure of HIV status to children aged between 6 and 12 years is critically important for their wellbeing (American Academy Paediatrics, 1999; World Health Organisation, 2011a). In 2011, following a systematic review of literature by an international group of academics and HIV experts, the WHO published guidelines for HIV disclosure counselling for children up to 12 years of age (World Health Organisation, 2011a). The guidelines recommend that age-appropriate information be given to children as early as possible with full disclosure taking place by the time the child is 12 years of age (World Health Organisation, 2011a).

Despite this recommendation, many children in Sub-Saharan Africa remain unaware of their HIV status (Turissini et al., 2013). There are many reasons why their HIV status is not disclosed. Primary caregivers, who are widely considered to have the principal role of telling children about their HIV status often do not disclose to their child because of concerns about the child's capacity to understand and their emotional readiness to cope with the diagnosis (Kiwanuka et al., 2014; Vreeman et al., 2014). Further, they have concerns about bringing stigma and discrimination to the family (Mburu et al., 2014a), and concerns about lack of support from healthcare workers (Kidia et al., 2014).

In 2015, there were 84,000 (1.6% of the total Malawian population) children under the age of 14 years living with HIV in Malawi (United Nations programme for HIV/AIDS Malawi, 2016). Of these, 60% were on HIV medications (United Nations programme for HIV/AIDS Malawi, 2016). The prevalence and current practices of HIV disclosure to children in Malawi have not previously been reported. Nonetheless, there are reports that the stigma surrounding HIV is substantial and discrimination against people living with HIV is common (Kim et al., 2015b; Nyando, 2014). Moreover, there are accounts that parents feel uncomfortable about discussing HIV, because it is considered inappropriate to talk to children about sexual issues (Mandalazi et al., 2014). Although the survival rate of children living with HIV in Malawi has increased due to the increased availability of antiretroviral medications, these children continue to experience numerous challenges negatively impacting on their physical and mental health (Malawi Government, 2015). These challenges include: high levels of poverty (Nyando, 2014; World Bank, 2013a) stigma, discrimination and bullying (Kim et al., 2015b; Pindani et al., 2014), and the loss of one or both parents (Schenk et al., 2010; Sefasi, 2010).

This study aimed to provide significant information regarding the prevalence of non-disclosure among children living with HIV in Malawi, the practice of disclosure of HIV status to children including the facilitators and the barriers, as well as prevalence of and factors associated with mental wellbeing of children living with HIV. The study also aimed to provide insight into primary caregivers' views about the proposed disclosure resource. This information is expected to be highly useful in the planning and development of the proposed story books. As well, the information would be valuable in the planning and development of community-based interventions to provide support for children and their families, so as to minimise significant mental health morbidity and the associated impact on families and communities. Finally, the findings of this study will also inform the development of disclosure policies and guidelines in Malawi.

3.2 METHODOLOGY

The following sections will present the methodology of the study. It will start with a description of the research questions and hypothesis. This will be followed by an outline of the study participants and recruitment criteria. The next sections will describe the study setting, preparatory stage of the study, and sample size considerations. Finally, the recruitment and data collection procedures will be provided.

3.2.1 Research questions and hypotheses

This study addressed the following four main research questions: (1) What are the knowledge and practice of primary caregivers in Malawi with regards to HIV status disclosure to their children living with HIV? (2) What are their views regarding the need, acceptability and benefits of the proposed children's story books for guiding the process of informing their children about their HIV status? (3) How does their decision to disclose HIV status to their children differ by demographics, child and family psychosocial factors, and child health factors? (4) How do their reports of emotional and behavioural problems of their children living with HIV in Malawi differ by demographics, child and family psychosocial factors, and child health factors?

Research questions 3 and 4 were guided by hypotheses because they assessed the quantitative relationships between variables.

The following hypotheses were examined for research question 3:

a) Non-disclosure of HIV status to children living with HIV in Malawi is independently associated with primary caregivers' region of residence, tribe, relationship with the child, age, gender, occupation, level of education, marital status, socioeconomic status, number of children younger or older than 12 years staying at home and spouse's occupation and level of education.
b) Non-disclosure of HIV status to children living with HIV in Malawi is independently associated with the child's age, gender, WHO HIV clinical stage, nutritional status, duration of taking ART, the child asking for reasons for taking ART, and the child's refusal to take ART.
c) Non-disclosure of HIV status to children living with HIV in Malawi is independently associated with primary caregivers' report of the child's emotional and behavioural problems, level of impact of illness on family, level of functional support, and number of stressful life events.

The following hypotheses were tested for research question 4:

1. Emotional and behavioural problems of children living with HIV are independently associated with primary caregivers' tribe, relationship with the child, age, gender, occupation, level of education, marital status, socioeconomic status, number of children younger or older than 12 years staying at home and spouse's occupation and level of education.
2. Emotional and behavioural problems of children living with HIV are independently associated with the child's age, gender, WHO HIV clinical stage, nutritional status, and duration of taking ART.
3. Emotional and behavioural problems of children living with HIV are independently associated with level of impact of illness on family, number of stressful life events in the family and level of functional social support.

3.2.2 Study participants and recruitment criteria

The study participants were 429 primary caregivers of children living with HIV. The recruitment criteria for primary caregivers were: parent of a child living with HIV or someone providing care to a child living with HIV between the ages of 6 to 12 years for more than six months; 18 years or older; and ability to provide informed consent.

3.2.3 Study setting

The study sites for primary caregivers were selected from the three administrative regions of Malawi, namely Northern, Central, and Southern regions. These regions exhibit great diversity in socioeconomic, cultural, and geographical features. The Southern Region is the most populous of the three with a population of 6.7 million, followed by the Central Region with 6.3 million and the Northern Region with 1.9 million

(Population Reference Bureau and Malawi Government, 2012). The largest proportion of women with formal education is found in the Northern region (96%), followed by the Central Region and the Southern Region (83% each) (National Statistical Office, 2011). Likewise, among men, the Northern Region also has the largest proportion (98%) who have formal education compared to the Southern and Central regions (93% each) (National Statistical Office, 2011). In terms of wealth, the Northern Region has the highest proportion of people in the wealthiest and wealthy quintiles while the Central region has the highest proportion of people in the poorest and poor quintiles, with the Southern region in between these. According to a national survey conducted by the Malawi National Statistics Office, on average each person spends 46,160 Kwacha (69 USD) per month in the Northern Region, 57,455 (86 USD) per month in the Central Region and 54, 269 Kwacha (81 USD) per month in the Southern Region (the regions include rural and urban) (Malawi National Statistical Office 2012). Overall the prevalence of HIV is highest in the Southern Region (17 %) followed by the Central Region (9%) and then the Northern Region (8%).

For administrative purposes, the country is further divided into districts. There are 28 districts in Malawi: 13 in the Southern Region, nine in the Central Region and six in the Northern Region. The number of districts selected from each region as study sites was determined by the total number of districts in the region. Eight districts (three from the Southern Region, three from the Central Region, and two from the Northern Region) were selected as study sites (see Table 3.1). Districts were grouped under their respective Regions before assigning them numbers according to the number of districts in the Regions. Random numbers were then generated corresponding to the number of districts required in the region.

The districts chosen were Mulanje, Nsanje, Mangochi, Salima, Dowa, Kasungu, Mzimba and Karonga. Each district in Malawi has a District Hospital which acts as a referral facility for all Health Centres and Community Hospitals within that district. In addition, each District Hospital has an ART Clinic. The ART Clinics are in designated areas in the District Hospitals. This is where primary caregivers and healthcare workers were recruited for study participation (see Table 3.1). ART Clinics were chosen as data collection study sites because these were convenient places where the primary caregivers of children living with HIV could be accessed when they brought their children for their monthly or quarterly collection of ART medications. The great majority of children living with HIV in Malawi are treated in the ART clinics.

Table 3.1: Research sites

Region	District	Health facility
Southern	Mulanje	Mulanje District Hospital
	Nsanje	Nsanje District Hospital
	Mangochi	Mangochi District Hospital
Central	Salima	Salima District Hospital
	Dowa	Dowa District Hospital
	Kasungu	Kasungu District Hospital
Northern	Mzimba	Mzimba South District Hospital
	Karonga	Karonga District Hospital

The following sub-section presents a comparison between districts regarding Malawi's rates of common health and socioeconomic problems. In the sub-sections after this the basic demographic characteristics and hospital facilities located in each of the eight districts are described.

3.2.3.1 Comparison between districts regarding Malawi's rates of common health and socioeconomic problems

According to the Malawi National Statistics Office (2012), Kasungu district had the highest prevalence of HIV (15.1%) followed by Nsanje (14.3%) and then Dowa 1(3.2%). The least proportion of people living with HIV was found in Salima (4.7%), Mzimba (5.2%) and Mangochi (5.3%) districts. With regard to accessibility to healthcare, Salima district had the largest proportion of people with inadequate healthcare (62.9%) followed by Nsanje ditrict (46.5%). On the other hand, Mulanje district had the least proportion of people with inadequate healthcare (14.4%) see Table 3.2).

In respect to socioeconomic problems, Nsanje district had by far the largest proportion of poor people (81.2%) followed by Mangochi district (73.2%), with Kasungu district having the least proportion (33.6%). The highest literacy level was found in Kasungu (78.8%), with Mangochi having the lowest literacy (34.1%) (see Table 3.2).

Table 3.2: Comparison between districts regarding Malawi's rate of common health and socioeconomic problems

District	Prevalence of HIV	Literacy level (%)	Poverty level	[a]Prevalence of common illnesses	Inadequate healthcare	Food shortage
Mulanje	10.5	62.3	65.3	20.3	14.4	85.5
Nsanje	14.3	45.5	81.2	15.3	46.5	52.9
Mangochi	5.3	34.1	73.2	13.0	33.8	54.0
Salima	13.2	70.3	45.6	20.4	48.8	43.0
Dowa	4.7	57.3	41.1	23.3	62.9	66.9
Kasungu	15.1	78.8	33.6	22.6	45.7	43.7
Mzimba	5.2	72.8	60.9	17.8	22.0	45.5
Karonga	12.1	74.9	61.7	14.0	22.5	42.9
Malawi	**8.8**	**65.4**	**50.7**	**17.8**	**32.7**	**49.1**

(Malawi National Statistical Office 2012) [a] Proportion of people reported to suffer from any of the following common illnesses; malaria, fever, diarrhoea, respiratory infection, headache, sore throat and flu

3.2.3.1.1 Mangochi District

Mangochi District is located in the Southern Region of the country and it covers an area of 6,273 km^2. The estimated population in 2015 was 1,017,070 (Malawi National Statistics Office, 2008) . Two thirds of the population are under 25 years of age. Four per cent of both males and females completed secondary education (ICEIDA, 2011). In 2015, 13 per cent of women and eight per cent of men were unemployed (Population Reference Bureau, 2014). The main sources of income in the district are fishing and farming (Population Reference Bureau, 2014). Tobacco is the main cash crop . More than 75 per cent of the population are from the Yao tribe (ICEIDA, 2011).

Mangochi District Hospital is the sole Government referral facility for all health centres and rural hospitals in the District. The ART Clinic is housed in a separate building. There is adequate space, however there are limited seats for patients (see Figures 3.1 and 3.2). Most patients sit on the floor. The building is not well ventilated, and it has limited windows. The clinic attends to more than 50 patients per day and it is open five days a week, from Monday to Friday. Thursdays are for children only.

Figure 3.1: ART group counselling for new patients at Mangochi District Hospital ART Clinic

Normally there are four members of staff on each clinic day; two Nurses, one Clinician, and one Data Clerk. It is difficult for healthcare workers to provide adequate individualised care because of the large number of patients. The members of staff at the clinic are of mixed age: young, middle-aged and the older. Good cooperation and interpersonal relationships were observed among the members of staff.

Figure 3.2: Patients waiting in the corridor at Mangochi District Hospital ART Clinic to collect medication

3.2.3.1.2 Mulanje District

Mulanje District is located in the Southern Region of the country and covers an area of 2, 056 km^2 (International Labour Organisation and Government of Malawi, 2011). The estimated population for 2015 was 572,305 (Malawi National Statistics Office, 2008). Ninety per cent of people had an improved source of drinking water and five per cent had access to electricity. Three per cent of females and nine per cent of males had completed secondary education. One in every five women and one in every 11 men were unemployed. Two thirds of the population were under 25 years of age (Population Reference Bureau, 2014).

Mulanje District Hospital is a referral hospital is a referral centre for more than 20 health facilities in the district (see Figure 3.3). The District Hospital provides a range of services, one of them being HIV care, which is provided at the ART Clinic. The Clinic is located in a separate building. It is open every weekday for both children and adults. The clinic receives more than 30 patients per day.

Figure 3.3: Mulanje District Hospital

Space and seats for patients are limited (see figure 3.4). On each clinic day, four members of staff (two nurses, one clinician, and one data clerk) are on duty. The members of staff at the clinic hold different qualifications in their field ranging from Certificate to Diploma. The majority of staff members have many years of experience working in the ART Clinic. A high level of cooperation and interpersonal relationships was observed among members of staff.

Figure 3.4: Patients and primary caregivers queuing at Mulanje District Hospital ART Clinic as they wait to collect medication

3.2.3.1.3 Nsanje District

Nsanje District is located in the Southern Region, approximately 179 kilometres South of Blantyre City. The district has a total area of 1,942 km^2. Nsanje had an estimated population of 281,552 in 2015 (Malawi National Statistics Office, 2008). Sena is the major tribe in the district. The majority of the population (90%) have access to an improved source of drinking water. Only five per cent of the population have access to electricity. In 2015, only three per cent of women and seven per cent of men had completed secondary education. The main source of income in the district is agriculture. The Shire River passes through the district as it flows into Zambezi River. A large part of the district is flat, as such it is prone to floods during the rainy season (Malawi Government, 2012b).

The Nsanje District Hospital is the district's public referral hospital. The hospital is located at the hub of the district. The hospital provides services, such as maternal health, child health, family planning, dental care, surgery and HIV care. HIV care is provided at ART Clinic. The Clinic operates every weekday, with more than 20 patients attending each day. The physical resources in the Clinic, such as space and seating, are adequate.

Nonetheless, there are limited clinic rooms for staff. In addition, basic equipment is inadequate. There are more than five members of staff in the clinic and on each clinic day three staff members are available to attend to patients. The health professionals in the clinic have Certificate and Diploma qualifications in their respective fields. Most of the staff members have several years experience of working in the ART clinic.

3.2.3.1.4 Salima District

Salima is a district located in the Central Region, 103 kilometres south of the capital city, Lilongwe. It covers an area of 2,196 km^2. In 2015, it had an estimated population of 419,448 (Malawi National Statistics Office, 2008). Chewa is the major tribe in the district followed by Yao. Eight per cent of the population have access to electricity. Fourteen per cent of women and 10 per cent of men are unemployed (Population Reference Bureau, 2014). Ninety per cent of the population depends on agriculture for income. One hundred square kilometres of the district is covered by Lake Malawi, with beaches along the lake shore a tourist attraction.

The district has a 168-bed capacity District Hospital, located at the centre. It acts as a referral facility to 12 healthcare centres, four dispensaries and 59 outreach clinics. The hospital has several departments including antiretroviral, dental, theatre, laboratory, and radiology. The ART Clinic is located in a new building, built by the Baylor College of Medicine in USA. The clinic opens every day from Monday to Friday and there are more than 20 patients on each clinic day. The Clinic is supported by both the District Hospital and the Baylor College of Medicine. The clinic has adequate space and seats for patients. In addition, the clinic rooms and basic equipment are also adequate. There are two categories of staff; those from the District Hospital and those from Baylor College. There are more than five members of staff on each clinic day. The members of staff are mostly middle aged with Certificate, Diploma and Degree qualifications. High levels of cooperation and good interpersonal relationships among the members of staff were observed.

3.2.3.1.5 Dowa District

Dowa district is located in the Central Region at a distance of 34 kilometres from Lilongwe, the capital city of Malawi. It covers an area of 3,041 km^2 and had an estimated population of 764,414 in 2014 (Population Reference Bureau, 2014). The Chewa are the main ethnic group followed by the Ngoni. Slightly less than three-quarters of the population (70%) have access to an improved source of drinking water. 97 per cent of the population have no access to electricity. Two per cent of females and four per cent of males have completed secondary education. Thirteen per cent of men and five per cent of women are unemployed (Malawi National Statistics Office, 2008).

Dowa has a hospital located at the centre of the district. The District Hospital acts as a referral facility for health centres and rural hospitals in the district. The District hospital has an ART Clinic. The clinic opens every day from Monday to Friday. However, children living with HIV are seen once a month (the last Monday of the month). More than 20 patients receive care at the clinic every day. The clinic is in a stand alone building. The building has limited space and seats for patients (see Figure 3.5). However, the clinic has essential basic equipment.

Figure 3.5: Patients waiting to receive ART in the corridor at Dowa District Hospital ART Clinic

The clinic has four members of staff, namely: Clinician, Nurse, Counsellor and Data Clerk. All members of staff are middle aged with qualifications ranging from Certificate to Diploma in their specific fields. All the four members of staff have many years of experience working in the hospital as well as the clinic. High levels of cooperation and good interpersonal relationships were observed among the members of staff.

3.2.3.1.6 Kasungu District

Kasungu is located in the Central Region, 124 km north of Lilongwe, Malawi’s capital city. It covers an area of 7,878 km^2. In 2015 it had an estimated population of 826,285 (Malawi National Statistics Office, 2008). The two main tribes in the district are Chewa and Tumbuka. Sixty per cent of the population have access to an improved source of drinking water. Five per cent of the population have access to electricity. Only three per cent of women and five percent of men have completed secondary education in the district. Thirty-six per cent of women and six per cent of men are unemployed (Population Reference Bureau, 2014). The economy of the district is mainly based on agriculture. The major crops grown in the district are maize, tobacco, beans groundnuts, and sweet potato. Tourism is also another source of income. The district has a national park located 65 kilometres to the West of the District Headquarters (Kasungu District Council, 2002).

The District Hospital is located at the District Headquarters. It is a government-funded hospital with 179-bed capacity (Kasungu District Council, 2002). The district hospital has an ART clinic located within the hospital premises. The clinic opens every weekday; two days (Wednesday and Thursday) for children and three days (Monday, Tuesday, and Friday) for adults. More than 20 patients receive healthcare on each clinic day. The clinic has adequate space and seating for patients. It has enough rooms for members of staff and adequate basic equipment. The clinic has more than five members of staff and there are five members of staff on each clinic day (two Nurses, one Clinician, one Data Clerk, and one Counsellor). The qualifications for members of staff in the clinic include certificate, diploma and degree. Most of the members of staff are middle aged and have many years of experience working at the hospital as well as the clinic. The researcher observed high levels of cooperation and good interpersonal relationships among the healthcare professionals working at the clinic.

3.2.3.1.7 Mzimba District

Mzimba district is located in the Northern Region of the country. It covers an area of 10,430 KM^2. In 2015, the district had an estimated 895,550 (Population Reference Bureau, 2014). The district has two main tribes Ngoni and Tumbuka. Tumbuka is the common language in the district. Eighty-four per cent of the population have access to an improved source of water. Eight per cent of the population have access to electricity. Only seven per cent of women and 10 per cent of men complete secondary education. Twenty per cent of men and five per cent of women are unemployed (Population Reference Bureau, 2014). People in the district depend on farming as a means of livelihood. Maize and beans are grown as staple and cash crops. Tobacco is grown as a subsistence crop. Due to job scarcity, many young men in the district migrate to South Africa in search of work, leaving their wives behind. This has contributed to the spread of HIV in the district (Muula, 2008).

Mzimba District Hospital ART clinic opens every day from Monday to Friday for patients. Three days a week (Monday, Tuesday and Friday) are open for adults, while two days a week (Wednesday and Thursday) are open for children. The clinic sees more than 20 patients per day. The clinic does not receive its own funding. The District Hospital management team provides resources to the clinic. There is limited space at the clinic to accommodate all the patients (see Figure 3.6).

Figure 3.6: Patients waiting to collect ART at Mzimba South District Hospital ART Clinic

There are more than five members of staff at the clinic who were trained in ART. The members who have received this training take rotation shifts at the clinic. On each clinic day there are three people who attend to the patients: the Clinician, Nurse, and Data Clerk, who also doubles as a Counsellor. The members of staff at the clinic are of mixed age groups; older, middle-aged, and young. Their qualifications range from Certificate to Degree. Most have many years working in the hospital as well as in ART clinic.

3.2.3.1.8 Karonga District

Karonga district is located in the Northern region, 200 kilometres North of the administrative capital of the region, Mzuzu and 595 km from Lilongwe, Malawi’s capital city. The district covers an area of 3,355 km^2. In 2015, the district had an estimated population of 337,448 (Malawi National Statistics Office, 2008). There are two main tribes in the district, Tumbuka and Nkhonde. More than three quarters (84%) of the population have access to an improved source of drinking water. Less than 10 per cent of the population have access to electricity. Five per cent of women and 10 per cent of men have completed secondary education. Twenty-five per cent of women and five per cent of men are unemployed (Population Reference Bureau, 2014). People depend on subsistence farming and fishing as a means of livelihood. The district also has a mining project, the Kayelekera Uranium Mine, which is run by the Paladin Company. The mine was opened in 2009 and has offered employment to people in the district.

The district has a 200-bed public District Hospital located at the District Headquarters. The hospital is a referral facility to two rural hospitals and 10 health centres in the district.

The common prevalent diseases in children are malaria, pneumonia and diarrhoea, these diseases also account for child mortality rate. HIV is the main cause of adult deaths in the district. The clinic sees more than 20 patients each clinic day. The clinic opens every weekday. It is open to children on Wednesdays. The resources used in the clinic are supplied by the District Hospital. With regards to physical resources, space is inadequate, and it is crowded on clinic days. The clinic has few benches for patient seating and some patients stand as they wait to be seen by the Clinician or Nurse (see Figures 3.7 and 3.8).

Figure 3.7: Benches for patient seating at Karonga District Hospital ART Clinic

The clinic has four rooms; one for the Nurse, another for the Clinician, the third one for the Data Clerk and last one for HIV testing. The clinic has limited equipment. There are more than five middle-aged members of staff with qualifications ranging from Certificate to Diploma. Most of the staff members have more than five years of work experience in the hospital and more than two years’ work experience in the ART clinic. The members of staff were observed to have high levels of cooperation and good interpersonal relationships.

Figure 3.8: Patients and primary caregivers waiting to collect medication at Karonga District Hospital ART Clinic

3.2.4 Preparatory stage of the study

This stage involved the planning and organisation of the data collection. The activities in this stage included: translation of study instruments; seeking ethical approval; recruitment and training of research assistants; and piloting data collection instruments. The preparatory stage activities were conducted between July 2014 and March 2015.

3.2.4.1 <u>Translation of study instruments</u>

Since the majority of primary caregivers in Malawi are illiterate and do not understand English, it was important to translate the English version of the primary caregiver questionnaire into Chichewa which is the Malawian local language. The translation followed the World Health Organisation's standardized and validated translation process (WHO, 2014). During forward translation, the English questionnaire was translated by a professional independent translator whose first language was Chichewa and who was familiar with terminology related to the research area. The translation was conducted for a fee and it took two weeks to be completed. During the translation, the translator liaised with the researcher through email and phone to seek or provide clarification about the questionnaire.

Three Malawian experts in Psychology, Nursing, and Public Health respectively, who were fluent in both English and Chichewa were then delegated to work with the professional translator to assess the accuracy of the vocabulary of the instruments and clarity of the items and address any problems. Specifically, the team was asked to resolve the following: 1) to verify if the translated Chichewa word had the exact equivalent meaning of the English word in the original questionnaire, 2) to find an alternative word if the translated Chichewa word was not the exact equivalent of the English word 3) to assess if the alternative Chichewa word would be easily understood by all the participants who would be responding to the questionnaire; and 4) to assess the clarity of the questionnaire items for the reader. The panel of experts met on three separate occasions to review the questionnaire. If there was not a suitable Chichewa word for a particular English word, the panel identified the simplest word that could be understood by the general Malawian population to replace the English word.

A small number of issues regarding the translation were raised. For example, for the translation of the term 'HIV', the translator felt that this should be left untranslated as there was no direct vernacular word for it. Furthermore, the translator reported that most Malawians knew the meaning of HIV. The panel of health experts, however, recommended that the term should be translated in a simpler way so that all participants could understand including those who were illiterate as such the term was changed to 'kachilombo komwe kamayambitsa matenda a Edzi' which means an organism that causes AIDS. The panel also had problems understanding the translation of the term 'composting toilet' which is a one of the response categories for Question A12, which asked about the type of toilet facility used by members of the household. Compositing toilet was translated as '*Chimbudzi chokolola manyowa*' meaning a type of toilet that act as a source of manure. One of the members felt the translation would be difficult for participants to understand and suggested that it should be changed to '*Nyumba ya chimbudzi yomwe imasunga chimbudzi mpaka chitasanduka manyowa*' which means a toilet that allows the human excreta to decompose. However, after discussion the panel felt the former translation was better than the latter because it was well known by the majority of Malawians. As a final example, the heading of Question E2 which reads 'burdens that come due to the illness of the child, was translated as '*mavuto womwe akudza chifukwa cha matenda a mwana*' meaning problems that come due to the child's illness. The panel members felt this changed the meaning of the original word "burden' and they, therefore, proposed that the translation should read '*Ziphinjo zakudza chifukwa cha matenda a mwana*' which means burdens associated with the child's illness.

After the addressing all the suggestions raised by the panel of experts, the questionnaire was then back-translated for a fee to English by another independent professional translator whose expertise was in English language. Once again, another panel of three experts with expertise in Psychology, Nursing, and Public Health respectively were asked to assess the back-translated questionnaire and correct all anomalies. The experts thought Question B3, which was about WHO clinical staging of HIV disease was unclear. The back translation had this question phrased as 'In which category of HIV is your child according to the HIV standards set by the World Health Organisation?' This was relatively different in meaning to the way the question was phrased in the original questionnaire 'what is your child's WHO clinical staging of HIV disease?' The experts thought that the word 'category' referring to stage had somehow changed the meaning, they advised that the forward translated version be checked to ensure that its meaning was aligned to stage of HIV rather than category. The questionnaire was finally corrected in line with the suggestion raised by the panel (see Appendix V).

3.2.4.2 Seeking ethical approval

The research proposal was first submitted to the Curtin Human Research Ethics Committee for ethics approval. Upon obtaining this approval, the proposal was then submitted to the Malawi National Health Science Research Committee for approval. Further consent to conduct the study was obtained from the heads of the hospitals (District Health Officers) where the study was conducted. The researcher also liaised with the Ministry of Health and heads of the study sites on the procedures of the study and type of support that was required for an effective data collection process.

3.2.4.3 Recruitment and training of research assistants

A data collection protocol was developed prior to the recruitment and training of research assistants. The data collection protocol included information regarding: self-introduction; respect for participants; how to dress during data collection; how to communicate effectively with participants; the appropriate time to collect data from participants; provision of confidentiality and privacy to participants during and after data collection; how to take care of the children while data collection was in progress; the provision of compensations to participants; important information to be provided to participants before and during data collection; and how informed consent was to be obtained from participants. Other topics covered in the protocol included study recruitment and the data collection procedure.

Two short forms for data collection were also developed. The first one was designed to collect general information related to the process of data collection from potential and actual participants who were approached to participate in the study. The form was used to collect the following information: date, day, and time of data collection; name of the research assistant who collected data; name of the health facility; the weather conditions during data collection; whether the potential participant agreed to participate in the study or not; and reasons provided by potential participants who declined to participate in the study. The participant's observed level of understanding was also recorded. The second form was designed to collect information on clinic resources and the number of patients attending the clinic. The form collected information about financial resources, physical resources, human resources, social resources, and the number of children and adults attended to by clinic staff.

Two Research Assistants per district with professional qualifications in Nursing, Public Health, and Clinical Medicine were employed. Under the supervision of the researcher, the Research Assistants were responsible for interviewing primary caregivers to collect questionnaire data. A two-day training workshop was organised for the Research Assistants. The first day focused on orienting them to the data collection instrument and protocols. On the second day of training, the participants were given practical experience of data collection. First, the Research Assistants observed while the researcher collected data from participants. Thereafter, the Research Assistants collected data from participants while the researcher was observing. These data did not form part of the data that were reported in this thesis. The Assistants were given feedback on areas they had done well and those that needed improvement.

3.2.4.4 Piloting the data collection

The study instruments were piloted at the Mapale Health Centre in Mzuzu, which was excluded from the study sample. The participants were 10 primary caregivers of children living with HIV. Twenty-four names of primary caregivers of children living with HIV within the ages of 6 to 12 years who had clinic appointments within the following two weeks were obtained from the register prior to appointment dates with assistance from the clinic in-charge. The ART clinics normally keep a register of children living with HIV and their caregivers. The register also contains appointment dates when children and their primary caregivers come to collect ART medications. The names obtained from the register were assigned numbers. Thereafter, a computer was asked to generate 10 numbers within the range of 1 to 24. The names of primary caregivers whose numbers matched the computer-generated numbers were selected as potential participants for the study. The 10 participants had three different appointment days, with three participants scheduled to come on the first appointment day, four the next appointment day, and the last three on the third appointment day.

Only one potential participant attended their appointment at the clinic on the first and second appointment days while two attended on the third appointment day. For this reason, the researcher changed the recruitment method for the remaining six potential participants by randomly selecting participants based on their arrival time to the clinic. The participants were first assigned numbers based on the arrival time to the clinic. The first to come was assigned number one, the next number two and the last to come was assigned the last number based on the number of eligible participants who came to the clinic on that day. The study protocols were altered after the pilot study.

The following paragraphs provide detailed information about sample size calculation, recruitment and data collection procedures of variable derivation and data analysis.

3.2.5 Sample size

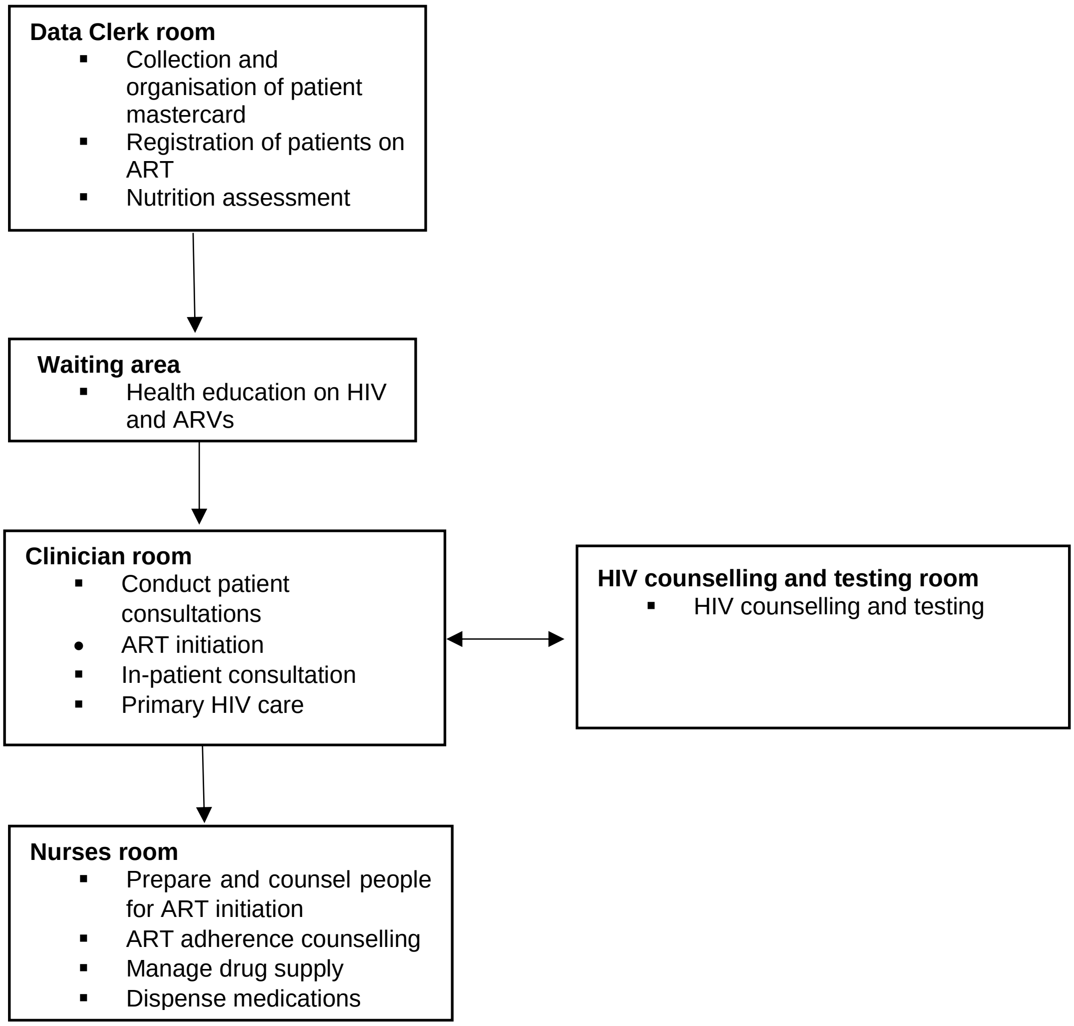
The sample size was calculated on the basis of the disclosure rate of HIV status among children aged nine to 12 years as reported in a recent study (Vreeman et al., 2014). It was calculated that a sample size of 318 was required to provide 90 per cent power to detect a difference in disclosure rate between the two age groups, with a five per cent chance that a significant difference was due to chance (Rosner, 2011). Assuming a response rate of 89 per cent which was achieved in a study conducted in Sub-Saharan Africa (Menon, Glazebrook, Campain, & Ngoma, 2007), a final sample size of 353 was calculated.

3.2.6 Service delivery and flow of patients at ART clinics in Malawi

In Malawi, ART clinics are open daily from Monday to Friday from 7.30 in the morning to 4.30 in the evening. The Clinics routinely provide two major services; primary healthcare services and the provision of ART to people living with HIV. As detailed previously, most clinics have special days in the week when they are open specifically for children living with HIV. On the clinic day, it is a requirement that children come to the clinic accompanied by their primary caregiver. On arrival at the clinic, the primary caregiver and his or her child are first seen by the clinic Data Clerk (see Figure 3.9). The primary caregiver collects the child’s Healthcare Mastercard from the Data Clerk. The card contains important information related to treatment. The card is kept at the clinic and is given to the primary caregiver on every clinic appointment day in order to be used for that day’s recording of services provided. The Data Clerks take the children’s anthropometric measurements, such as weight and height. From the Data Clerk’s room, the primary caregiver and child go to the waiting area where they are given health talks on various aspects of HIV. The talks are aimed to equip the primary caregiver with information that can help them to take care of the child.

After the health talk, the child is seen by a Clinician who assesses the child for any ART complications (see Figure 3.9). If the child is coming to start ART treatment, he or she is assessed for eligibility. Children that require HIV status confirmation are referred to the HIV testing and counselling room for HIV testing. Children are also treated for any other condition that they may have. From the Clinician room, the child and primary caregiver are referred to the Clinic Nurse to collect the medications. The Clinic Nurse also provides education on medication compliance and side effects, as well as what to do in case of adverse side effects. The Clinic Nurse then provides the next clinic appointment date to the primary caregiver.

Figure 3.9: The flow of patients at ART clinic in Malawi



3.2.7 Recruitment Procedure

Upon obtaining ethics clearance from the Malawi National Health Sciences Research Committee, the researcher sought permission to conduct the study from the District Health Officers (DHOs) of the eight district hospitals. The researcher met all the DHOs separately to brief them on the study protocol. A copy of the proposal was given to the DHOs to enable them have a full understanding of the study. After granting permission to conduct the study at their facility, the DHOs communicated with the Head of the ART clinics, instructing them to give the necessary support to the researcher. A meeting was thereafter arranged between the research team and the Head of each ART clinic. During the meeting, the researcher briefed the Clinic Head on the study protocol. Issues related to the study that were discussed included: topic, aims, objectives of the study, and eligibility criteria for study participants. The study recruitment plan was also discussed in detail. The research team asked the Clinic Head for support with other logistic issues, such as rooms where data collection could be conducted and the dissemination of information about the study to clinic staff.

On the clinic day, study participants were recruited using the systematic approach trialled during the piloting phase. Potential participants were assigned an odd or even number starting from one, based on the time of their arrival at the clinic. Those who were assigned an odd number were screened according to the inclusion/exclusion criteria prior to their participation in the study. A member of the research team who was not part of the clinic staff gave the potential participants information related to aims, procedure, outcomes, benefits and risks of the study as well as their rights in relation to participation or withdraw from the study. Those who were willing to participate in the study were given consent forms to sign or put their thumbprint, if they could not read or write (see Appendix B, C, D).

3.2.8 Data collection procedure

Data collection was conducted from March to July 2015. The research team was assigned a room for data collection within the HIV clinic. The normal waiting time for primary caregivers at the antiretroviral therapy clinic was two to three hours depending on the number of patients in attendance on that day. Data collection took place within the waiting time or after participants had been attended to by the healthcare workers. To prevent inadvertent HIV status disclosure to children, children were separated from their primary caregiver during data collection and were entertained with children’s cartoon shows on a portable DVD player. One Research Assistant was assigned to look after the children. Face to face interviews were used to collect data from study participants. The researcher or Research Assistants administered the questionnaire and recorded participants’ responses. The data collection process took 30 to 40 minutes to be completed. The study parcipants were given a one-kilogram packet of sugar at the end of the interviews as a gift to compensate them for their time. The participants were not told about the gift until the interviews were completed so that it would not be an inducement to participate.

3.2.8.1 Data collection instruments

Data were collected using validated and reliable instruments. The study questionnaire was translated from English to Chichewa (Malawian local language) and then back-translated to English, as described earlier. The questionnaire had six sections: a) demographic and socioeconomic characteristics; b) child's anthropometric measurements and HIV clinical staging; c) disclosure of HIV status to the child and need for the disclosure resource; d) children's psychosocial adjustment; e) family life and impact of the child's illness; and f) family support.

3.2.8.1.1 Section A: Demographic and socioeconomic characteristics

The questionnaire collected the following demographic data for the primary caregiver: relationship to the child; age; tribe; gender; occupation; occupation of spouse; level of education; level of education of spouse; number of children aged 12 years or younger; number of children older than 12 years; and marital status (see Appendix D). Examples of questions included in this section are: *What is your child's age? (6 years/7 years/8 years, etc); What is your child's gender? (Male/Female); What is your marital status? (married/single/widowed/divorced).* Socioeconomic status was measured by the Wealth Index, a tool developed by the World Bank to measure the household socioeconomic status in developing countries on the basis of household's ownership of consumer goods, dwelling characteristics, type of drinking water source, toilet facilities, and other characteristics (Gwatkin, Rutstein, Johnson, Pande, & Wagstafff, 2000) (see Appendix D). These household assets were combined into a composite index of economic status by applying weights from the 2010, Malawi National Demographic Health Survey. The tool has been used and validated in Malawi (Houweling, Kunst, & Mackenbach, 2003; Morris, Carletto, Hoddinott, & Christiaensen, 2000).

3.2.8.1.2 Section B: HIV clinical staging and anthropometric measurements

The researcher and Researcher Assistants used the children's Health Profile Books as well as clinic patient files to collect and record data on their HIV clinical stage. WHO clinical staging classifies the severity of the child's HIV infection in order to assess their eligibility for ART in low resource settings (WHO, 2005). One of the questions included in this section is; *what is your child's WHO HIV clinical stage? (Stage 1/stage 2/ Stage 3/ Stage 4)* (this information was obtained from the child's health profile book) (see Appendix D). With informed consent from the primary caregivers, children's weight, and height were measured and recorded in the questionnaire by the researcher and Research Assistants at the time of their visit to an ART clinic. The 2000 Centre for Disease Control BMI-for-age percentile cut-offs were used in order to identify children who were either: normal weight, underweight, or overweight/obese (Kuczmarski et al., 2002).

3.2.8.1.3 Section C: Disclosure of HIV status to the child and need for the disclosure resource

Specific questions about the disclosure of HIV status to children living with HIV were adapted from a questionnaire assessing disclosure of HIV status, ART adherence, stigma, facilitators, and barriers to disclosure of HIV status and adherence (Vreeman et al., 2014). The questionnaire was developed and used in Kenya which is one of the sub-Saharan countries with a high HIV prevalence rate among children. The questionnaire also contained items related to the need, acceptability and development of HIV status disclosure resource (see Appendix D). Examples of the questions included in this section include: *Does your child know that he/she has HIV? (Yes, No); Who disclosed the HIV status to your child? (Tick all that apply) (Parents, Healthcare worker, etc)*.

3.2.8.1.4 Section D: Children's psychosocial adjustment

Children's psychosocial adjustment was assessed by the Strengths and Difficulties Questionnaire (SDQ), parent version (Goodman, 1997). It is a well-validated instrument which has been translated into 60 languages including Chichewa (Malawian local language). Although the instrument is not validated in Malawi, it has been widely used in studies in many African countries (Doku, 2009; Menon et al., 2007). The SDQ has 25 items rated on a three-point Likert scale; not true, somewhat true and certainly true. Examples of intems included in this scale are*: Considerate of other people's feelings (not true/somewhat true/certainly true); and Restless, overactive, cannot stay still for long (not true/somewhat true/certainly true).* The questionnaire has five subscales; emotional symptoms, conduct problems, hyperactivity, peer relationship problems and prosocial behaviours (see Appendix D). The five scales assess emotional, conduct, hyperactivity/attention, peer relationship and prosocial problems. Each subscale has five items. For each subscale the score can range from 0 to 10 if all items are completed. The first four subscale items (emotional symptoms, conduct problems, hyperactivity, peer relationship problems) added together generate the total difficulties score. The difficulties score ranges from 0 to 40. The scale has adequate internal consistency (Cronbach's alpha ranging from 0.78 to 0.82) and validity (Goodman, 1997; Theunissen, Vogels, de Wolff, & Reijneveld, 2013). A binary variable (close to average and slightly raised/high/very high) was created from the newer band categorisation of the SDQ total difficulties score (0-13 'close to average'; 14-16 'slightly raised'; 17-19 'high'; > 19 'very high') (Goodman, 2014). Close to average was classified as not having a behavioural or emotional problem while 'slightly raised/high/very high' was classified as having an emotional or behavioural problem (Goodman, 2014).

3.2.8.1.5 Section E: Family life and impact of the child's illness

The Life Stress Scale (LSS), adapted from Tennant and Andrews (Tennant & Andrews, 1976) for use in the Western Australian Pregnancy Cohort (Raine) Study , was used to assess families experience of life-stress (Oddy et al., 2010). The LSS is a 15-item questionnaire with 'yes' or 'no' answer options to the items. For example, participants were asked the following questions: *In the last year, have any of the following happened to you? pregnancy problems (Yes/No); separation or divorce (Yes/No).* The scale has reported adequate reliability (Cronbach's alpha 0.70 to 0.90) and validity (Tennant, Smith, Bebbington, & Hurry, 1979). Primary caregivers were asked to identify all stressful life events that they had experienced in the last year. A binary variable was created by classifying those who experienced less than three stressful life events in one category and those that experienced three or more stressful life events in another category (Oddy et al., 2010).

The impact of the child's illness on the family was measured by the Impact on Family Scale (Stein & Riessman, 1980) which has 29 items, each rated on a four-point Likert scale: strongly agree, agree, disagree, and strongly disagree. For example, participants were asked to indicate if they strongly agreed or agreed or disagreed or strongly disagreed with the following items: *the illness is causing financial problems for the family; time is lost from work because of hospital appointments.* The scale has acceptable internal reliability (Cronbach's alpha ranging from 0.86 to 0.87) and validity in previous studies (Cronin, Shapiro, Casiro, & Cheang, 1995; Hunfeld, Tempels, Passchier, Hazebroek, & Tibboel, 1999; Stein & Riessman, 1980). Total scores range from 15 to 60 with high scores indicating a great impact of the child's illness on the family and lower scores indicating little impact (Stein & Jessop, 2003). A level of impact variable with three categories (low-level impact, significant impact, and very serious impact) was then computed by applying the following cut-off scores; 30 or less as low-level impact, 31 to 45 as significant impact and above 45 as serious impact (Anderson, Elliott, & Zurynski, 2013; Stein & Jessop, 2003).

3.2.8.1.6 Section F: Family support

Primary caregivers' needs for different types of help and assistance was measured by the Support Function Scale, short form version (Dunst, Trivette, & Cross, 1986). The scale has 20 items each rated on a 5-point scale ranging from 1 for 'never need this type of support' to 5 for 'quite often need this type of support'. Participants were asked to what extent they felt a need for any of the following types of help or assistance: *someone to talk to about things that worry you; someone to provide money for food, clothes and other things etc.* The scale has demonstrated adequate internal consistency (Cronbach's alpha ranging from 0.77 to .87) and validity in previous studies (Dunst et al., 1986; Sheeran, Marvin, & Pianta, 1997). Total scores range from 0 to 80 with high scores indicating less need for support and low scores indicating the great need for support. A binary categorical variable on level of support needed (high-level support or low-level support) was computed by applying cut-off scores of 55 or less for the great need for support and above 55 for less need for support (Dunst, Trivette, & Deal, 1988).

3.2.8.2 Data analysis

After data collection, the questionnaires were thoroughly checked for completeness. Descriptive analysis was conducted to identify missing data, outliers and wrong codes. Wrong codes were corrected. There were few missing data, which were at random. The main outcomes of the study were non-disclosure of HIV to children and emotional and behavioural problems of children living with HIV. Variables that estimated the prevalence of child and family characteristics as well as the practice of HIV disclosure were tabulated. Bivariate analyses were conducted to assess the likelihood, or odds, of all child and family socioeconomic, demographic, clinical, and psychosocial variables being associated with HIV non-disclosure or behavioural and emotional problems. Variables that were significantly associated with non-disclosure or emotional and behavioural problems with p-values of ≤ 0.25 on bivariate analysis (Sun, Shook, & Kay, 1996) were then entered into a multivariate logistic regression model using the "Enter" method in order to obtain the adjusted odds of these factors being associated with HIV non-disclosure and emotional and behavioural problems (Charry, Coussement, Demoulin, & Heuvinck, 2016). The Enter method in binary regression allows the inclusion of all variables in the model irrespective of their level of significance in bivariate analysis (Charry et al., 2016). While none of the psychosocial variables (child emotional and behavioural wellbeing, the impact of illness on the family, stressful life events, and family functional support) were significantly associated with non-disclosure in bivariate analysis, they were entered in regression model to find out the strength of their association with HIV non-disclosure following adjustment. Data were analysed using SPSS version 22 and p-values ≤ .05 were considered statistically significant.

3.3 RESULTS

3.3.1 Response rates

A total of 432 primary caregivers from the three administrative regions of Malawi were approached to participate in the study. Three primary caregivers declined to participate;

two were teachers on their way to school, while one needed to attend to family matters at home. A total of 429 primary caregivers were finally recruited into the study representing a response rate of 99.3 per cent. The presentation of the findings is guided by the research questions and hypothesis.

3.3.2 Family socio-demographic characteristics

Table 3.3 presents the prevalence of a range of family socio-demographic characteristics. Table 3.3 shows that all the eight districts and three regions of Malawi were well represented. Mangochi, Nsanje, Kasungu, Karonga and Mzimba districts accounted for 13 per cent each of the total proportion of participants followed by Mulanje and Salima with 12 per cent each and Dowa had the least proportion (11%). In terms of regions, the southern region had the highest proportion of participants (38%), followed by the central (37%) and northern (25%).

Table 3.3 also show that more than half of the primary caregivers (61%) were the biological mothers of children living with HIV, 15 per cent were biological fathers. Half of the primary caregivers (50%) were above 40 years of age. Female primary caregivers accounted for 77 per cent of the study sample compared to their male counterpart (23%). Sixty-four per cent of the primary caregivers were married, while the remainder were either widowed, single, or divorced. More than half of the primary caregivers (56%) had some primary school education, while 22 per cent had no formal education. Almost half (49%) of the participants' spouses had some primary school education, 34 per cent had some secondary or tertiary education and 17 per cent had no education.

The majority of the primary caregivers' (73%) reported that they had less than three children under the age of 12 years while the remaining 27 per cent reported that they had three or more children under the age of 12. Three-quarters of the primary caregivers (76%) reported that they had three or more children older than 12 years and 24 per cent had less than three children older than 12 years. In terms of tribe, the Chewa accounted for 37 per cent of the primary caregivers followed by the Yao (17%), Lomwe and Sena had 13 per cent each, Tumbuka (12%) and other tribes (Tonga, Nkhonde, Mang'anja) 14 per cent.

Table 3.3: Prevalence of family sociodemographic and child characteristics (N=429)

Characteristic	n (%)	Characteristic	n (%)
District Hospital		Marital status of primary caregiver	
Mangochi	55 (13)	Married	273 (64)
Mulanje	53 (12)	Single	43 (10)
Nsanje	55 (13)	Widowed	75 (17)
Kasungu	55 (13)	Divorced	38 (9)
Dowa	49 (11)	Education level of primary caregiver	
Salima	53 (12)	None	94 (22)
Karonga	54 (13)	Primary	240 (56)
Mzimba	55 (13)	Secondary/tertiary	95 (22)
Region		Education level of spouse (n=273)	
Southern	161 (38)	None	47 (17)
Central	159 (37)	Primary	134 (49)
Northern	109 (25)	Secondary/tertiary	92 (34)
Tribe		No of children aged ≤12 years at home	
Chewa	132 (31)	≤ 2	312 (73)
Yao	74 (17)	≥ 3	117 (27)
Tumbuka	53 (12)	No of children aged 12 years at home	
Lomwe	54 (13)	≤ 2	103 (24)
Sena	57 (13)	≥ 3	326 (76)
Others	59 (14)	Occupational status of primary caregiver	
Relationship with the child		Employed/self employed	131 (30)
Mother	263 (61)	Farming	196 (46)
Father	63 (15)	Looking for a job	29 (7)
Grandparent	50 (12)	Home duties	73 (17)
Others	53 (12)	Occupational status of spouse (n=273)	
Age of primary caregiver		Employed/self employed	106 (39)
18-30	51 (12)	Farming	110 (40)
31-40	164 (38)	Looking for a Job	15 (6)
41-50	132 (31)	Home duties	42 (15)
Above 50	82 (19)	Wealth quintiles	
Gender of primary caregiver		Poorest	52 (12)
Male	99 (23)	Poor	43 (10)
Female	330 (77)	Middle	75 (18)
		Wealthy	78 (18)
		Wealthiest	181 (42)

With regard to occupation, 46 per cent of the primary caregivers were earning their livelihood through farming, 30 per cent through business or employment, 17 percent were doing house work while seven per cent were searching for jobs. Forty per cent of the participants' spouses were farmers, 39 per cent were employed or doing business while 15 per cent were doing home duties and the remaining six per cent were searching for jobs. With respect to wealth, sixty per cent of the primary caregivers were either in the wealthy or wealthiest quintiles while 22 per cent were either in the poor or poorest quintiles and the remaining 18 per cent were in the medium quintile.

3.3.3 Ownership of household assets

Table 3.4 displays the prevalence of assets owned by the primary caregivers. Table 3.4 shows that slightly more than half of the primary caregivers owned a radio, wrist watch, and cellular phone (55%, 55% and 53 % respectively). Furthermore, 26 per cent of the primary caregivers had a sofa set, 23 percent had a bank account and 23 percent had a television set. Proportions of 17 per cent and 13 per cent had electricity and a refrigerator in their homes respectively. Fewer than 10 per cent of the primary caregivers owned a landline telephone, motorcycle or scooter, an oxcart, or a car.

Table 3.4: Household ownership of assets (N=429)

Asset	**Availability**	
	Yes **n (%)**	**No** **n (%)**
Electricity	75 (17)	354 (83)
Koloboyi (a traditional lamp)	119 (28)	310 (72)
Paraffin lamp	140 (33)	289 (67)
Radio	235 (55)	194 (45)
Television	98 (23)	331 (77)
Cellular phone	229 (53)	200 (47)
Telephone (landline)	38 (9)	391 (91)
Watch	235 (55)	194 (45)
Bank account	98 (23)	331 (77)
Bed with a mattress	186 (43)	243 (57)
Sofa set?	110 (26)	319 (74)
Table and chair	188 (44)	241 (56)
Refrigerator	57 (13)	372 (87)
Bicycle	176 (41)	253 (59)
Motorcycle or scooter	19 (4)	410 (96)
An oxcart	14 (3)	415 (97)
A car	13 (3)	416 (97)

3.3.4 Household characteristics

Table 3.5 presents the prevalence of household characteristics in terms of the source of drinking water, type of toilet facility, cooking energy, materials of house floor, roof and exterior wall. Table 3.5 shows that 51 per cent of the primary caregivers were getting their drinking water from the borehole, 16 per cent from the tap piped into the yard, 11 per cent from the public taps and less than 10 per cent from protected spring, unprotected spring, protected well, unprotected well, taps piped into dwelling house, and other water sources. More than 60 per cent of the participants were using pit latrines without a slab while 21 per cent were using pit latrines with a slab. Less than 10 percent were using flush toilets, shared flush toilets, ventilated improved individual pit latrines, shared ventilated improved latrines, shared pit latrine with a slab, shared pit latrine without a slab and bush. The majority of the primary caregivers (82%) reported using wood as a source of cooking fuel, 11 per cent were using charcoal, three per cent electricity, another three per cent grass or dung while one per cent said that they were not cooking in the house.

The floor of the house of close to 60 per cent of the primary caregivers was made of sand or earth, 36 per cent from cement, two per cent from dung, one per cent from ceramic tiles, and another one per cent from broken bricks. Fifty-one per cent of primary caregivers had the roof of their houses made of grass, followed by iron sheets (45%) and roofing tiles (4%). As shown in Table 3.5, 41 per cent of primary caregivers had houses with exterior walls made of burnt bricks, 22 per cent unburnt bricks, 14 per cent stones smeared with mud and less than 10 per cent bamboo or tree trunks with mud, cement, dirt, grass, and other rudimentary materials.

Table 3.5: Household characteristics (N=429)

Characteristic	n (%)
Drinking water source	
Piped into dwelling	17 (4)
Piped to yard or plot	69 (16)
Public taps/standpipe	147 (11)
Borehole	218 (51)
Protected well	23 (5)
Unprotected well	10 (2)
Protected spring	16 (4)
Unprotected spring	11 (3)
River, stream, pond, lake or dam	13 (3)
Other source	5 (1)
Toilet facility	
Flush toilet	10 (2)
Shared flush toilet	3 (1)
Ventilated improved latrine	7 (2)
shared pit latrine (VIP)	3 (1)
Pit latrine with a slab	92 (21)
Shared pit latrine w slab	20 (5)
Pit latrine without a slab/one pit	263 (61)
Shared pit latrine w/o slab	20 (5)
No facility/bush/field	8 (2)
Other type	3 (1)
Cooking fuel	
Electricity	12 (3)
Coal/charcoal	47 (11)
straw/shrubs/grass, dung	12 (3)
Wood	353 (82)
No food cooked in the house	5 (1)
Materials of house floor	
Earth/sand	252 (59)
Broken bricks	6 (1)
Ceramic tiles	6 (1)
Cement	156 (36)
Dung	9 (2)
Material of the roof	
Palm/bamboo/grass	217 (51)
Iron sheets	195 (45)
Made of finished materials/roofing tiles	17 (4)
Material of the exterior walls of the house	
Bamboo/tree trunks with mud	12 (3)
Cement	17 (4)
Burnt bricks	177 (41)
Unburnt bricks	95 (22)
Stone smeared with mud	59 (14)
Made of dirt	12 (3)
Made of other materials	23 (5)
Made of cane/palm/trunks/grass materials	21 (5)
Made of stone/mud and rudimentary materials	13 (3)

3.3.5 Ownership of agricultural land and food security

The prevalence of primary caregivers’ ownership of agricultural land, livestock, and food security is presented in Table 3.6. Table 3.6 shows that more than three-quarters of the primary caregivers reported that they owned land while the remaining 23 per cent did not. For those who owned land, 49 per cent had one to two acres, 25 per cent had three to five acres, 10 per cent had more than five acres, and 16 per cent did not know the dimensions of their land.

Table 3.6: Ownership of agricultural land, livestock and food security (N=429)

Characteristic	n (%)
Ownership of agricultural land	
Yes	328 (77)
No	101 (23)
No of acres owned	
1-2	161 (49)
3-5	81 (25)
>5	33 (10)
I don't Know	53 (16)
No of meals in the last 7 days	
1	15 (4)
2	155 (36)
≥3	259 (60)
Household food sufficiency in the last year	
Yes	205 (48)
No	224 (52)
Ownership of livestock	
Yes	265 (62)
No	164 (38)
Type of Livestock owned	
Goats	99 (38)
Pigs	25 (9)
Cattle	25 (9)
Chickens	116 (44)

Table 3.6 shows that shows that despite sixty per cent of the primary caregivers reporting that they had three or more meals per day, more than half of the primary caregivers (52%) reported that they had food insufficiency in the last year. Sixty-two per cent reported that they owned livestock while 38 per cent reported that they did not. For those who had livestock, 44 per cent had chickens, 38 per cent had goats, nine per cent had pigs, and another nine per cent had cattle.

3.3.6 Child demographic data and health characteristics

The prevalence of key child demographic and health characteristics are presented in Table 3.7. Table 3.7 shows that children in the full range of ages of interest were well represented. The proportion of male children was slightly higher than that of females (52 per cent and 48 per cent respectively). With respect to the World Health Organisation's clinical staging of HIV, stage three had the highest proportion of children (51%) followed by stage one (21%), stage two (19%) and stage three (9%). Sixty per cent of the children were identified to have normal weight, 29 per cent were underweight and 11 per cent were either overweight or obese.

Table 3.7: Child demographic data and health characteristics (N=429)

Characteristic	n (%)
Child's age	
6	76 (18)
7	72 (17)
8	69 (16)
9	53 (12)
10	47 (11)
11	49 (11)
12	63 (15)
Gender	
Male	221 (52)
Female	208 (48)
WHO HIV clinical staging	
Stage I	89 (21)
Stage II	80 (19)
Stage III	219 (51)
Stage IV	41 (9)
Nutritional status	
Underweight	258 (60)
Normal	125 (29)
Overweight/obese	46 (11)

3.3.7 Research question 1

What are the knowledge and practice of primary caregivers in Malawi with regards to HIV status disclosure to their children living with HIV?

3.3.7.1 Prevalence for primary caregivers' knowledge and practice on disclosure of HIV status to children

Table 3.8 presents prevalence for primary caregivers' knowledge and practice on disclosure of HIV status to children. As shown in Table 3.8, 64 per cent of primary caregivers reported that their children did not know that they have HIV. Seventy-six per cent of children who knew their HIV status were told about their HIV status by their parents, 17 per cent by healthcare workers and seven per cent by their grandparents. Of those who had disclosed, close to three-quarters (70%) of the primary caregivers discussed HIV issues such as cause, mode of transmission, prevention and treatment prior to disclosure of HIV status. Sixty-one per cent of primary caregivers reported that the disclosure process was gradual while 39 per cent said that it was a one-time event.

As shown in Table 3.8, primary caregivers gave varied reasons for disclosing HIV status to their child. The most commonly reported reasons were: they believed that the child was old enough to understand his or her HIV condition; they were advised by healthcare workers to do so; and the child was refusing to take medications

Table 3.8: Prevalence of primary caregiver knowledge and practice of HIV disclosure (N=429)

Characteristic	n (%)
Disclosure of HIV status	
Was the child disclosed his/her HIV status	
Yes	156 (36)
No	273 (64)
Who disclosed the HIV status to the child (n=156)	
Parents	119 (76)
Healthcare worker	27 (17)
Grandparents	10 (7)
Where HIV issues discussed prior to HIV disclosure (n=156)	
Yes	109 (70)
No	47 (30)
How was your child told about his/her HIV status (n=156)	
As a one-time event	61 (39)
As a gradual process	95 (61)
*Reason for telling the child his/her HIV status (n=156)	
Child is old enough to understand his condition	103 (26)
Advised by healthcare worker	92 (24)
Child asked about his illness	90 (23)
Child refusing to take HIV medicine	54 (14)
Child condition got worse	35 (9)
Parent condition got worse	17 (4)
Do you have adequate knowledge of HIV status disclosure	
Yes	149 (34)
No	280 (66)
Best person to disclose HIV to a child	
Primary caregiver	279 (65)
Healthcare worker	61 (14)
Teacher	2 (1)
Primary caregiver and healthcare worker	87 (20)
*Reasons for nondisclosure of HIV status to the child	
Child's inability to handle the news	265 (29)
Fear of stigma and discrimination	153 (17)
Lack of support from healthcare workers	123 (13)
Lack of knowledge on how to disclose HIV status	172 (19)
Feelings of guilt or shame	116 (14)
The child not showing signs of sickness	86 (8)

*Multiple response variables

Table 3.8 shows that almost two-thirds of the participants (65%) identified the primary care giver as the best person to disclose HIV status to a child, followed by primary caregiver and healthcare worker working together (20%), and healthcare worker (14%). Primary caregivers whose children were unaware of their HIV status, identified the following as reasons for non-disclosure of HIV status to children living with HIV: child's inability to handle the news (29%); lack of knowledge on how to disclose HIV status, fear of stigma and discrimination (17%), feeling of guilty and shame (14%), lack of support from healthcare workers (13%), and child not showing signs of disease (8%).

3.3.7.2 Taking of ART

Table 3.9 shows the prevalence of children taking ART and the prevalence of other factors associated with taking medication. As shown in Table 3.9, a large proportion (93%) of the children were receiving ART. Thirty-two per cent of the children had been taking ART medication for two to three years, 25 per cent for more than five years, 23 per cent for four to five years, 12 per cent for six months to one year and nine per cent for less than six months. Sixty-three per cent of the children were unaware that they were taking ART. Half of the children (51%) were asking why they were taking the antiretroviral medication and 27 per cent were refusing to take it. The majority of participants (84%) reported that they were unable to give ART to their children in front of other people. More than three-quarters (86%) of primary caregivers whose children were unaware that they were taking antiretroviral medication had no problems giving it to their child. Eighty-three per cent of the children had no problems taking the medication on time every day.

Table 3.9: Prevalence and factors associated with taking ART (N=429)

Characteristic	**N (%)**
Is your child currently taking medicines for HIV	
Yes	401 (93)
No	28 (7)
If yes, for how long has your child been on the HIV medicine [a] (n=401)	
Less than 6 months	30 (8)
6 months to 1 year	48 (12)
2 to 3 years	129 (32)
4 to 5 years	92 (23)
More than 5 years	102 (25)
Does the child know that she/he is taking medicines for HIV	
Yes	157 (37)
No	272 (63)
Does the child ever ask questions about why he /she is taking medicine [a] (n=401)	
Yes	204 (51)
No	197 (49)
Does the child ever refuse to take medicines that he or she is supposed to take? [a] (n=401)	
Yes	291 (73)
No	110 (27)
Do you ever not give medicines to the child because you do not want to give them in front of other people [a] (N=401)	
Yes	64 (16)
No	337 (84)
Do you ever have problems with giving the medicines because the child does not know why he/she is taking them? [a] (N=401)	
Yes	56 (14)
No	345 (86)
Does the child ever have problems taking the medicines on time every day? [a] (N=401)	
Yes	68 (17)
No	333 (83)

[a] Twenty-eight participants are missing in this variable because they were not yet on ART despite attending the ART clinic

3.3.7.3 HIV status disclosure and peer problems

Table 3.10 shows some of the peer problems faced by children living with HIV. These results only apply to primary caregivers whose children knew their HIV status. With regard to the prevalence of peer problems faced by children living with HIV. One-tenth of the primary caregivers reported that their children were being teased or called hurtful names because of their HIV status while 90 per cent reported that their children had no such problems. Rejection by fellow peers was identified by 13 per cent of primary caregivers as a problem faced by children living with HIV while 87 per cent reported that their children were not rejected by friends. The per cent of primary caregivers who reported that other children were avoiding to play with their children because of their HIV status was (13 %), while 87 per cent reported that their children had no such problem (see Table 3.10).

Table 3.10: HIV status disclosure and peer related problems (N=156)

Characteristic	n (%)
Do other children tease or call the child names because of his/her HIV status	
Yes	16 (10)
No	140 (90)
Has your child been rejected by friends or family because of the illness	
Yes	20 (13)
No	135 (87)
Do other children avoid playing with the child because of his/her HIV status	
Yes	21 (13)
No	135 (87)

Only those who indicated that the child knew his or her HIV status were asked questions related to peer related problems

3.3.8 Research question 2

What are the participants' views regarding the need, acceptability and benefits of the children's story books for guiding the process of informing their children about their HIV status?

Table 3.11 presents findings regarding the participants' views on the proposed HIV story books. Almost all participants (99%) reported that it was a good idea to develop the story books and 99 per cent reported that they would use the resource once it is developed. As regards to the importance of the resource, 98 per cent reported that it would improve their knowledge and confidence. The majority of primary caregivers (98%) reported that the resource would reduce their worries on how to disclose HIV to children.

Table 3.11: Participants' views on the proposed HIV status disclosure resource (N=429)

Characteristic	Strongly agree/ agree % (n)	Neither agree nor disagree % (n)	Strongly disagree/ disagree % (n)
It is a good idea to develop the resource	398 (99)	0 (0)	3 (1)
I will use the resource if developed	385 (99)	1 (0)	4 (1)
The resource will improve my knowledge on HIV disclosure	383 (98)	2 (1)	5 (1)
The resource will improve my confidence in disclosure of HIV	368 (99)	1 (0)	3 (1)
The resource will reduce my worries on how to disclose HIV to children	368 (98)	3 (1)	5 (1)

3.3.9 Children's psychosocial characteristics

Table 3.12 shows the results of descriptive analysis of children's emotional and behavioural problems. The mental health status was measured by a parent report, Strength and Difficulties questionnaire. According to the newer, four band categorisation of Strengths and difficulties questionnaire, 69 per cent of the children had a total Difficulties score of close to average, 11 per cent slightly raised, nine per cent high, and 11 per cent very high. On the prosocial subscale, 15% of children were in the slightly raised band, 19 per cent in high, and 24 per cent in very high. On the peer problems subscale, 13 per cent of children were in the slightly raised band, 14 percent high, and

16 per cent very high. On the conduct problems subscale, 12 per cent of children were in the slightly raised band, 18 per cent high, and eight per cent very high. With regard to emotional problems, 14 per cent of children were in the slightly raised band, 12 per cent high, and eight per cent very high. On the hyperactivity subscale, only 16 per cent of children were in the slightly raised band and two per cent were in the high band (see Table 3.12).

Table 3.12: Child psychosocial characteristics (N=429)

Study measures	**Frequency n (%)**
Total difficulties score	
Close to average	296 (69)
Slightly raised	49 (11)
High	38 (9)
Very high	46 (11)
Emotional problems score	
Close to average	282 (66)
Slightly raised	62 (14)
High	51 (12)
Very high	34 (8)
Conduct problems score	
Close to average	269 (62)
Slightly raised	51 (12)
High	76 (18)
Very high	33 (8)
Hyperactivity score	
Close to average	354 (82)
Slightly raised	68 (16)
High	7 (2)
Very high	0 (0)
Peer problems score	
Close to average	246 (57)
Slightly raised	54 (13)
High	61 (14)
Very high	68 (16)
Prosocial score	
Close to average	178 (42)
Slightly raised	66 (15)
High	81 (19)
Very high	104 (24)
Total difficulties score (SDQ)	
Close to average	296 (69)
Slightly raised/high/very high	133 (31)

3.3.10 Family psychosocial characteristics

Table 3.13 presents findings with regard to the impact of illness on the family, stressful life events, and social support. A significant or serious impact of the child’s illness on the family was identified in 75 per cent of the study participants, while 49 per cent reported three or more stressful life events. With regard to functional support, 80 per cent of primary caregivers reported they had a high level of support.

Table 3.13: Family psychosocial characteristics (N=429)

Study measures	Frequency n (%)
Impact of illness on family	
Low level	106 (25)
Significant	252 (59)
Very serious	71 (16)
Stressful life events	
<3	217 (51)
>3	212 (49)
Level functional support	
Low	344 (80)
High	85 (20)

3.3.11 Bivariate association between family socio-demographic characteristics and non-disclosure of HIV status to children.

Table 3.14 shows the bivariate association between family socio-demographic characteristics and non-disclosure of HIV status to children. Few statistically significant relationships were found. The following caregiver characteristics were not associated with non-disclosure: relationship with the child, age, gender, occupation of spouse, level of education, level of education of spouse, number of children less than 12 years of age at home, or level of wealth. Primary caregivers from Northern and Southern Regions of Malawi were more likely not to disclose HIV compared to those from the Central Region (uOR 1.5 and 2.0 respectively). However, only the difference with the former was statistically significant (p<0.01). Compared to the Sena tribe, the Chewa, Yao, Tumbuka, Lhomwe, and a group of other smaller tribes (Nkhonde, Mang'anja and Tonga) were more likely not to disclose HIV status (uOR 1.8, 2.1, 3.2, 5.4 and 3.4 respectively), all differences were statistically significant with exception of the Chewa tribe (p<0.05). Primary caregivers who were doing home duties were 2.3 times more likely not to disclose HIV status than those who were looking for jobs. However, the difference was statistically insignificant. Primary caregivers who were farmers and those who were working or running a business were more likely not to disclose HIV as compared to those who were looking for jobs (uOR 2.3 and 3.1 respectively) and these differences were statistically significant. Primary caregivers with two or less number of children aged 12 years or older, were 2.6 times more likely not to disclose HIV as compared to those who had 3 or more children aged 12 years or older (uOR 2.6). This difference was statistically significant. Compared to those who were married, those who were widowed, and single were more likely not to disclose HIV status (OR 1.6, and 2.9). However, only the latter difference was statistically significant.

Table 3.14: Association between socio-demographic variables and non-disclosure of HIV status to children (N=429)

Variable	Disclosed n (%)	Not disclosed n n (%)	Unadjusted odds ratio (uOR)	95% CI
Region				
Central	71 (45)	88 (55)	Reference	
South	56 (35)	105 (65)	1.5	0.9-2.4
North	29 (27)	80 (73)	**2.2**	**1.3-3.7****
Tribe				
Sena	32 (56)	25 (44)	Reference	
Chewa	55 (42)	77 (58)	1.8	0.9-3.4
Yao	28 (38)	46 (62)	**2.1**	**1.1-4.2***
Tumbuka	15 (28)	38 (72)	**3.2**	**1.5-7.2****
Other tribes	16 (27)	43 (73)	**3.4**	**1.6-7.5****
Lhomwe	10 (18)	44 (82)	**5.6**	**2.4-13.5*****
Relationship with the child				
Father	24 (38)	39 (62)	Reference	
Other	20 (38)	33 (62)	1.0	0.5-2.2
Grandparent	18 (36)	32 (64)	1.1	0.5-2.4
Mother	94 (36)	169 (64)	1.1	0.6-2.0
Age of primary caregiver				
18-30	20 (39)	31 (61)	Reference	
31-40	52 (32)	112 (68)	1.4	0.7-2.7
41-50	52 (39)	80 (61)	1.0	0.5-1.9
>50	32 (39)	50 (61)	1.0	0.5-2.1
Gender of primary caregiver				
Male	36 (36)	63 (64)	Reference	
Female	120 (36)	210 (64)	1.0	0.6-1.6
Occupation of primary caregiver				
Looking for a job	17 (59)	12 (41)	Reference	
Home duties	28 (38)	45 (62)	2.3	0.9-5.5
Farming	70 (36)	126 (64)	**2.6**	**1.2-5.6***
Work/business	41 (31)	90 (69)	**3.1**	**1.4-7.1****
Occupation of spouse				
Looking for a job	6 (40)	9 (60)	Reference	
Home duties	14 (33)	28 (67)	1.3	0.4-4.5
Farming	35 (32)	75 (68)	1.4	0.5-4.3
Work/business	29 (27)	77 (73)	1.8	0.6-5.4
Level of education of primary caregiver				
None	36 (38)	58 (62)	Reference	
Primary	94 (39)	146 (61)	1.0	0.6-1.6
Secondary/tertiary	26 (27)	69 (73)	1.6	0.9-3.0
Level of education of spouse				
None	31 (66)	16 (34)	Reference	
Primary	92 (69)	42 (31)	1.1	0.6-2.3
Secondary/tertiary	150 (61)	98 (39)	1.3	0.6-2.8
Number of children <12 years old at home				
≤2	116 (37)	196 (63)	Reference	
≥3	40 (34)	77 (66)	1.1	0.7-1.8
Number of children >12 years old at home				
≤2	22 (21)	81 (79)	**2.6**	**1.5-4.3*****
≥3	134 (41)	192 (59)	Reference	

Continuation of Table 4.12

Variable	Disclosed n (%)	Not disclosed n n (%)	Unadjusted odds ratio (uOR)	95% CI
Marital status of primary caregiver				
Widowed	42 (56)	33 (44)	1.6	0.8-3.1
Single	18 (42)	25 (58)	2.9	**1.7-4.8***
Divorced	12 (32)	26 (68)	1.0	0.5-2.2
Married	84 (31)	189 (69)	Reference	
Wealth quintiles				
Poorest	20 (39)	32 (61)	Reference	
Poor	15 (35)	28 (65)	1.2	0.5-2.7
Medium	30 (40)	45 (60)	0.9	0.5-1.9
Wealthy	38 (49)	40 (51)	0.7	0.3-1.3
Wealthiest	53 (29)	128 (71)	1.5	0.8-2.9

***P<0.001, **p<0.01, *p<0.05

3.3.12 Bivariate association between child demographic and health factors and non-disclosure of HIV status to children

Table 3.15 shows the bivariate association between child demographic and health factors and non-disclosure of HIV status. Primary caregivers whose children were within the age group of 6 to 8 years were 5.4 times more likely not to disclose HIV status as compared to those whose children were within the ages of 11-12 years (p<.001). The child’s gender was not associated with non-disclosure. Children who were in the WHO HIV clinical stages one, two and three were more likely not to be disclosed HIV status as compared to those in stage four (uOR 3.3,1.4 and 1.5) only the difference with stage one was statistically significant. Compared to children with a normal body mass index score, children who were in the underweight or overweight and obese categories were more likely to be unaware of their HIV status (uOR 1.9 and 2.0). Both differences were statistically significant. Children younger than 4 years were more likely not to be disclosed HIV status as compared to those aged 4 years or older (uOR 1.6 and 1.5), these differences were not statistically significant. The duration of taking ART medication was not related to non-disclosure. Children who were not asking why they were taking ART were more likely not to be aware of their HIV status as compared to those who were asking (uOR 2.6; p<.001). The child’s refusal to take ART was not associated with non-disclosure.

Table 3.15: Association between child demographic and health factors and non-disclosure of HIV status (N=429)

Variable	Disclosed n (%)	Non-disclosed n (%)	Unadjusted odds ratio (uOR)	95% CI
Child's age				
6-8	44 (20)	173 (80)	**5.4**	**3.3-9.0*** **
9-10	47 (47)	53 (53)	1.6	0.9-2.7
11-12	65 (58)	47 (42)	Reference	
Child's gender				
Female	78 (38)	130 (62)	Reference	
Male	78 (35)	143 (65)	1.1	0.7-1.6
WHO HIV clinical staging				
Stage I	20 (22)	69 (78)	**3.3**	**1.5-72** **
Stage II	32 (40)	48 (60)	1.4	0.7-3.1
Stage III	84 (28)	135 (62)	1.5	0.8-3.0
Stage IV	20 (49)	21 (51)	Reference	
Nutritional status				
Normal	109 (41)	149 (59)	Reference	
Underweight	35 (28)	90 (72)	**1.9**	**1.2-3.0** **
Overweight/obese	12 (26)	34 (74)	**2.0**	**1.1-4.2***
Duration on ART				
≤ 1 year	25 (32)	53 (68)	1.6	0.9-2.8
2-3 years	44 (34)	85 (66)	1.5	0.9-2.3
≥4 years	84 (43)	110 (57)	Reference	
Child asking why he/she is taking ART				
Yes	98 (48)	106 (52)	Reference	
No	51 (26)	146 (74)	**2.6**	**1.7-3.9*** **
Child refusing to take ART				
Yes	111 (38)	180 (62)	Reference	
No	40 (36)	70 (64)	1.1	0.7-1.7

***P<0.001, **p<0.01, *p<0.05

3.3.13 Bivariate association between psychosocial factors and non-disclosure of HIV status

Table 3.16 shows the bivariate association between psychosocial factors and non-disclosure of HIV status to children. Bivariate statistics revealed no difference in terms of HIV status non-disclosure between children who had close to average total difficulties score and those whose total difficulties score was slightly higher or high or very high (uOR 1.0). As shown in table 3.16, primary caregiver's who reported low and significant impact were more likely not to disclose HIV status as compared to those who reported very serious impact (uOR 1.3 and 1.2 respectively). However, the differences were not statistically significant. No statistically significant difference was found between primary caregivers with low-level functional support and those with high level function support in relation to non-disclosure of HIV status (uOR 1.0). With regard to stressful life events, primary caregivers who reported less than three stressful life events were more likely not to disclose HIV as compared to those who reported having three or more stressful life events (uOR 1.3), but again, the difference was not statistically significant.

Table 3.16: Association between psychosocial factors and non-disclosure of HIV status (N=429)

Variable	Disclosed n (%)	Not disclosed n (%)	Unadjusted odds ratio (uOR)	95% CI
Total difficulties score (SDQ)				
Close to average	125 (36)	220 (64)	1.0	0.7-1.6
Slightly high/high/very high	31 (37)	53 (63)	Reference	
Level of impact of the child condition on family				
Low level impact	37 (35)	69 (65)	1.3	0.7-2.5
Significant impact	90 (36)	162 (64)	1.2	0.7-2.1
Very serious impact	29 (41)	42 (59)	Reference	
Level of functional support				
Low	125 (36)	219 (64)	Reference	
High	31 (36)	54 (64)	1.0	0.6-1.7
Number of stressful life events				
<3	74 (34)	143 (66)	1.3	0.9-1.9
≥3	82 (39)	130 (61)	Reference	

3.3.14 Research question 3:

How does primary caregiver’s decision to disclose HIV status to children differ by demographics, child and family psychosocial factors and child health factors in Malawi? This question was tested by the following three hypotheses.

3.3.14.1 Hypothesis 3a

Hypothesis 3a examined that non-disclosure of HIV status to children living with HIV in Malawi is independently associated with primary caregivers’ region of residence, tribe, relationship with the child, age, gender, occupation, level of education, marital status, socioeconomic status, number of children younger or older than 12 years staying at home and spouse’s occupation and level of education.

Table 3.17 shows factors independently associated with non-disclosure of HIV status to children in multivariate statistics. Compared to primary caregivers from the central region, primary caregivers from the southern and northern regions were more likely not to disclose HIV status (aOR 1.8 and 2.8 respectively), but these differences were not statistically significant. Therefore, the hypothesis was not supported. In terms of tribal affiliation, primary caregivers of the Chewa, Yao, Tumbuka, and Lhomwe tribes and a combination of other tribes such as Nkhonde, Mang’anja and Tonga were more likely not to disclose HIV status as compared to the Sena tribe (aOR 1.8, 2.8, 1.9, 3.9, and 3.0 respectively). Only the differences between the Yao and the Sena and that between the Lhomwe and the Sena were statistically significant. This finding supported the hypothesis. With respect to occupation, primary caregivers who were involved in home duties, farming and business or working in jobs were more likely not to disclose HIV status to children than those who were looking for jobs (aOR 2.6, 3.4 and 2.6 respectively). Only the difference between primary caregivers who were farming and those who were looking for jobs was statistically significant. This also supported hypothesis 3a.

With respect to the number of children 12 years or older staying at home, primary caregivers with with less than three children staying at home were almost four times more likely not to disclose HIV than those who had three or more children staying at home (aOR 3.7). The difference between the two groups was statistically significant. This finding supported the hypothesis. Widowed and single primary caregivers were more likely not to disclose compared to married primary caregivers (aOR 1.7 and 2.2, respectively), however these differences were not statistically significant. Thus, the hypothesis was not supported. Similarly, the hypothesis regarding the relationship between primary caregiver's divorce and disclosure of HIV status to children was not supported. Other findings that did not support hypothesis 3a include the relationship between HIV status non-disclosure to children and primary caregivers' characteristics such as being poor, male, biological parents, younger age, and having a lower level of education.

3.3.14.2 Hypothesis 3b

This hypothesis tested that non-disclosure of HIV status to children living with HIV in Malawi is independently associated with the child's age, gender, WHO HIV clinical stage, nutritional status, duration of taking ART, the child asking for reasons for taking ART, and the child's refusal to take ART.

As shown in Table 3.17, compared to 11 to 12-year old children, children who were aged 6 to 8 years and 9 to 10 years were more likely to be unaware of their HIV status (aOR 3.8 and 1.5 respectively). However, only the difference with 9 to 10 year old children was statistically significant. This finding supports the hypothesis. Both underweight and overweight or obese children were more likely to be unaware of their HIV status as compared with children with normal body mass index (aOR 1.9; $p<0.05$ and aOR 1.6; $p>0.05$, respectively). The relationship between underweight and not knowing one's status among children supported the hypothesis. Compared to children who were asking why they were taking ART, children who were not asking about their ART were almost three times more likely to be unaware of their HIV status (OR 2.8; $p< 0.001$). Hypothesis 3b was therefore supported. Multivariate analysis also revealed that children in WHO HIV clinical stages one, two and three were more likely to be unaware of their HIV status than those in stage four (aOR 3.0; $p<0.05$, aOR 1.1; $p>0.05$ and aOR 2.1; $p>0.05$ respectively). Only the association between non-disclosure of HIV status and stage one of WHO clinical staging was statistically significant.

3.3.14.3 Hypothesis 3C

Hypothesis 3c examined that non-disclosure of HIV status to children living with HIV in Malawi is independently associated with primary caregivers’ report of the child’s emotional and behavioural problems, level of impact of illness on family, level of functional support, and number of stressful life events

As shown in Table 3.17, hypothesis 3c is not supported by the study findings. The findings of the study revealed that children’s emotional and behavioural problems were not associated with non-disclosure of HIV status (aOR 1.1). Primary caregivers who reported low-level impact and significant impact of th child illness on the family were more likely not to disclose HIV status to their children compared to those who reported very serious impact of illness on the family (aOR 1.6 and 1.5). However, these differences were not statistically significant. Primary caregiver’s reports of functional support and stressful life events were not associated with non-disclosure of HIV status (aOR 1.0, aOR 1.1).

Table 3.17: Factors associated with non-disclosure of HIV status in multivariate analysis (N=429)

Variable	Adjusted odds ratio (uOR)	95% CI
Family factors		
Region		
Central	Reference	
South	1.8	0.8-4.2
North	2.8	0.9-8.9
Tribe		
Sena	Reference	
Chewa	2.3	0.8-6.8
Yao	**2.8**	**1.1-7.7***
Tumbuka	1.9	0.4-8.9
Other tribes	3.0	0.8-12.0
Lhomwe	**3.9**	**1.4-10.8***
Occupation of primary caregiver		
Looking for a job	Reference	
Home duties	2.6	0.9-7.5
Farming	**3.4**	**1.2-9.3***
Work/business	2.6	0.9-7.6
Number of children >12 years old at home		
≤ 2	**3.7**	**1.9-7.0*****
≥ 3	Reference	
Marital status of primary caregiver		
Widowed	1.7	0.9-3.4
Single	2.2	0.9 -5.4
Divorced	0.5	0.2-1.3
Married	Reference	
Child factors		
Child's age		
6-8	**3.8**	**2.1-6.8*****
9-10	1.5	0.8-3.0
11-12	Reference	
Nutritional status		
Normal	Reference	
Underweight	**1.9**	**1.1-3.3***
Overweight/obese	1.6	0,7-3,8
Child asking why he/she is taking ART		
Yes	Reference	
No	**2.8**	**1.6-4.7*****
WHO HIV clinical staging		
Stage I	**3.0**	**1.1-8.6***
Stage II	1.1	0.4-3.0
Stage III	2.1	0.9-4.9
Stage IV	Reference	
Psychosocial factors		
Total difficulties score (SDQ)		
Close to average scores	1.1	0.6-2.0
Slightly high/high/very high scores	Reference	
Level of impact of the child condition on family		
Low level impact	1.6	0.7-3.9
Significant impact	1.5	0.8-3.0
Very serious impact	Reference	
Level of functional support		
Low	Reference	
High	1.0	0.5-1.8
Number of stressful life events		
<3	1.1	0.6-1.8
≥3	Reference	

***P<0.001, **p<0.01, *p<0.05

3.3.15 Bivariate association between family socio-demographic variables and children's emotional and behavioural problems

Table 3.18 presents the bivariate analysis of the association between family socio-demographic variables and children's emotional and behavioural problems. The primary caregiver's relationship with the child was not associated with the report of emotional and behavioural problems. Compared to primary caregivers who were older than 50 years, those who were 30 years or younger were more likely to report that their children had emotional and behavioural problems (uOR 2.8; p<0.05). Female primary caregivers were more likely to report that their children had emotional and behavioural problems compared to male primary caregivers (uOR 1.9; p<0.05). In relation to tribe, the Chewa and Yao were more likely to report that their children had emotional and behavioural problems as compared to primary caregivers from the Sena tribe (uOR 3.3; p<0.01,and uOR 12.4; p>0.001 respectively).

As displayed in Table 3.18, compared to primary caregivers who were working or doing business, primary caregivers who were farming and doing home duties were more likely to report that their children had emotional and behavioural problems (uOR 2.0, p<0.05; uOR 2.8, p>0.05, respectively). There was no association between spouse's occupation and children's emotional and behavioural problems. Primary caregivers with no formal education or primary school education only were more likely than those with secondary and tertiary level education to report that their child had an emotional or behavioural problem (uOR 3.6, p<.01; uOR 4.1, p<.001, respectively). Primary caregivers whose spouse had no formal education were also more likely than those whose spouse had secondary and tertiary level education to report that their child had an emotional or behavioural problem (uOR 2.2, p<.05). Neither number of children living at home or the marital status of the primary caregiver was associated with children's emotional and behavioural problems. Compared to primary caregivers in the wealthiest quintile, those in the poorest, poor, and medium wealth quintiles were more likely to report that their children had emotional and behavioural problems (uOR 2.2, p<0.05; uOR 2.8, p<0.01; uOR 2.2, p<0.05, respectively).

Table 3.18: Bivariate association between family socio-demographic variables and child mental health problems (N=429)

Variable	**Emotional & behavioural problems No n (%)**	**Emotional & behavioural problems Yes n (%)**	**Unadjusted odds ratio (uOR)**	**95% CI**
Relationship with the child				
Grandparent	38 (76)	12 (24)	Reference	
Other relationship	40 (75)	13 (25)	1.0	0.4-2.5
Father	47 (75)	16 (25)	1.1	0.5-2.6
Mother	171 (65)	92 (35)	1.7	0.8-3.4
Age of primary caregiver				
18-30	26 (51)	25 (49)	**2.8**	**1.3-5.8***
31-40	117 (71)	47 (29)	1.2	0.6-2.1
41-50	92 (70)	40 (30)	1.3	0.7-2.3
>50	61 (74)	21 (26)	Reference	
Gender of primary caregiver				
Male	78 (79)	21 (21)	Reference	
Female	218 (66)	112 (34)	**1.9**	**1.1-3.3***
Tribe of primary caregiver				
Sena	50 (88)	7 (12)	Reference	
Other tribes	47 (80)	12 (20)	1.8	0.7-5.0
Tumbuka	42 (79)	11 (21)	1.9	0.7-5.3
Lomwe	40 (74)	14 (26)	2.5	0.9-6.8
Chewa	90 (68)	42 (32)	**3.3**	**1.4-8.0****
Yao	27 (37)	47 (63)	**12.4**	**4.9-31.3*****
Occupation of primary caregiver				
Work/business	104 (79)	27 (21)	Reference	
Farming	128 (65)	68 (35)	**2.0**	**1.2-3.4****
Looking for a job	22 (76)	7 (24)	1.2	0.5-3.2
Home duties	42 (58)	31 (42)	**2.8**	**1.5-5.3****
Spouse occupation				
Work/business	68 (64)	38 (36)	1.3	0.8-2.2
Farming	76 (69)	34 (31)	1.0	0.6-1.8
Looking for a job	9 (60)	6 (40)	1.5	0.5-4.6
Home duties	34 (81)	8 (19)	Reference	
Level of education of primary caregiver				
None	62 (66)	32 (34)	**3.6**	**1.7-7.5****
Primary	151 (63)	89 (37)	**4.1**	**2.1-7.9*****
Secondary/tertiary	83 (87)	12 (13)	Reference	
Spouse level of education				
None	24 (51)	23 (49)	**2.2**	**1.1-4.3***
Primary	90 (67)	44 (33)	1.1	0.7-1.9
Secondary/tertiary	73 (79)	19 (21)	Reference	
Number of children <12 years old at home				
≤ 2	220 (70)	92 (30)	Reference	
≥ 3	72 (62)	45 (38)	1.3	0.8-2.0
Number of children >12 years old at home				
≤ 2	66 (64)	37 (36)	1.3	0.8-2.1
≥ 3	230 (71)	96 (29)	Reference	
Marital status of primary caregiver				
Widowed	56 (75)	19 (25)	Reference	
Divorced	27 (71)	11 (29)	1.2	0.5-2.9
Married	187 (69)	86 (31)	1.4	0.8-2.4
Single	26 (61)	17 (39)	1.9	0.9-4.3
Wealth quintiles				
Poorest	31 (60)	21 (40)	**2.2**	**1.2-4.3***
Poor	23 (54)	20 (46)	**2.8**	**1.4-5.7****
Medium	45 (60)	30 (40)	**2.2**	**1.2-3.9****
Wealthy	58 (74)	20 (26)	1.1	0.6-2.1
Wealthiest	139 (77)	42 (23)	Reference	

***P<0.001, **p<0.01, *p<0.05

3.3.16 Bivariate association between children's demographic and health factors and children's emotional and behavioural problems.

Children's demographic and health factors were compared with emotional and behavioural problems in bivariate analysis and results are shown in table 3.19. Neither age, gender, nor duration on ART were associated with problems. Children in WHO clinical stage one and two were more likely to have emotional and behavioural problems compared to those in phase four (uOR 1.3; p>0.05 and uOR 3.3; p<0.01 respectively). On the contrary, children in WHO HIV clinical stage three were less likely to have emotional and behavioural problems as compared to those in stage four (uOR 0.8; p>0.05). In respect to nutritional status, children who were of normal weight, or were overweight or obese, were more likely to have emotional and behavioural problems compared with children who were underweight (uOR 1.3; p>0.05 and uOR 3.0; p< 0.01).

Table 3.19: Bivariate association between child demographic and health factors and mental health problems (N=429)

Variable	Emotional & behavioural problems No n (%)	Emotional & behavioural problems Yes n (%)	Unadjusted odds ratio (uOR)	95% CI
Age				
6-8	151 (70)	66 (30)	Reference	
9-10	66 (66)	34 (34)	1.2	0.7-2.0
11-12	79 (70)	33 (30)	1.0	0.6-1.6
Gender				
Male	147 (67)	74 (33)	1.3	0.8-1.9
Female	149 (72)	59 (28)	Reference	
WHO HIV clinical staging				
Stage I	61 (69)	28 (31)	1.3	0.6-2.9
Stage II	36 (45)	44 (55)	**3.3**	**1.5-7.6****
Stage III	169 (77)	50 (23)	0.8	0.4-1.7
Stage IV	30 (73)	11 (27)	Reference	
Nutritional status				
Underweight	94 (75)	31 (25)	Reference	
Normal	179 (69)	79 (31)	1.3	0.8-2.1
Overweight/obese	23 (50)	23 (50)	**3.0**	**1.5-6.1****
Duration on ART				
≤ 1 year	52 (67)	26 (33)	1.2	0.7-2.1
2-3 years	84 (65)	45 (35)	1.3	0.8-2.1
≥4 years	137 (71)	57 (29)	Reference	

***P<0.001, **p<0.01, *p<0.05

3.3.17 Bivariate association between family psychosocial problems and children's emotional and behavioural problems

Table 3.20 shows that primary caregivers who reported significant or very serious impact of the child illness on the family were more likely to report that their child had an emotional or behavioural problem compared to those who reported a low level of impact (uOR 2.9 and 8.4, respectively). These differences were statistically significant. Furthermore, primary caregivers who reported that they had a low-level of functional support were more likely to report that their child had an emotional or behavioural problem compared to those who reported that they had a high level (uOR 1.7, $p<.05$). Lastly, primary caregivers who reported three or more stressful life events were almost twice as likely to have children with emotional and behavioural problems compared to those who reported less than three stressful life events (uOR 1.8; $p<0.05$).

Table 3.20 Bivariate association between family psychosocial variables and child mental health problems (N=429)

Variable	Emotional & behavioural problems No n (%)	Emotional & behavioural problems Yes n (%)	Unadjusted odds ratio (uOR)	95% CI
Level of impact of illness on family				
Low level impact	92 (87)	14 (13)	Reference	
Significant impact	174 (69)	78 (31)	**2.9**	**1.6-5.4****
Very serious impact	31 (44)	40 (56)	**8.4**	**4.0-17.4*****
Number of stressful life events				
<3	169 (78)	48 (22)	Reference	
≥3	133 (63)	79 (37)	**1.8**	**1.2-2.7***
Level of functional support				
Low	245 (71)	99 (29)	**1.7**	**1.1-2.7***
High	51 (60)	34 (40)	Reference	

***P<0.001, **p<0.01, *p<0.05

3.3.18 Research question 4

How does primary caregiver’s report of emotional and behavioural problems of children living with HIV in Malawi differ by demographics, child and family psychosocial factors, and child health? This was examined through the following hypotheses.

3.3.18.1 Hypothesis 4a

This hypothesis tested that emotional and behavioural problems of children living with HIV are independently associated with primary caregivers’ tribe, relationship with the child, age, gender, occupation, level of education, marital status, socioeconomic status, number of children younger or older than 12 years staying at home and spouse’s occupation and level of education

Table 3.21 shows family socio-demographic, child health and family psychosocial factors associated with emotional and behavioural problems in multivariate analysis. Compared to primary caregivers of the Sena tribe, primary caregivers of Tumbuka, Lhomwe, Chewa, Yao, and other tribes were likely to report that their children had emotional and behavioural problems (aOR 2.2, 2.7, 4.5, 7.4 and 2.1 respectively), only the differences with primary caregivers of the Chewa and Yao tribes were statistically significant. Thus, the hypothesis is supported. With respect to age, primary caregivers who were 30 years or younger were more likely to report that their children had emotional and behavioural problems compared to those who were older than 50 years (aOR 3.6; p<0.01). Again, this finding supported the hypothesis.

Table 3.21 shows that compared to primary caregivers who were working or doing business, those involved in household duties were more likely to report that their children had emotional and behavioural problems (aOR 2.7; p< 0.05). Again, the hypothesis is supported by this finding. Regarding education, primary caregivers who had no formal education and those who had primary school level education were likely to report that their children had emotional and behavioural problems compared with those who had some secondary or tertiary education (aOR 1.9, ns; OR 2.6, <0.05, respectively). The relationship between primary school education and non-disclosure of HIV status to children supports hypothesis 4a. Table 3.21 also shows that neither: the primary caregiver's gender or wealth were associated with children's emotional and behavioural problems.

3.3.18.2 Hypothesis 4b

Hypothesis 4b tested that emotional and behavioural problems of children living with HIV are independently associated with the child's age, gender, WHO HIV clinical stage, nutritional status, and duration of taking ART. This hypothesis is not supported by the findings of the study where no significant relationship was found between child's emotional and behavioural problems and child's age, gender, WHO HIV clinical stage, nutritional status, and duration of taking ART.

3.3.18.3 Hypothesis 4c

This hypothesis tested that emotional and behavioural problems of children living with HIV are independently associated with level of impact of illness on family, number of stressful life events in the family and level of functional social support.

The findings from multivariate logistic regression revealed that primary caregivers who reported a significant or a very serious impact of the illness on the family were more likely to report that their children had emotional and behavioural problems compared to those with low impact (aOR 3.1 and 9.4, respectively). These differences were statistically significant. Therefore, hypothesis 4c is supported. Primary caregivers who had a low level of functional support were more likely to report that their children had emotional and behavioural problems compared to those with a high level of support (aOR 2.0; p<0.05). Again, this finding supports hypothesis 4c. On the other hand, multivariate logistic regression revealed that the number of stressful family life events was not associated with children's emotional and behavioural problems. This finding does not support hypothesis 4c.

Table 3.21: Factors associated with mental health problems in multivariate analysis (N=429)

Variable	adjusted odds ratio (aOR)	95% CI
Family factors		
Gender of primary caregiver		
Male	Reference	
Female	1.7	0.8-3.1
Tribe		
Sena	Reference	
Other tribes	2.1	0.6-6.9
Tumbuka	2.2	0.6-7.7
Lomwe	2.7	0.9-8.3
Chewa	**4.5**	**1.6-12.5****
Yao	**7.4**	**2.5-21.8*****
Age of primary caregiver		
18-30	**3.6**	**1.4-9.5****
31-40	1.5	0.7-3.4
41-50	1.5	0.7-3.3
>50	Reference	
Wealth quintiles		
Poorest	1.2	0.5-2.9
Poor	1.9	0.7-4.7
Medium	1.7	0.8-3.6
Wealthy	0.9	0.4-1.8
Wealthiest	Reference	
Occupation of primary caregiver		
Work/business	Reference	
Farming	1.8	0.9-3.4
Looking for a job	0.9	0.3-2.7
Home duties	**2.7**	**1.3-5.9***
Level of education of primary caregiver		
None	1.9	0.7-5.1
Primary	**2.6**	**1.2-5.7***
Secondary/tertiary	Reference	
Child factors		
Nutritional status		
Normal	Reference	
Underweight	1.1	0.6-2.1
Overweight/obese	1.5	0.6-3.8
WHO HIV clinical staging		
Stage I	1.8	0.6-5.2
Stage II	2.7	1.0-7.7
Stage III	0.8	0.3-1.9
Stage IV	Reference	
Disclosure of HIV status		
Yes	Reference	
No	1.1	0.6-1.9
Psychosocial factors		
Level of impact of illness on family		
Low level impact	Reference	
Significant impact	**3.1**	**1.5-6.5****
Very serious impact	**9.4**	**1.7-23.8*****
Level of function support needed		
Low	**2.0**	**1.1-4.1***
High	Reference	
Number of stressful life events		
<3	Reference	
≥3	1.2	0.7-2.0

***P<0.001, **p<0.01, *p<0.05

The results of this study indicate that providing age appropriate disclosure is a complex process for primary caregivers and a significant proportion of children living with HIV have mental health problems. Disclosure materials in form of story books are therefore needed to support primary caregivers to disclosure HIV status to their children in a way that will promote the mental wellbeing of children.

The next chapter will present the methodology and results of the healthcare workers' survey. The study was conducted to evaluate healthcare workers' practice and knowledge of HIV disclosure to children living with HIV in Malawi and assess their views regarding the need and acceptability of children story books that can guide the disclosure process.

4 CHAPTER 4: HEALTHCARE WORKERS SURVEY (STUDY 2)

4.1 INTRODUCTION

This chapter provides information about the methodology and findings of the healthcare worker survey. The chapter begins with a brief background information of the study. A description of the research questions and hypotheses is then provided. This is followed by an outline of the participants recruitment criteria and study setting. The next section describes, sample, procedure, instrumentation, and data analysis. Thereafter the findings are presented.

Despite the WHO recommendations and guidelines for HIV status disclosure to children living with HIV, recent studies reveal that the rate of disclosure of HIV status to children in the sub-Saharan region remains low (Nzota et al., 2015; Skeen et al., 2014). The disclosure rate identified in studies in South Africa, Zambia Tanzania, Kenya, and Ethiopia have ranged from 11 per cent to 34 per cent only (Biadgilign et al., 2011; Nzota et al., 2015; Skeen et al., 2014; Turissini et al., 2013; Vreeman et al., 2014). While the WHO guidelines recommend that disclosure of HIV status to children can be carried out by any person acting in the best interests of the child (World Health Organisation, 2011a), most of the published literature endorse the primary caregiver as the person with the principal responsibility to disclose to their child (Brown et al., 2011; Kallem et al., 2011; Madiba & Mokgatle, 2015; Vaz et al., 2011b; Watermeyer, 2015). However, recent studies have revealed that many primary caregivers find the disclosure process difficult and require considerable assistance from healthcare workers (Alemu, Berhanu, & Emishaw, 2013; Madiba, 2013; Madiba, 2016).

Healthcare workers are potentially central to the disclosure process because they provide medical and psychosocial care to both children living with HIV and their families (Fair & Walker, 2011; Madiba & Mokgatle, 2015; Watermeyer, 2015). Moreover, they share the secret of the child’s HIV status with the primary caregiver (Biadgilign et al., 2011). Due to the stigma associated with the child’s HIV diagnosis, many parents are reluctant to discuss their concerns within the community and seek psychosocial support (Lorenz et al., 2016). As such, healthcare workers are in the best position to assist the primary caregiver in decision-making regarding when, how and who is the most appropriate person to disclose to their child (Fair & Walker, 2011; Watermeyer, 2015). Nonetheless, studies have shown that many healthcare workers are not actively involved in the disclosure process (Demmer, 2011; Wachira, Middlestadt, Vreeman, & Braitstein, 2012). A lack of professionalism and empathy among healthcare workers was reported to hinder primary caregivers disclosing to their child in a study conducted in Kenya (Wachira et al., 2012). A South African study reported complaints from primary caregivers of rude and uncaring behaviour among some healthcare workers when they came with their children to receive care (Demmer, 2011). On the other hand, studies which have assessed healthcare workers' experiences of disclosure of HIV to children in sub-Saharan Africa have revealed that a lack of training and skills about the disclosure process , lack of cooperation from primary caregivers, lack of time (Kidia et al., 2014; Madiba & Mokgatle, 2015; Rujumba, Mbasaalaki-Mwaka, & Ndeezi, 2010a), and lack of standardised disclosure policies and materials (McCleary-Sills et al., 2013) are the major impediments.

In Malawi, there is very little data on the current practice of HIV disclosure to children living with HIV. Moreover, to the best of the researcher's knowledge, no study in Malawi has assessed healthcare workers' involvement in the disclosure of HIV status to children. It is thus timely to assess these perspectives. Given the significant role they play in caring for children living with HIV. This study was conducted to assess the current disclosure practices of healthcare workers and the challenges they face in disclosing HIV status to children aged between 6 and 12 years in Malawi.

As discussed above, healthcare workers play a major role in the care of children living with HIV. The act as the source of health information for primary caregivers. Thus, assessing their perspectives regarding the practice of HIV disclosure and the need for story books will help to: have adequate understanding about healthcare worker's current practice of HIV disclosure, knowledge about how to effectively inform children of their HIV status, barriers and facilitators of HIV disclosure and the need and acceptability of the disclosure resource. This information will help to inform the development of the story books as well as other interventions that will promote disclosure of HIV to children. In addition, these findings will also help to inform the development of paediatric HIV disclosure guidelines.

4.2 METHODOLOGY

The following sections will present the methodology of the study. The section will start with a description of the research questions and hypothesis. This will be followed by an outline of the study participants and recruitment criteria. The next sections will describe the study setting and sample size. Finally, the recruitment and data collection procedures will be provided.

4.2.1 Research question and hypotheses

This study addressed the following three main research questions:

1. What are the healthcare workers' responses regarding knowledge and practice of HIV status disclosure to children living with HIV in Malawi?

2. What are their views regarding the need, acceptability and benefits of the children story books intended to guide the process of telling children about their HIV status in Malawi?
3. How does their decision to disclose HIV status to children differ by demographics in Malawi? Research question?

Research question 3 was guided by the hypothesis below because it involved assessing the relationships between variables.

Healthcare workers’ region of residence, age, gender, years of working in the ART clinic, profession cadre, and not receiving in-service training on disclosure of HIV status are independently associated with non-disclosure of HIV status to children living with HIV in Malawi?

4.2.2 Study participants and recruitment criteria

The participants of the study were healthcare providers working in ART clinics in Malawi. To participate in the study, potential participants were required to meet the following eligibility criteria: (i) working in the ART clinic, (ii) be a nurse, clinical officer/doctor or counsellor, and (iii) provide consent to participate in the study. While not an exclusion criterion, it was anticipated that all participants would be conversant in English. All healthcare professionals working in ART clinics in government District and Central Hospitals in Malawi were approached to participate in the study and those who consented were recruited. Normally, each ART clinic has a minimum of three healthcare workers (a clinical officer, a nurse, and a counsellor/clerk).

In Malawi, registered nurses undergo three to four years of university training in nursing before qualifying with a Diploma or Degree in Nursing. With regard to ART care, their duties include: provision of medications, providing counselling to new patients, and assessing patients for drug compliance and adherence. Nurse technicians are a group of nurses who undergo a three years nursing training at a nursing college that is not affiliated with a university. They qualify with a College Diploma in Nursing and Midwifery. Their duties in the ART clinic are similar to those of a registered nurse, however, they do not have a supervisory role. The clinical officers (clinicians) receive four years full training in clinical medicine including supervised clinical practice and internship and they qualify with a Diploma in Clinical Medicine. Due to the critical shortage of medical doctors in Malawi, clinical officers work as medical officers. Their main duties in the ART clinic are assessing patients for ART eligibility and commencing them on treatment. Another group of healthcare workers assigned to the ART clinic are counsellors. These are health workers who were previously working as health surveillance assistants, patient attendants or data clerks. They undergo an in-service training on counselling. Their duties in the ART clinic including the provision of pre- and post-HIV testing counselling as well as testing people who want to know their HIV status.

4.2.3 Setting

Healthcare professionals were recruited in ART clinics in all Government District and Central Hospitals in Malawi. Of the 28 districts in Malawi, 23 have Government District Hospitals. The five districts with no Government District Hospital either rely on Government Central Hospitals or the Christian Association of Malawi hospitals for services. There are four Government Central Hospitals in Malawi available to provide ART services. However, only three Central Hospitals (Mzuzu, Zomba and Queen Elizabeth Central Hospitals) were included in data collection. The remaining Central Hospital (Kamuzu Central Hospital) was excluded as it did not have a Government ART clinic, although it was serviced by two privately run ART clinics (Baylor College and Lighthouse clinics) for ART services. Each Central or District Hospital has an HIV department known as the ART clinic where people living with HIV, including children, receive ART and other related HIV care services. The ART clinics are designated areas in the hospitals where data collection took place.

4.2.4 Sample size

All healthcare professionals working in ART clinics in 23 Government Districts and 3 Central Hospitals in Malawi were approached to participate in the study and those who consented were recruited. District hospitals in Malawi offer secondary level of healthcare while Central hospitals offer tertiary level of health care. Each ART clinic has a minimum of three healthcare workers (a clinical officer, a nurse, and a counsellor/clerk).

4.2.5 Procedure

District Nursing Officers and Nursing Officers were chosen as focal people to assist in recruiting participants and distributing and collecting questionnaires. Orientation sessions were held to inform them about the purpose of the study and the data collection procedure. Questionnaires, information sheets, and consent forms (See Appendices E, F, G), all in English, were mailed to them, along with a stamped return envelope. The focal people were asked to approach all health professionals in their respective health facilities who met the recruitment criteria. Those who consented to participate in the study were given the questionnaire to complete with instructions on how to complete it. Signed consent forms and completed questionnaires were returned to the focal people who subsequently sent them to the researcher by post. Participants were instructed not to write their names on the completed questionnaires, as it was important that responses remained anonymous.

4.2.6 Data collection instrument

The healthcare worker questionnaire (see Appendix G) had two sections. At the beginning of the questionnaire the participants were instructed to write the name of their health facility and the administrative region of the country where it was located.

Section A questions were on knowledge, attitudes, practices, and challenges related to HIV disclosure to seropositive children. Question one asked if it was necessary to disclose HIV status to children living with HIV. Question two asked if the healthcare worker had ever disclosed HIV status to children living with HIV at least once. Question three asked whether the healthcare worker discussed with the child, HIV related issues such as causes, transmission and treatment, prior to disclosure of HIV status. Question four asked if the healthcare worker provided a follow-up care to the child after disclosure of HIV status. Question five was about the number of occasions the disclosure process took to be completed. Question six asked the appropriate age for children to be disclosed their HIV status. Question seven asked about the best person to disclose HIV status to a child. Question eight asked healthcare workers to rate the proportion of HIV disclosure at their facility. Question nine asked if the healthcare worker had ever received in-service training on disclosure of HIV status to children. Question 10 asked about the factors that hinder healthcare workers to disclose HIV status to children. The question contained six items, each one asking about a specific factor known to hinder HIV disclosure to children. Each item had five response categories: strongly disagree, disagree, neither agree nor disagree, agree and strongly agree. Question 11 asked healthcare workers if they thought there was need to develop an HIV disclosure resource and how important the disclosure resource will be if developed. The question had seven items and each item had five response categories: strongly disagree, disagree, neither agree nor disagree, agree and strongly agree.

Section B asked for socio-demographic information including: age, gender, professional level, and duration of service in the ART clinic (See Appendix G).

4.2.7 Data analysis

After data collection, the questionnaires were thoroughly checked for completeness. Descriptive analysis was conducted to identify missing data, outliers and wrong codes. Wrong codes were corrected. Missing data were very few in number. Descriptive statistics of healthcare workers' demographic characteristics and knowledge, challenges, and practices of disclosure were tabulated. Bivariate analysis was conducted using logistic regression in order to find the odds of all independent variables being associated with HIV non-disclosure. Variables significant in bivariate analysis with p-values of ≤ 0.25 (Sun et al., 1996), were then included in a multivariate logistic regression model using the ‘Enter’ method in order to find adjusted odds ratio of variables associated with non-disclosure (Charry et al., 2016). The level of significance was set at $p \leq 0.05$.

4.3 STUDY RESULTS

4.3.1 Response rates

A total of 175 healthcare workers from 26 research sites (3 tertiary and 23 district Government hospitals) were approached to participate in the study. Two refused to participate for no apparent reason and three did not meet the eligibility criteria (one was laboratory technician while the other two were patient attendants working in the ART clinic). A total of 170 questionnaires were collected representing a response rate of 99% among the eligible participants. Two questionnaires were excluded during data analysis because they were completed incorrectly. A total of 168 questionnaires were include in the analysis. The presentation of the study findings is guided by the research questions.

4.3.2 Socio-demographic characteristics of healthcare workers

Table 4.1 presents the prevalence of the socio-demographic characteristics of the healthcare workers. Table 4.1 shows that the ages of healthcare workers were evenly distributed between the three categories (21-30, 31-40, >40 years). Nurse technicians were the largest professional group (33%), followed by counsellors (29%), clinicians (23%), and registered nurses (14%). The majority of healthcare workers (76%) had more than two years’ experience working in an ART clinic. All regions of Malawi were well represented; however, the highest proportion of healthcare workers came from the Southern region which is the most heavily populated. Almost equal numbers of males and females responded to the survey.

Table 4.1: Socio-demographic characteristics of study participants (N=168)

Characteristic	N (%)
Age	
21-30	60 (36)
31-40	57 (34)
>40 years	51(30)
Profession	
Nurse Technician	56 (34)
Registered Nurse	24 (14)
Counsellor	49 (29)
Clinician	39 (23)
Years of working in ART clinic	
0-1	40 (24)
2-3	67 (40)
≥ 4 years	61(36)
Region	
Central	48 (29)
North	39 (23)
South	81 (48)
Gender	
Female	86 (51)
Male	82 (49)

4.3.3 Research question 1

What are the healthcare workers responses regarding knowledge and practice of HIV status disclosure to children living with HIV in Malawi?

Table 4.2 shows results of descriptive analysis of healthcare worker's knowledge and practice on disclosure of HIV status to children living with HIV. Ninety-eight per cent reported that it was necessary to disclose HIV status to children. More than half of the healthcare workers (63%) reported that they had disclosed HIV status to a child at least once. For those who had disclosed HIV status to a child, 96 per cent reported that they had prepared the child prior to disclosure by telling them about the causes and transmission of the disease. Almost half (49%) reported that the disclosure process took more than six occasions to be completed. The majority of the healthcare workers (60%) identified six to 12 years as the best age range in which to disclose HIV status to children. However, 31 per cent identified 13 years and over to be best. Twenty-two per cent of healthcare workers reported that they were best placed to disclose HIV status, 22 per cent reported that the primary caregiver was the best person, while more than half (56%) reported that it was best when primary caregivers and healthcare workers were both involved in HIV disclosure to a child. When participants were asked about the rate of HIV disclosure at their facility, 51 per cent reported that it was between zero and 25 per cent, 25 per cent said it was between 26 and 55 per cent, and 24 per cent said it was above 55 per cent (Each ART clinic in Malawi has a patient register which indicate the number of children who are aware of their HIV status including those who were disclosed at the hospital). Less than half of the healthcare workers (47%) reported that they had in-service training on the disclosure of HIV status to children.

Table 4.2: Participant's knowledge and practice of disclosure of HIV status to children (N=168)

Characteristic	(n) %
Necessary to disclose to children	
Yes	165 (98)
No	3 (2)
Ever disclosed HIV to a child	
Yes	107 (63)
No	61 (37)
Prepared the child prior to disclosure	
Yes	103 (96)
No	4 (4)
Provided follow-up care to the child after disclosure	
Yes	95 (89)
No	12 (11)
Duration of the disclosure process	
one occasion only	15 (14)
2-3 occasions	33 (31)
5-6 occasions	7 (6)
over 6 occasions	52 (49)
Best age for HIV disclosure	
<6 years	12 (7)
6-12 years	101 (60)
≥ 13 years	51 (31)
I don’t know	4 (2)
Best person to disclose HIV to a child	
Primary caregiver	37 (22)
Healthcare worker	37 (22)
Primary caregiver and healthcare worker	94 (56)
Rate of HIV disclosure to children at the facility	
0-25%	86 (51)
26-55%	42 (25)
Above 55%	40 (24)
Received in-service training on disclosure of HIV	
Yes	79 (47)
No	89 (53)

Table 4.3 presents factors which participants reported were hindering disclosure of HIV status to children. The majority of healthcare workers (more than 80%) reported inadequate knowledge on disclosure, a lack of a standard tool for disclosure, and a lack of training on HIV status disclosure as major barriers to the disclosure of HIV status to children. Unwillingness of primary caregivers and a lack of cooperation from primary caregivers were identified by 63 per cent and 44 percent of the sample, respectively, as barriers to HIV status disclosure.

Table 4.3: Barriers to HIV disclosure to children living with HIV (N=168)

Characteristic	Strongly agree/ agree n (%))	Neither agree nor disagree n (%)	Strongly disagree/disagree n (%))
Inadequate knowledge on disclosure	142 (85)	10 (6)	16 (9)
Lack of standard tool for disclosure	141 (84)	9 (5)	18 (11)
Lack of training on disclosure	142 (85)	12 (7)	14 (8)
Pressure of work	79 (47)	26 (15)	63 (38)
Lack of cooperation with primary caregivers	74 (44)	17 (10)	77 (46)
Unwillingness of primary caregivers	106 (63)	11 (7)	51 (30)

4.3.4 Research question 2

What are the healthcare workers' views regarding the need, acceptability and benefits of the proposed children story books intended to guide the process of telling children about their HIV status in Malawi?

Table 4.4 presents the views of healthcare workers on the proposed HIV status disclosure resource. Ninety-eight per cent of healthcare workers supported the idea of developing the HIV status disclosure resource, 97 per cent agreed that they would use the resource to disclose HIV status to children, while 95 per cent reported that they would use the resource to guide primary caregivers to disclosure HIV status to children. With regard to the importance of the resource, 98 per cent reported that the proposed resource would help to improve their knowledge on HIV status disclosure, 97 per cent that the resource would improve their confidence in disclosure of HIV status, 91 percent that the resource would improve the rates of HIV disclosure to children at their facility, and 86 percent that the resource would reduce their worries regarding disclosure of HIV status to a child.

Table 4.4: Participants' views on the proposed HIV disclosure resource for children (N=168)

Characteristic	Strongly agree/ agree n (%))	Neither Agree nor disagree n (%)	Strongly disagree/disagree n (%))
It is a good idea to develop the resource	164 (98)	3 (2)	1 (0)
I will use the resource if developed	162 (97)	6 (3)	0 (0)
I will use the resource to guide primary caregivers on disclosure	160 (95)	6 (4)	2 (1)
The resource will improve my knowledge on HIV disclosure	165 (98)	3 (2)	0 (0)
The resource will improve my confidence in disclosure of HIV	162 (97)	6 (3)	0 (0)
The resource will improve the rates of HIV disclosure to children	153 (91)	9 (5)	6 (4)
The resource will reduce my worries on how to disclose HIV to children	144 (86)	9 (5)	15 (9)

4.3.5 Research question 3

How does healthcare workers' decision to disclose HIV status to children differ by demographics in Malawi?

The question was tested by a hypothesis that healthcare workers' region of residence, age, gender, years of working in the ART clinic, profession cadre, and not receiving in-service training on disclosure of HIV status are independently associated with non-disclosure of HIV status to children living with HIV in Malawi.

Factors that were identified in bivariate analysis to be associated with non-disclosure of HIV status to children living with HIV among healthcare workers are presented in Table 4.5. Table 4.5 shows that neither region nor the age of the healthcare worker was associated with non-disclosure. Registered Nurses were the professional group who were least likely to disclose (67% non-disclosure vs. 33 % disclosure). They were five times more likely not to disclose than Counsellors (uOR 5.0, p<0.01). The number of years spent working in an ART clinic was also associated with HIV disclosure. Those who had worked in a clinic for less than two years were three times more likely not to disclose (uOR 3.0; p<0.05) than those who had worked two years or more. Female healthcare workers were two times more likely not to disclose than their male counterparts (OR 1.9; p<0.05). Healthcare workers who had no training in HIV disclosure were seven times (OR 7.2; p<0.001) more likely not to disclose than those who had undergone training.

Table 4.5: Factors associated with non-disclosure of HIV status among healthcare workers (N=168)

Variable	Disclosed n (%)	Not Disclosed n (%)	Unadjusted odds ratio (uOR)	95% CI
Region				
South	50 (69)	31 (31)	1.0	
Central	33 (59)	15 (41)	1.5	0.6-3.7
North	23 (62)	16 (38)	1.4	0.6-2.9
Age				
21-30	36 (60)	24 (40)	1.8	0.8-3.9
31-40	33 (58)	24 (42)	1.9	0.9-4.3
>40 years	37 (72)	14 (28)	1.0	
Profession				
Counsellor	35 (71)	14 (29)	1.0	
Clinical officer	27 (69)	12 (31)	1.1	(0.4-2.9)
Nurse Technician	36 (64)	20 (36)	1.4	(0.6-3.2)
Registered Nurse	8 (33)	16 (67)	5.0	**1.7-14.3****
Years of working in ART clinic				
0-1 year	17 (42)	23 (58)	**3.0**	**1.3-6.8**
2 to 3 years	47 (70)	20 (30)	0.9	0.4-2.0
≥4 years	42 (69)	19 (31)	1.0	
Gender				
Female	48 (56)	38 (44)	**1.9**	**1.1-3.6***
Male	58 (71)	24 (29)	1.0	
Undergone disclosure training				
No	39 (44)	50 (56)	**7.2**	**3.4-15.1*****
Yes	67 (85)	12 (15)	1.0	

*p < 0.05, ** p < 0.01, *** p < 0.001

Table 4.6 presents factors that were associated with non-disclosure of HIV status to children in multivariate analysis. Table 4.6 shows that in multivariate analysis, gender and disclosure training were the only healthcare workers factors to independently be associated with non- disclosure of HIV status. Female healthcare workers were two and one-half times more likely not to disclose HIV status to children than males (aOR 2.4 p<0.05). With respect to in-service training, healthcare workers who had not received in-service training in disclosure to children were 7.7 times more likely not to disclose HIV status than those who had in-service training (aOR 7.7; p<0.001). These findings supported the hypothesis.

Table 4.6: Factors associated with non-disclosure of HIV status to children in multivariate regression analysis among healthcare workers (N=168)

Variable	**aOR**	**95% CI**
Profession		
Counsellor	1.0	
Clinician	0.9	0.3-2.7
Nurse Technician	0.9	0.3-2.3
Registered Nurse	2.6	0.8-8.8
Duration working in ART clinic		
0-1 years	1.4	0.5-3.6
2-3 years	0.7	0.3-1.6
≥4 years	1.0	
Gender		
Female	**2.4**	**1.1-5.5***
Male	1.0	
Undergone disclosure training		
No	1.0	
Yes	**7.7**	**3.4-17.6*****

*p < 0.05, ***p <0.001,

Healthcare workers' perspective on disclosure of HIV status is critical to better understanding of disclosure practice. It is evident that even though most healthcare workers in Malawi believe it is necessary to disclose HIV status to children, the rate of disclosure is low. This study highlights the need for providing appropriate training in HIV disclosure for healthcare workers and the provision of standardised disclosure materials.

Having discussed the healthcare workers' survey, the next chapter will present the methodology and results of the qualitative study. The study was conducted to assess the perception and knowledge of primary caregivers, healthcare workers, teachers, and community leaders regarding disclosure of HIV status to children living with HIV in Malawi, and to assess their views regarding the need and acceptability of children story books that can guide the disclosure process.

5 CHAPTER 5: QUALITATIVE STUDY (STUDY 3)

5.1 INTRODUCTION

This chapter provides information about the methodology and findings of a qualitative study. The chapter starts with a brief background information of the study. A description of the research questions is then provided. This is followed by an outline of the participants recruitment criteria and study setting. The next sections describe sample, procedure, instrumentation, and data analysis. The findings are then presented.

The WHO recommended that primary caregivers seek support from, and share the disclosure process with, teachers, healthcare workers, and community leaders (World Health Organisation, 2011). There is evidence that health outcomes for children are enhanced when their medical and psychosocial care is shared with supportive adults (Wattradul & Sriyaporn, 2014). In addition to the important role that primary caregivers and healthcare workers play in disclosing HIV status to children as discussed in chapter 3 and 4, school teachers and administrators play a role in helping children to adapt to HIV and achieve good academic outcomes ((Ebersöhn & Ferreira, 2011; UNESCO, 2008). Research has shown that making schools HIV friendly is one of the best ways to provide children living with HIV a safe, protective, caring, and supportive environment (Conway, 2005). According to UNESCO, schools should provide education, counselling, and psychosocial support, and assist children to access adequate nutrition and healthcare services (UNESCO, 2008). This is crucial because children living with HIV face a number of challenges at school, including stigma and discrimination from other students, absenteeism due to sickness, lack of the privacy required for taking HIV medications, and difficulty obtaining permission to attend hospital appointments when teachers are not aware of their HIV status (Campbell et al., 2016; Campbell et al., 2014; Mutwa et al., 2013; Punpanich, Gorbach, & Detels, 2012; UNESCO, 2008). Ideally, school teachers do need to know when children have HIV because the HIV infection can affect motor and neurocognitive development, thereby impacting on academic performance (Abubakar, Van Baar, Van de Vijver, Holding, & Newton, 2008). While schools are supposed to be safe, protective, and caring environments, this is not always the case according to the authors of research conducted in Malawi, Kenya, and Zimbabwe (Campbell et al., 2014; Kendall & O'Gara, 2007).

Communities where children and their families live have been identified as an important source of psychosocial support for children living with HIV in sub-Saharan Africa (Mburu et al., 2014a; Petersen et al., 2010). Religious leaders, traditional village headmen, the leaders of community-based organisations, and the leaders of support groups can all play an important role in mobilising communities to support children living with HIV

(Mupambireyi et al., 2014). Community leaders can assist in raising awareness of HIV, disseminating information, providing pastoral support to children and their families living with HIV, and promoting the sustainability of their care (World Health Organization, 2008). In addition, community leaders can advocate for the rights of people living with HIV and help to fight stigma and discrimination (International Center for Research on Women and London School of Hygiene & Tropical Medicine, 2010). Nonetheless, despite the significant role community leaders can play in mobilising community support, they rarely are involved to any great extent (Allison & Siberry, 2015).

The lack of materials to use in informing children about their HIV status has been reported to affect the rate of HIV status disclosure in sub-Saharan countries (World Health Organisation, 2011a). To date, rates of HIV disclosure to children living in most sub-Saharan African countries remain below 40 per cent (Dachew et al., 2014; Kajubi et al., 2014). In 2011, the World Health Organisation (WHO) identified the need for health experts to develop materials to help healthcare workers and primary caregivers with the HIV disclosure process (World Health Organisation, 2011a). Despite the great need for disclosure materials, little has been done to address this issue (Beima-Sofie et al., 2014; Sariah et al., 2016).

While it is well known in Malawi that parents, healthcare workers, teachers, and community leaders all play major roles in caring for, and supporting, children living with HIV, no previous research has focused on all these four groups regarding their perceptions and experiences of the disclosure process. The findings of this study will, therefore, help to develop a culturally appropriate intervention which addresses challenges of HIV disclosure to children in Malawi. In addition, the findings of this study will help to inform the development of community interventions to promote the practice of HIV status disclosure to children in Malawi. Furthermore, involvement of important people in the care of a child in this study will also ensure that disclosure of HIV status to children is conducted in a coordinated manner, and that children going through the disclosure process are well supported in all settings.

5.2 METHODOLOGY

The following sections will present the methodology of the study. The section will start with a description of the research questions. This will be followed by an outline of the study participants and recruitment criteria. The next sections will describe the study setting, sample size, the recruitment and data collection procedures, and data analysis.

5.2.1 Research question

The study was guided by the following research questions:

1. What are the thoughts of primary caregivers, healthcare workers, teachers and community leaders regarding the importance and process of disclosing HIV status to children living with HIV?
2. What are their views regarding their involvement in the process of disclosing HIV status to children?
3. What are their barriers and facilitators to their involvement in disclosure of HIV status to children?
4. What are their views regarding the need, acceptability and contents of story books intended to guide the process of disclosing HIV status to children.

5.2.2 Participants and recruitment criteria

The study was conducted with primary caregivers, healthcare workers, teachers, and community leaders recruited from eight districts in the three administrative regions of Malawi). The eligibility criteria of the participants are presented in Table 5.1.

Table 5.1: Eligibility criteria of the study participants

Participants	Sample size	Eligibility criteria	Recruitment location
Primary caregivers,	6 focus groups	• Parent of a child living with HIV or someone providing care to a child living with HIV between the ages of 6 to 12 years for more than six months • 18 years or older • Ability to provide informed consent	Antiretroviral therapy clinics
Healthcare workers	7 one-on-one interviews	• Working in children's antiretroviral therapy clinics • Being a nurse, counsellor or clinician • Ability to provide informed consent	Antiretroviral therapy clinics
Primary school teachers	6 focus groups	• Teaching at a primary school • Ability to provide informed consent	Primary schools surrounding participating hospitals
Community leaders	7 one-on-one interviews	• Living near the participating hospitals • Being 18 years or older • Having a certain responsibility within the community such as being a community-based organisation leader or a village headman • Ability to provide informed consent	Communities surrounding participating hospitals
Adolescents living with HIV	5 one-on-one interviews	• Between 13 to 18 years old • Living with HIV • Aware that they have HIV • Leader of children HIV support groups • Ability to provide informed consent	Antiretroviral therapy clinics Community support groups surrounding participating hospitals

5.2.3 Setting for in-depth interviews

The study settings for healthcare workers and community leaders were the eight randomly selected districts (Nsanje, Mulanje, Mangochi, Dowa, Salima, Kasungu, Mzimba and Karonga) where primary caregivers were recruited. Details of these districts have been described in Chapter 3. The community leaders who took part in the interviews were from communities located near the District Hospitals. Details are presented in Table 5.2. Table 5.2 shows that these comprised leaders of HIV community-based organisations, adolescents living with HIV, and village headmen. In total, 12 community leaders were interviewed across the eight districts.

Table 5.2: Setting for community leaders who participated in in-depth interviews

District	Number of interviews conducted	Community leader interviewed	Name of community leader's organisation	Location of the organisation in the district
Karonga	1	Adolescent living with HIV	Karonga District Hospital Teen Club	Karonga District Hospital
Mzimba	1	Community-based organisation leader	Gwazawana Nyirenda Community-Based Organisation	Mzimba District Trading Centre
Kasungu	1	Adolescent living with HIV	Young Positives	Kasungu District Family Planning Association of Malawi Office
Dowa	2	Adolescent living with HIV	Zotheka Youth Support Group	Dowa District Family Planning Association of Malawi Office
Salima	2	Community-based organisation leader	Sangu Assemblies of God Support Group	Salima District Trading Centre
		Adolescent living with HIV	Sangu Assemblies of God Support Group	Salima District Trading Centre
Mulanje	1	Group Village Headman	Nankhunyu Village	Nankhunyu Village, Traditional Authority (T/A) Mkanda
Nsanje	1	Community-based organisation leader	Ubale support Group and Dinde Community-Based Organisation	Chiphwembwe Village, T/A Malemia
Mangochi	3	Community-based organisation leader	Chikondi Support Group	Balamanja Village, T/A Nankumba
		Adolescent living with HIV	Chipalamawamba Youth Club	Chipalamawamba, Village, T/A Mponda
		Group Village headman	Namwera Group Village Headman	Namwera, T/A Jalasi

Seven in-depth interviews were conducted with healthcare workers in the ART clinics, one each from the following district hospital ART clinics; Karonga, Kasungu, Dowa, Salima, Nsanje, Mangochi, and Mulanje.

5.2.4 Setting for focus group discussions

The settings for primary school teachers and primary caregivers' focus group discussions were the eight randomly selected districts where primary caregivers who participated in survey were recruited. Teachers from six Primary Schools participated in the focus group discussions. Bwiba Primary School in Karonga District and one primary school in Mzimba District were selected from the Northern region. Chankhanga Primary School in Kasungu, one Primary School in Dowa District, and Kambwiri Primary School in Salima were selected from the Central region. Nyamizere Primary School in Nsanje District was selected from the Northern region. All Primary Schools were located at the centre of their respective districts.

In addition, six focus group discussions were conducted with primary caregivers attending ART clinics at the following District Hospitals; Karonga, Kasungu, Dowa, Mulanje, Nsanje and Mangochi.

5.2.5 Sample

As described earlier, qualitative data were collected through focus group discussions and in-depth interviews. The participants for focus group discussions comprised two groups: the primary caregivers of children living with HIV and primary school teachers. Similarly, in-depth interviews were undertaken with two groups of participants: healthcare workers and community leaders. As recommended, purposive sampling was used to recruit participants (Fossey, Harvey, Mcdermott, & Davidson, 2002). The researcher took account of the participants' age, sex and ethnicity so as to create a heterogeneous group. According to Fossey et al. (2002), qualitative research should aim at recruiting participants who can best inform the study. The number of interviews and focus group discussions were determined by saturation of data (Walker, 2012).

5.2.6 Procedure

The data collection procedures for primary caregivers, healthcare workers, teachers, and community leaders were slightly different. Therefore, the data collection procedure for each group of participants is presented separately. At the commencement of interviews, the researcher collected demographic information of the participants such as age and gender. The researcher facilitated all focus groups and interviews and a Research Assistant audio recorded the proceedings. An interview or focus group guide was used to ensure the topic of HIV disclosure was discussed uniformly (see Appendices J, M, P & S). Interviews took approximately 30 to 50 minutes and focus groups took approximately 45 to 60 minutes to be completed.

5.2.6.1 Focus group discussion with primary caregivers

Primary caregivers of children aged 6 to 12 years living with HIV, who were not part of the survey sample, were approached to participate in a focus group discussion on their appointment day at the clinic. An arrangement was made with ART clinic staff to inform all primary caregivers of children aged 6 to 12 years who came regularly to the clinic for medications about the research study and request their participation. They were then approached by a Research Assistant who asked them if they would like to participate in a focus group discussion regarding HIV disclosure. Almost all primary caregivers who were approached agreed to participate in the study and were asked to sign informed consent. Participants were given approximately 10 to 30 minutes to decide if they wanted to participate in the study. The focus group discussions took place in a quiet, private room after the primary caregivers and their children had been seen by the clinic staff.

Children were kept separate from the primary caregivers during the focus groups to avoid inadvertent disclosure. They were entertained with cartoon shows on a portable DVD player in a separate room.

5.2.6.2 In-depth interviews with healthcare workers

Healthcare workers who participated in in-depth interviews were recruited from the eight ART clinics described previously. The researcher or a Research Assistant contacted the Head of the ART clinic for permission to conduct the study. Upon getting permission, the research team contacted healthcare workers who were on duty on that particular day. Information regarding the study was provided. Thereafter, those who were interested in participating in the study were given detailed information related to the objectives and significance of the study and confidentiality issues related to the study (see Appendices N, O and P). Almost all healthcare workers who were approached agreed to participate in the study. The interviews were conducted after working hours. Due to a limited number of healthcare professionals working in the ART clinics, some of the healthcare workers participated in both the survey and in-depth interviews. At the end of each interview, a summary of the interview proceedings was given to the participant.

5.2.6.3 Focus group discussion with teachers

Upon obtaining ethical clearance, the researcher sought further permission from the District Education Managers to conduct the study among teachers. Teachers were recruited from primary schools where student ages ranged between 6 and 12 years. The researcher met with the head teacher of each school and following their approval teachers were informed about the research study. Of approximately 30 teachers in each school, 27 were willing to participate. The first six to nine individuals (considered to be the optimal number for the focus group (Newlyn, 2012)) were approached by the researcher requesting them to participate in the focus group discussion. Those who accepted to participate in the study, were asked to provide an informed consent. Reflecting the gender distribution of primary school teachers in Malawi, the participants were predominantly female. The focus groups were organised to take place at a convenient time in a quiet, private room at the school after class hours.

5.2.6.4 In-depth interviews with community leaders

The group described as community leaders comprised leaders of HIV community-based organisations and support groups, village headmen, and adolescents living with HIV who were part of the community leaders. Community leaders were recruited from across Malawi with assistance from the District ART clinic staff, the District National Organisation of People Living with HIV (NAPHAM), and the National Family Planning Association of Malawi (FPAM). FPAM is an organisation that works with youth who are living with HIV while NAPHAM is a support organisation for all people living with HIV in Malawi. The management staff of the District ART Clinic, FPAM and NAPHAM provided names and contact information for the community leaders who were subsequently contacted and briefed about the study objectives. Community leaders who accepted to participate in the study, were asked to provide an informed consent. Dates and venues for the interviews were arranged for those who expressed interest in participating. There were no refusals. Interviews were conducted either at the participant's home or one of the offices of the three organisations.

5.2.7 Instruments

Four interview guides (one each for primary caregivers, healthcare workers, primary school teachers, and community leaders) were developed by the researcher who was guided by the study aims and research questions and informed by literature related to the disclosure of HIV status to children (Kidia et al., 2014; Madiba & Mokwena, 2012; Vaz et al., 2010; Vreeman et al., 2013; Vreeman et al., 2014). Thereafter, the supervisory team examined the interview guides during weekly meetings with the researcher to verify that the guides addressed all the research questions. During this process some questions were removed while some were added depending on the agreement between the researcher and the supervisory team. Following this process, the final copies of the interview guides were developed (see Appendices J, M, P & S). After developing the interview guides, they were translated to Chichewa by a professional translator, as explained in detail in Chapter 3 (see translated Appendices J and S). The translated interview guides were reviewed by experts in Public Health, Nursing and Psychology in order to check for any consistency, clarity and cultural congruence. The translated interview guides were piloted before being used in the study. The idea of the series of storybooks was introduced to participants by reading out the following statement to participants: "We are intending to make children's books that will be used by primary caregivers of children living with HIV, healthcare workers and teachers and community leaders to tell children that they have HIV. The books will contain pictures, stories, and songs about what HIV is and how it can affect people's lives. The books will be in Chichewa (Malawian Local language) and will have information for primary caregivers, healthcare workers, teachers and community leaders on how to use the books".

5.2.7.1 Primary caregivers' focus group interview guide

The primary caregiver interview guide contained questions to elicit their views regarding: disclosure of HIV status to children; the person best responsible for disclosing HIV status in the family; how to inform a child living with HIV about their HIV status; the type of support the primary caregivers would need in order to disclose HIV to children; barriers and facilitators of HIV status disclosure to children; and participants' views on the proposal of developing children’s books to guide the disclosure resource and what content they would like or not like to be included in the books (see Appendix J).

5.2.7.2 Primary school teachers’ focus group interview guide

The interview guide for the primary school teachers included questions on the following: challenges faced by children at school; the kind of support that teachers provide to children living with HIV; teachers’ thoughts regarding telling children living with HIV about their HIV status; their thoughts regarding involving teachers in the process of disclosing HIV status to children; the kind of support teachers would need if they are to be involved in the disclosure process; and their thoughts regarding the proposed development of children’s books to guide the disclosure process (see Appendix M).

5.2.7.3 Community leaders’ interview guide

The interview guide for the community leaders included questions on the following: the challenges faced by children living with HIV in the community; their views related to disclosing HIV status to children living with HIV; their thoughts regarding involving community leaders in the process of disclosing HIV status to children; how community leaders can promote disclosure of HIV status to children; the kind of support that they would need if they are to be involved in the disclosure process; and their views regarding developing children’s books to guide the disclosure process. Adolescent leaders were asked an additional question about their experience of how HIV status was disclosed to them, and how they would want the disclosure process to be conducted (see Appendix S).

5.2.7.4 Interview guide for the healthcare workers

The healthcare workers were asked questions about the following: their understanding about HIV disclosure; their thoughts regarding telling children about their HIV status; the kind of support to be given to a child undergoing disclosure process; challenges related to disclosure of HIV status to children; facilitators of disclosure of HIV status to children; and their views regarding the proposal to develop children books to help with disclosing HIV status to children living with HIV (see Appendix P).

5.2.8 Data analysis

Data was analysed manually guided by the six steps of thematic analysis described by Braun and Clarke (2006) to analyse data collected the focus group discussion and one-on-one interview data: a) familiarisation with the data, b) coding, c) searching for themes, d) reviewing themes, e) defining and naming themes, and f) writing-up.

5.2.8.1 Familiarisation with the data

Prior to data analysis, audio recordings of the interviews were transcribed by the researcher and Research Assistants. The researcher was involved in the transcription as a way to familiarise himself with the data. Since the recordings were in Chichewa, the Malawian local language, data from the recordings were first transcribed into Chichewa prior to translation into English. Before translation of the Chichewa data, the researcher verified the transcription by re-reading the transcribed data while listening to the recorded data. Areas that were incompletely or incorrectly transcribed were noted and corrected. The researcher also used reflective notes to verify atypical issues that arose during data collection as well as the interview environment. Once the transcription was completed, the supervisory team examined the transcripts.

5.2.8.2 Coding

This step involved the researcher reading and re-reading the transcript in order to identify the patterns in the data. The researcher developed a list of codes and collated the codes to extracts. A table was used to help with this process. Upon identification of the codes, an independent researcher with experience in qualitative research but who had no knowledge of the research was asked to review the transcripts and the identified codes to confirm if the codes were arising from the transcripts and to verify that all important codes were captured. Thereafter, the supervisory team examined the identified codes and the extract during weekly meetings with the researcher. Some codes were added whiles others were removed depending on the suggestions of the independent researcher and supervisory team.

5.2.8.3 Searching for themes

In this step the researcher examined and re-examined the codes and extracts and thereafter grouped the codes according to commonalities in order to identify potential themes. A table was used to sort the codes according to their commonalities. The researcher then asked the same independent researcher who initially reviewed the codes to review the grouped codes once again. Thereafter, the researcher discussed the grouped codes with the supervisory team during weekly meetings. During this process some of the grouped codes were added, some were changed, and some were discarded.

5.2.8.4 Reviewing themes

Upon grouping the codes, the researcher and the supervisory team identified the potential themes from the grouped codes during the usual weekly meeting. A table was developed that had the all the grouped codes and the related identified themes. This table was used during the meeting with the supervisory team to identify themes from the codes. The integrative deductive-inductive theme identification approach was used. The approach was inductive because the coding was based on participants' experiences as reported during the interviews and focus group discussion. Given that one of the major limitations of thematic analysis is the inability to describe data in detail if a theoretical framework is not used (Braun & Clarke, 2006), Bronfenbrenner and Ceci (1994)'s bioecological model (reciprocal interaction between the child and persons, objects and symbols in the various contexts of the child's environment) was employed to guide the process of identifying the themes.

5.2.8.5 Defining and naming themes

During this step, the researcher and the supervisory team carefully examined the identified list of themes in order to identify suitable informative name for each theme. This was done during several meetings. The supervisory team and the researcher reviewed all codes and themes emanating from the transcripts. Any discrepancies regarding the name of the themes were discussed among the research team members until agreement was reached. Thereafter, the researcher identified quotations to elucidate the identified themes and subthemes. The quotations were verified by the supervisory team.

5.2.8.6 Writing-up

The final stage involved the researcher writing a detailed account of the findings from the analysis. The report was guided by a theoretical framework which emerged through the thematic analysis. Within this framework, themes and the related quotations were clearly described. The supervisory team reviewed the report and made comments and suggestions for improvement.

5.2.9 Quality of data

The validity and reliability of qualitative data are measured by the trustworthiness of data (Barusch, Gringeri, & George, 2011; Morrow, 2005; Shenton, 2004). The trustworthiness of data is assessed by credibility, replicability, neutrality, dependability, applicability or transferability (Barusch et al., 2011; Guba, 1981).

5.2.9.1 Credibility (internal validity)

Credibility in qualitative research is similar to internal validity in quantitative research (Morrow, 2005). Credibility entails trusting the findings of the study (Barusch et al., 2011; Guba, 1981). There are several ways of ensuring the credibility of the study, some of which are explained in this paragraph. One of the ways to ensure validity of the study findings is through triangulation that involves the use of different data collection methods and informants. Credibility can also be achieved by ensuring the honesty of participants.

Another way of ensuring the credibility of the study is debriefing sessions of the progress of the study by the research team. In addition, peer scrutiny of the research project also improves the credibility of the study by ensuring that the correction of data, data analytical methods and interpretation are empirically supported. Participants' checks during data collection can also provide insight into areas that need further clarification and examination of previous research findings (Guba, 1981).

The research team ensured the credibility of the study findings in the following ways. Data were triangulated by collection through focus group discussions and in-depth interviews. In addition, data was collected from participants with different backgrounds. The use of different methods compensates for limitations of individual methods at the same time maximizing their individual strengths (Barusch et al., 2011; Guba, 1981). Before the beginning of each interview or focus group, the participants were asked to provide frank or honest responses. At the end of each interview or focus group discussion, the researcher provided a summary of the responses from the participants of the study. This provided a chance for the participants to highlight the areas that were missed or misunderstood. In addition, the researcher and Research Assistant had a debriefing session after each interview, during which issues related to data collection were resolved. The study methodology was also scrutinised by the research supervisors and other academic and research experts, including research members of staff at Curtin University and those from the University of Malawi.

5.2.9.2 Confirmability or neutrality (objectivity)

This is similar to objectivity in a quantitative study. Confirmability describes the extent to which the researcher's bias, motivation or interest are controlled thereby ensuring that the findings of the study are determined by the respondents' ideas and experiences and not the researcher's (Barusch et al., 2011; Morrow, 2005). Barusch et al. (2011); Guba (1981) outline three ways of ensuring confirmability: external audit, audit trail, and triangulation. An external auditor is a researcher not involved in the research process who assesses the methods and results of the study in order to ensure that the study finding, interpretation and conclusions are supported by the collected data. An audit trail entails the description of the research steps taken from the start of the research project to the time of writing the report of the study findings (Barusch et al., 2011; Morrow, 2005).

The researcher ensured that confirmability of the study by keeping a reflexive journal throughout the data collection process. The researcher wrote down all important information such as methodological and logistic issues in the journal in order to ensure that important issues related to the research study were not missed out during the write-up of the study methodology and findings. In addition, the researcher employed methods for triangulation of data sources to ensure that a fuller spectrum of participants' ideas and experiences were captured.

5.2.9.3 Dependability or consistency (reliability)

This is similar to reliability in a quantitative study, and it measures the extent to which similar results will be produced if the study was repeated in the same context, using the same population and methods (Barusch et al., 2011; Morrow, 2005). This is achieved by involving an external auditor. An external auditor is a researcher not involved in the research process who assesses the methods and results of the study. The purpose is to evaluate if the study findings, interpretations and conclusions are supported by data (Leung, 2015). In order to ensure dependability of the study, the researcher must describe in details all the procedures involved in the study so that future researchers might obtain similar results if the study is repeated (Morrow, 2005).

The researcher has described the methodology and study findings in detail. In addition, an external researcher who is a staff member at Curtin University, experienced with qualitative research and not involved in the research process, assessed and examined the transcripts and the themes that emerged from thematic analysis.

5.2.9.4 Applicability or transferability (external validity or generalizability)

Transferability entails that the findings can be applied in another context (Leung, 2015). It is similar to external validity in a quantitative study (Leung, 2015; Morrow, 2005). According to Leung (2015), transferability can be achieved by describing the phenomenon in detail in order to assess if the conclusion of the research findings can be applicable to other settings, times, people and situations. In order to assess if the results of the study might be applicable to people from different settings, another study with the same method should be conducted in another setting or environment (Leung, 2015; Morrow, 2005).

The researcher described in detail all the steps of the study from conception to writing up of the study findings to enable the reader to make such a transfer as recommended by (Shenton, 2004) and Holloway (1997).

5.3 FINDINGS

5.3.1 Characteristics of study participants

In all, 12 focus group discussions and 19 interviews were conducted involving a total of 106 participants. Eighty-seven participants participated in the focus group discussions. The demographic characteristics of the study participants are presented in Table 5.3. Of the 106 participants, 42 were primary caregivers, seven were healthcare workers, 45 were teachers, seven were community leaders, and five were adolescents living with

HIV. The mean age of primary caregivers, healthcare workers, teachers, community leaders and adolescent living with HIV were 44, 41, 37, 46 and 15 years, respectively. The majority of participants were females with the exception of the community leaders group, where males predominated (See Table 5.3). The majority of primary caregivers (57%) were biological mothers of children living with HIV. With regard to healthcare workers' professional carder, nurse technicians had the largest proportion (43%) with clinician and counsellors having the least proportion of 14 per cent each.

Table 5.3: Demographic characteristics of study participants who were recruited in the qualitative study (N=106)

Characteristic	n (%)	Characteristic	n (%)
Primary caregivers	n= 42	**Teachers**	n=45
Primary caregiver's Age		Age	
Age range in years (mean age)	18-69 (M=44)	Age range in years (Mean)	31-48 (M=37)
Age of the primary caregiver's child		Sex	
Age range in years (Mean)	6-12 (M=10)	Male	12 (27)
Sex		Female	33 (73)
Male	8 (19)	Level of grade teaching	
Female	34 (81)	Grade 1-3	16 (36)
Relationship to the child		Grade 4-6	19 (42)
Biological mother	24 (57)	Grade 7-8	10 (22)
Biological father	7 (17)	Teaching experience	
Grandparent	8 (19)	Range in years (Mean)	3-16 (M=7)
Others	3 (7)	**Community leaders**	n=7
Education level		Age	
No education	12 (29)	Age range in years (Mean)	41-53 (M=46)
Primary	21 (50)	Sex	
Secondary	5 (12)	Male	5 (71)
College/ university	4 (9)	Female	2 (29)
Occupational status		Type of community leader	
No employment	8 (19)	Community based organisation	5 (71)
Farming	19 (45)	Traditional leaders	2 (29)
Self-employment	9 (22)	**Adolescents living with HIV**	n=5
Employment	6 (14)	Age	
Healthcare workers	n=7	Age range in years (Mean)	13-18 (M=15)
Age		Sex	
Age range in years (Mean)	32-52 (41)	Male	1 (20)
Male	2 (29)	Female	4 (80)
Female	5 (71)	Education level	
Professional group		No education	1 (20)
Registered nurse	2 (29)	Primary	2 (40)
Nurse technician	3 (43)	Secondary	2 (40)
Counsellors	1 (14)	Duration since HIV disclosure	
Clinician	1 (14)	Range in years (Mean)	1-3 (M=2)
Working experience in ART clinic			
Range in years (Mean)	1-7 (M=3)		

5.3.2 Overview of themes and conceptual model

Twelve focus group discussions (six with primary caregivers and six with teachers) and 19 one on one interviews (seven with healthcare workers and 12 with community leaders) were conducted. Data were analysed using thematic analysis. Data for the four groups of participants (primary caregivers, healthcare workers, teachers and community leaders) were analysed separately. The same themes emerged from the transcripts across the four groups of study participants. As such, the results of the analysis have been presented concurrently. Three main themes were identified namely; ‘talking about HIV’, ‘open communication’, and ‘shared responsibility’. The three themes had a common concept of ‘Working together’. A ‘Working together’ conceptual model was, therefore, built around this concept. The following sections present an explanation of the themes and conceptual model. The participants own words are used to illustrate the issues that were raised. Pseudonyms have been used for each quote in order to protect participants’ confidentiality.

5.3.3 Theme one: Talking about HIV

The first theme ‘Talking about HIV’ was identified through participants’ expression of the need for all stakeholders to discuss HIV status as a way of promoting disclosure of HIV status to children living with HIV, despite being constrained by the complexity and potentially negative consequences of the disclosure. Several primary caregivers and teachers said that they welcomed the opportunity to meet together to talk about HIV and disclosure to children. Aida, the mother of one child, said that: *“This forum has benefited me a lot and I will start getting free with him and start disclosing slowly”*. Patuma, another mother said that: “*Today, I had the opportunity to learn about what to tell her based on what my friends are saying here. I think I have found an answer”.* One of the teachers, Yosefe, made the following comment:

> *“I am ... happy that ... you have involved us at the grassroots [level] because ... most of you like to just involve healthcare workers and leave us out in programs affecting children and you find that such programs are not effective because they missed important issues that could have been included if they involved us”.*

Participants reported several reasons why HIV disclosure was not often discussed. These reasons, and participants’ suggestions for breaking down barriers, are presented in the following paragraphs.

5.3.3.1 Reasons for not disclosing HIV

While most participants recognised the importance of HIV disclosure to the child, they reported that disclosure was rarely discussed because of the fear of stigma and discrimination, cultural factors, protecting the child from negative consequences of disclosure, complexity of the disclosure process, and primary caregiver’s feelings of guilt about transmitting the virus to the child.

5.3.3.1.1 Stigma and discrimination

Stigma and discrimination against people living with HIV were reported by most of the participants as the main reason for non-disclosure. Sainabu, a mother of a seven year old child said that “*We are afraid to tell a young child of seven years about his HIV status because he may end up telling his friends about his condition who may then discriminate against him*”. Joyce a mother of a ten year old explained how her child was about to quit school because of stigma. One nurse reported that, in her experience, stigma and discrimination against people who were known to be HIV positive were still common in some communities. Mrs Banda, a teacher, reported how children suspected of having HIV were stigmatised at school *“When we are teaching, you find that some children start mentioning names of the pupils they suspect to have HIV, they are like…madam, this one has HIV*”. In addition, Yohane, an adolescent living with HIV explained how the experience of stigma and discrimination in her community affected her:

> *“The problem is that when we are going to the hospital to collect medication, people near our home call us names like …. look at children who are HIV positive, they are now going to the hospital to receive ART…. We are always sad to hear something like that”.*

The primary caregivers reported that stigma and discrimination had negative psychosocial implications on the lives of the children such as sadness, worries, distress and depression. One of the primary caregivers reported that her child was considering dropping out of school because of the stigma and discrimination she was experiencing at school.

> “*Like my child who is ten years old, she reached a point of telling me that she would stop going to school because her friends were talking about her that she has a small animal [HIV]…. it reached a point when she was feeling sad and withdrawn”. (Alinafe, primary caregiver)*

Three-quarters of teachers in all the six focus groups reported that children were facing various forms of stigma and discrimination at school.

> *“We have HIV lessons that we teach in class. When we are teaching, most pupils start staring at children who are known to have HIV, and they think that the lesson is talking about such children and their families. The children who are stared at, they are normally shy because they think that the whole class is talking about them”. (Mr Phiri, teacher)*

On the contrary, some teachers reported that most of the children who are living with HIV tend to have skin infections, as such other children avoid sitting close to them or getting in contact with them.

> *“As you know some children with HIV have skin sores so it is difficult for other children to come closer or to get in contact with them as a result they might think that they are being discriminated against but what other children are afraid of is the skin infection”. (Mr Mwagomba, teacher)*

Notably, some of the teachers and community leaders expressed concern that some of the children living with HIV were even being discriminated by their own parents.

> *"Some parents tell their HIV positive children to drop out of school because they think that such children have no future". (Alabu, HIV supportive group leader)*

On the other hand, the two traditional chiefs who were interviewed reported that they had put in place measures to fight the practice of discrimination such as punishment in the form of fines to those who were found discriminating against people living with HIV. They thought this had helped to reduce stigma and discrimination in the villages.

> *"I have told people that I should never hear anyone calling people with HIV names because these people are like everyone else in this village, and it seems people are following the advice because they are afraid of being fined". (Mr Makaka, traditional chief)*

One of the adolescent participants reported that he had not told anyone about his HIV status because he was afraid that he would be stigmatised and discriminated against. *"I have not told anybody about my HIV condition because I am afraid that they can start discriminating against me". (Sainabu, an adolescent living with HIV)*

On the other hand, one healthcare worker reported that some primary caregivers use different ways of concealing the HIV status of their child living with HIV from those who are HIV negative in the house. She cited an example of a primary caregiver who was giving HIV negative children, a tablet of Aspirin daily, each time their child with HIV was taking ART, in order to avoid raising suspicion.

> *"There is a certain woman who is taking care of a child living with HIV, the child is not her biological son. All her biological children are HIV negative. The woman is forced to give aspirin to her HIV negative children every time the child with HIV is taking HIV medication to avoid suspicion". (Flora, Nurse)*

5.3.3.1.2 Worries about shame and embarrassment

Primary caregivers from the three focus groups reported that they were worried that if people discovered that the child had HIV, they would be talked about in the community, and that would bring shame and embarrassment to both the child and the family.

> *"Mostly I feel its fear of embarrassment that if you tell the child, he might tell his friends who might tell others, and it will be a continuous vicious chain that will make people to be talking about us, which I feel is a big problem". (Rose, primary caregiver)*

5.3.3.1.3 Cultural barriers

Many participants thought that cultural practices that discouraged parents from discussing HIV sexual related topics were barriers to HIV status disclosure to children.

One community based leader reported that "*it is difficult for parents to disclose HIV to a child because of culture…..when parents are telling a child about HIV, a child can be surprised and say "what are my parents trying to tell me?"* Many healthcare workers also reported that some parents felt uncomfortable discussing the issue of HIV with their young child because it was related to sex. "*Some parents will find it difficult to discuss reproductive health issues with their children, but it is important information for children with this condition".* Tamala, a mother of a 12 year old reported that the mode of HIV transmission made it hard for primary caregiver to discuss the disease with the child; "*This is a difficult issue to discuss with the child because of the way the child got the infection"*.

5.3.3.1.4 Protecting the child from negative consequences of HIV disclosure

The majority of the participants reported that children living with HIV are not told about their infection because parents want to protect them and their family from the negative consequences of HIV disclosure. Elida, a primary caregiver of a nine years old child reported that:

> *"If you tell your child that he has HIV, he might tell his friends who might laugh at him, in the end, he can be worried and in his mind, he will be asking …"I have HIV, where did this disease come from?"*

5.3.3.1.5 Complexity of disclosure

Many healthcare workers, teachers and community leaders acknowledged that explaining HIV to the child was a difficult task which required confidence and necessary skills to initiate. Lesinati, a teacher, felt that disclosure was a difficult task because of the poor outcomes of HIV infection. "*If you have been found with HIV that marks the end of your life, so you have to take care on how you inform the child about his condition. It requires you to go along very well with the child, it is, of course, a long process".* One of the nurses who was interviewed said that some primary caregivers do not know how to disclose to the child. *"it is a difficult issue especially for some primary caregivers… they have problems to inform their child about her/his status".*

5.3.3.1.6 Guilt and fear of family disharmony

Most healthcare workers and teachers thought that many of the children who had HIV acquired the infection from their mother and that many primary caregivers felt guilty and did not want to disclose to their child for fear of bringing disharmony to their homes. Patuma, a mother of a10 year old boy said that:

> *"Sometimes when you tell your child about her HIV status, for instance, a 12-year-old child, she can ask you….I have never slept with a man how did I get this disease?... You gave me this disease…. so this causes conflicts".*

Abasi, a counsellor, explained his experience of a child who blamed his parents for failing to protect him from the infection.

> *"I was following up a certain bright and knowledgeable child who was living with HIV and when the child was disclosed to; he blamed his parents for failure to protect him from contracting the virus. The child had knowledge about prevention of mother to child transmission of HIV, and he thought his mother did not do anything to protect him".*

One of the teachers, reported that parents were afraid to disclose because of the fear that the child may confront them. *"It is difficult to tell older children that they have the disease. Once you tell them they become very angry and they do not take any advice".* One of the adolescents living with HIV made the following comment:

> *"It is a different case if you got the infection because you were involved in promiscuous behaviour, you can blame yourself, but getting it from parents like I did is difficult to understand. I had no chance to confront my parents on this because I lost them both when I was young".*

5.3.3.2 Breaking down barriers

Most of the participants felt that it was important to break down the barriers to talking about HIV disclosure. They acknowledged the need to disclose HIV status to a child and discuss the disclosure process and need for story books to guide the disclosure process.

5.3.3.2.1 The need for disclosure

Many participants reported that it was necessary to inform children of their HIV status because doing so would help to protect children from reinfection, promote autonomy in care and treatment as well as help children to live a healthy life. The majority of participants felt that disclosure would help children to understand about the disease and treatment. Mr Sauli, the father of an eight old child said that "*It is important to explain to the child while he is still young so that he can grow up knowing his disease and the medications that he is taking".* One of the counsellors reported that "*when a child is aware of his HIV status, he adheres to ART prescription… because he knows the benefits of the medication."* Mrs Khoma, a teacher said that disclosure can protect the child and others from HIV infection*. "If we tell the child while young, he cannot spread the infection to others and he can also know how to protect others from the infection".*

Participants identified several factors they thought facilitate disclosure to take place. These included; right time to disclose, perception that disclosure is protective and promotes autonomy, and perception that disclosure encourages a child to live a healthy life. In addition, participants felt that disclosure was a complex process which required guidance from healthcare workers to be effectively conducted.

5.3.3.2.1.1 The right time to disclose

Despite some participants supporting disclosure, the age of the child was seen as an important determining factor when deciding on the appropriate time to disclose to the child. Regarding the appropriate age for disclosure, three schools of thoughts emerged among primary caregivers; the first one supported that children should be informed about their HIV status when they are still young. The second group thought that children should be told about their HIV status when they were older, and the last group thought children should be told about their HIV status when they start asking about their HIV status regardless of their age.

One-quarter of the primary caregivers were of the opinion that children should be told when they are relatively young so that they can grow up knowing their HIV status. This group also felt that when children are told while young, they easily understand their condition and they do not argue or ask questions regarding the source of their infection which the opposite of what might happen if they are told when they are relatively older.

> *"When the child is still young he does not have problems to understand his condition, and he does not ask too many questions regarding how he got the infection." (Rose, primary caregiver)*

On the other hand, more than half of the primary caregivers thought that children should be told when they are relatively older when they can understand their condition and can keep it secret. *"The child should be told his condition when he is old enough to understand his condition because he cannot tell anybody about his condition" (Abiti Ajusu primary caregiver).*

The last group of less than a quarter of primary caregivers thought that cognitive development varies among children. Some children become cognitively mature at a younger age while others do not, as such participants in this group thought that the best way to determine if the child is ready for disclosure is when they start asking questions about their illness and the medications that they take*. "When children are growing up it is when they realise and start to ask questions about their health. This is the best time to tell them about their condition" (Sabina, primary caregiver).*

Three-quarters of primary caregivers who supported that children should be told when they are old thought that the appropriate age for disclosure should be 12 years or older. "*For me, the best time to disclose to a child is when he or she is 12 years or older because that is when he or she can easily understand about his or her illness" (Lucy, primary caregiver).* On the other hand, the majority of primary caregivers who thought disclosure should be done at an earlier age suggested six years and above as the appropriate age for disclosure. "*I feel that even six years is appropriate to tell the child provided the child is knowledgeable and shows maturity" (Alinafe primary caregiver).*

Three-quarters of the healthcare workers were of the opinion that children should be told about their HIV gradually, beginning at a younger age with full disclosure when they start showing signs of mental maturity such as asking about their condition and treatment regardless of their age.

> *"I think it depends on the development of the child so, if the child is clever, I think you can partially disclose to them with full disclosure from nine years of age. It all depends on how the child is like because sometimes you can have a 13-year-old child but from the way he looks you cannot even disclose to him while there are others of nine years of age who are clever, and you can disclose their HIV status to them." (Grace, nurse)*

In terms of age, more than half of the healthcare workers who were interviewed thought that partial disclosure should start when the child is seven years of age with full disclosure when the child is thirteen years of age. The healthcare workers thought that full disclosure should be done early to protect the child from being careless with their sexual life during adolescence. *"It might be between 7 years and 12 years of age when we can start gradually telling this child about his HIV status so that by the time the child is 13 or 14 years he is aware that he has HIV" (Mercy nurse).*

There was an agreement among teachers regarding the right time to disclose HIV status to children. Teachers from all the six focus groups thought it was very important that children should be told about their HIV status when they were still young. Teachers thought that the importance of telling children when they are young was that they can easily understand and accept their condition. The teachers though that if children are told about their HIV status when they are older, they can be in shock and can be furious and distressed. The teachers thought that children should be told about their condition between the ages of six and twelve years.

> *"A child is supposed to grow knowing that he is HIV-positive. If you tell an older child about his HIV status he goes through a lot because it becomes like a shock to him but if he is told while he is still young, he can easily accept his condition". (Sambanani, teacher)*

The majority of the community leaders were also of the opinion that children should be told their condition when they are still young. More than half of the community leaders apart from adolescents thought that nine to ten years was the best age range to tell children about their HIV status because by that time they can easily understand about their condition and keep it secret. "*If the child is nine or ten years, you can start telling him about his condition so that he can grow while knowing his condition" (Singini, community leaders).* On the other hand, the majority of the adolescents interviewed thought that children should be told about their HIV status starting from the age of six years so that they can grow up knowing their HIV status. *"The child should be told about* *his or her condition from the age of six years going up yeah. Because by then they can talk and even understand issues." (Sainabu, adolescent living with HIV)*

5.3.3.2.1.2 Disclosure is protective and promotes autonomy

There was a common agreement among primary caregivers, healthcare workers, teachers and community leaders that disclosure of HIV status to a child helped to promote drug adherence and the child's autonomy on treatment. Participants felt that having HIV infection was a complicated situation because of the nature of the disease. HIV was seen as a chronic condition that required a person to take ART for the rest of their life if they are to have good health outcomes.

> *"The good thing with disclosing HIV status to a child is that you give a good future for your child because he is aware of everything. He knows that his future is dependent on medication and when you are not there, the child can take the medication on his own". (Patuma, primary caregiver)*

Furthermore, some primary caregivers felt that disclosure can protect the child from worries that come because of ignorance of one's status, for example, primary caregivers felt that a child who is the only person living with HIV in the house might get worried about being the only one in the house who takes the ART daily if he is not told about his HIV status.

> *"It is important to tell the child about his HIV status so that he should not be worried that he is the only one among the siblings taking the medication. He might even ask you... why is it that I am the only one who is taking these medication in this house?" (Asiyatu, primary caregiver)*

Most of the healthcare workers felt that it would be difficult to convince a child to take ART daily without knowing the reason for taking them. "*He can stop taking HIV medication because he does not know the importance of taking such drugs every day, yeah he can stop" (Abasi, counsellor).* They reported that drug adherence was low among HIV children in Malawi because of lack of HIV disclosure.

> *"Medication adherence is poor among people living with HIV in Malawi because of lack of disclosure, if disclosure was started earlier, and if there was uniformity on how to disclose then medication adherence rate could have increased". (My Nyirenda, counsellor)*

Moreover, some healthcare workers felt that if the child was aware of their HIV status they can develop autonomy in taking medications.

> *"For a child who is aware of his HIV status, he does not depend on parents to remind him of taking the medication, but he will take a leading role in taking the medication because he knows the benefits of doing so. He also becomes free and mature, and he knows what he is doing". (Abasi, counsellor)*

The majority of the healthcare workers, community leaders and teachers felt that disclosure of HIV status was important because it empowers children to protect themselves from further infections as well as preventing the spread of the virus to others. The participants thought that if children are told about their HIV status early once they reach adolescence, the period when they become sexually active they can engage in protective sexual behaviours.

> *"Once the child realises that he has HIV then he can know how to protect others from the infection and also how to protect himself from further infection in this way we can even protect the whole country, yeah". (Mr Banda, teacher)*

While adolescents living with HIV agreed with primary caregivers that disclosure of HIV helps to improve drug adherence and promote autonomy, they also pointed out that disclosure of HIV can equip children living with HIV with knowledge on how to deal with stigma and discrimination, which are common in many communities in Malawi. *"It is very important to tell children living with HIV because it can help to fight stigma and discrimination" (Sainabu, adolescent living with HIV).*

5.3.3.2.1.3 Encouraging the child to live a healthy life

A third of the healthcare workers, teachers and community leaders regarded disclosure as a way of encouraging children living with HIV to live a healthy life. Participants felt that many children and even adults think that once a person has HIV, then that is the end of their life. Nevertheless, participants felt that the perception was misleading because a person can live longer if they are taking medications and following medical advice. So reassuring children that having HIV is the not the end of life was identified as an important element that could be addressed by disclosure of HIV.

> *"Disclosure of HIV can help a child to know that having HIV is not the end of life. If he has been diagnosed with HIV while young, he can still grow up, go to secondary school and complete his studies, he can even get employment and help develop this country". (Sala, adolescent leader living with HIV)*

Importantly, more than half of the healthcare workers and a third of primary caregivers felt that once the child had been told that they have HIV, they can be encouraged to join clubs or support groups for children living with HIV. Through these clubs, children can meet other children living with HIV, which can help them to realise that they are not alone in their situation.

> *"My child was talking about a certain club for children with HIV which is known as Teen Club, which he joined. This club has children of different ages. It is important that children should be going there so that they can know that they are not alone in this situation, other children have the same problem too". (Nyakandawire, primary caregiver)*

5.3.3.2.1.4 Disclosure is complex

Although many participants acknowledged the need for disclosing HIV status to the child, some primary caregivers, teachers and healthcare workers reported that it was not easy to disclose HIV to a child. Some primary caregivers felt that the mode of transmission of HIV put them in an awkward position to disclose HIV status to their child. Culturally in Malawi, it is regarded as a taboo for parents to discuss sex related issues with their children. This makes disclosure of HIV to children more difficult for primary caregivers. *"This is a difficult issue to tackle with the child because of the way the child got the infection" (Elida, primary caregiver).*

Teachers felt that because of lack of a cure, HIV was considered as a death sentence hence making the whole process of disclosure quite fraught and complicated. Some teachers perceived telling a child that they have HIV as tantamount to telling them that they would be dying. As such, they felt that it was important to follow necessary steps when disclosing HIV status to a child in order to help the child to accept his condition.

> *"Disclosing HIV to a child is similar to telling a child that your mother has died, what can that child do? He can collapse, the same with HIV if you have HIV that marks the end of your life, so you have to be careful with how you inform the child about his condition". (Mr Jere, teacher)*

Despite primary caregivers' cultural challenges related to disclosure of HIV status to a child, healthcare workers thought that primary caregivers still had an obligation to disclose, as that was the best way to promote the child's health and wellbeing.

> *"While culturally it might be difficult for the parent to discuss some of the issues about HIV with their children, but I think we are supposed to be free with the children and tell them everything about their disease including how it is contracted because the nature of the disease warrants so". (Janet, nurse)*

On the other hand, primary caregivers, while acknowledging their role of disclosing HV status to the child, felt that they had little knowledge on how best to do this, and they needed support and guidance from healthcare workers to effectively disclose to a child.

> *"It is very important that the health department should provide effective aid or strategy so that we should have a better means of disclosing to a child without causing mental health problems" (Alinane, primary caregiver)*

5.3.3.2.2 Need to discuss the disclosure process

Participants had different views regarding the best age and person to disclose as well as how the disclosure process should be conducted. Participants also expressed their opinions regarding the appropriate person to disclose HIV status to the child as well as the effective way to disclose. Issues related to the need and importance of developing an HIV disclosure resource were also identified in the participants' transcripts.

5.3.3.2.2.1 Perspectives about who should disclose HIV status to the child

The majority of participants identified primary caregivers as the principle people to disclose HIV to the child with support from healthcare workers and others. One of the nurses said that *"The guardian or parent of the child should be the one to disclose to the child because she is the one who stays with the child, they are close but also they trust each other".* Primary caregivers went further to suggest the person in the family closest to the child should disclose. Fanny, the mother of a six-year-old child reported that "*You assess the parents, the one who is close to the child should be the one to disclose to the child*". Some participants thought that primary caregivers and healthcare workers should disclose to the child together. Chifundo, a mother of a 6 year old child said that *"The best way is….. parents and healthcare worker should together inform the child about his HIV status. In this way, the child can easily understand about his condition"*. On the other hand, some thought that any trustworthy or responsible person could disclose to the child. Mr Jere a primary school teacher suggested that "*Sometimes as a parent you can be uncomfortable to explain this to a child, and you can ask people that you trust to do that for you".* In addition, there were some participants who were of the opinion that community leaders, primary caregivers, teachers and healthcare workers should all take part in the disclosure process. Janet, a nurse, commented that *"Anyone who is responsible and who has knowledge can disclose to the child be it parents, community leaders or teachers".* There was also an agreement among participants on the need for healthcare workers to assist primary caregivers with knowledge and skills of how to disclose to a child. One of the healthcare workers suggested:

> *"Once the child has tested positive to HIV, primary caregivers should be informed and taught how to gradually tell the child about his HIV status because if the child is told when he is older it would be too much for him to take it".*

5.3.3.2.2.2 Perspectives about how to disclose

Furthermore, participants gave their thoughts on how disclosure of HIV status should be conducted. Most of the participants thought that disclosure of HIV should be a gradual process as opposed to a one-off event. Primary caregivers from three of the six focus groups thought that a child should be gradually disclosed their HIV status while those from the other three focus groups had mixed feelings, with some reporting that disclosure should be gradual whereas others were not sure on how disclosure should be conducted. The primary caregivers felt that disclosing HIV status gradually to the child could help the child understand their condition.

> *"You continue gradually telling the child about his or her condition, today you tell him part of the issue then tomorrow you will tell him another component of his illness yeah, like that". (Makote, primary caregiver)*

In addition, the participants thought that gradual disclosure could protect the child from the negative impacts of abrupt disclosure such as worries and treatment non-compliance.

> *"The parents should be told that if they abruptly tell the child about his condition, then he might become depressed or refuse to take medication or can even commit suicide by hanging himself". (Shefasi, primary caregiver)*

Six of the seven healthcare workers who were interviewed felt that disclosure should be conducted in a gradual process. While primary caregivers reporting a gradual disclosure, process did not specify how this should be conducted, the healthcare workers categorised the disclosure process into two groups; partial disclosure and full disclosure. The participants explained that during partial disclosure, the person disclosing to the child should avoid mentioning terms like HIV, ARV and ART.

> *"During partial disclosure, we avoid mentioning certain terms like HIV and instead we use words like the enemy. Other terms we avoid are ART or ARV. The child learns very well, but he or she does not understand clearly about the disease. The aim is to assess the child's readiness for full disclosure". (Abasi, HIV counsellor)*

The healthcare workers reported that partial disclosure was important because it could help to assess the child's readiness for full disclosure. The healthcare workers also reported that during full disclosure words that were avoided in partial disclosure such as HIV should be used. "*During full disclosure, we explain in detail what we told him in partial disclosure because by this time the child is mentally ready for full disclosure" (Abasi, HIV Counsellor).*

Most of the community leaders and teachers also felt that children should be told about their HIV status gradually, starting when they are young in order to help them to slowly learn about their condition. *"If parents start the process of HIV disclosure when they child is still young, by the time the child is 10 years, he or she would have understood most of the important issues about HIV" (Jere, teacher).*

Adolescents living with HIV reported that the disclosure process should be gradual in order to lessen the anger and fear that can arise with knowing one's HIV status. One adolescent pointed out that when told about her HIV status in a one-off disclosure, she was affected emotionally.

> *"The child should be told bit by bit with the aim of relieving the anger and fear associated with the disease. Because if you tell a child on one occasion it*

> *becomes difficult for him to accept the condition and it is hard for him to take it. For instance, I was told about my HIV status on one occasion, so I cried because I was not expecting that to happen in my life". (Chimwemwe, adolescent living with HIV)*

5.3.3.2.3 Perspectives about the role of the books in the disclosure process

Participants were asked to give their thoughts regarding the need for the development of children's books that could be used to guide the disclosure process. More than three-quarters of the participants felt that it was a good idea to develop such books. Participants reported that they would use such books to disclose HIV to a child. Primary caregivers, healthcare workers, community leaders and teachers thought that the books would help to improve knowledge and understanding about HIV, guide the disclosure process, assist in the consistency of HIV information giving, encourage children to be courageous, support positive health behaviours, and improve the relationship among teachers, primary caregivers, and healthcare workers. On the other hand, one of the healthcare workers, despite supporting the development of such books, thought the books could lead to stigma and discrimination if used by primary caregivers because people in the community will associate possessing such books with having HIV*.*

5.3.3.2.3.1 Perspectives about the books improving knowledge and understanding of HIV and treatment

The majority of the participants thought that the books would improve primary caregivers', teachers', community leaders', and healthcare workers' knowledge on how to take care of children living with HIV as well as disclose HIV status to the child*.*

> *"These books will assist us healthcare workers or parents to have important information for disclosure and we will not have problems with disclosure. Even the parents will not have problems with disclosure because they will have all the information in the books". (Grace, nurse)*

In addition, participants thought that the books would help children learn about their condition*. "It is a good idea; the children can read on their own and know about their condition" (Abiti Sipokolo, primary caregiver).*

5.3.3.2.3.2 Perspectives about books guiding the disclosure process and giving consistent disclosure information

All the participants felt that the books would act as a standard tool to be used in the disclosure of HIV status to the child. Participants thought that books would help in the provision of consistent information about disclosure to the child and primary caregiver. In addition, primary caregivers felt that children living with HIV would find no difference in information related to HIV given by the healthcare workers, primary caregivers, teachers or community leaders and the one that they will read in the books.

> *"If the books are produced, the children will be able to relate what we tell them and what is in the books and they will see that they are not different. They will say, …this is what my dad was telling me". (Chifuniro, primary caregiver)*

In addition, adolescents living with HIV reported that the support groups they belong to, go to the villages to sensitize people on HIV issues including disclosure, however, they felt that they were not providing all the necessary information because of lack of guidance, and they thought that if the books were developed, they would act as a guide for providing HIV disclosure messages.

> *"Currently we go around the village meeting children with HIV and discussing issues related to HIV but because we do not have a guide like the books that you are talking about, we sometimes miss important information that children with HIV should know so if the books can be produced we will be able to provide the necessary information to children." (Madalitso, adolescent living with HIV)*

Healthcare workers felt that there was a lack of uniformity in the way disclosure was being conducted in Malawi because of lack of a standard tool to use during disclosure, and they felt that if the books were developed, they would help to bring uniformity in disclosure.

> *"if a health program is not uniform in a country it becomes difficult to achieve good results, from instance a person living with HIV transfers from Dowa to Nsanje district, he will find that the way disclosure is conducted there is very different from the way it is done here at Dowa District Hospital which is not good. If these books are developed, they can help to resolve this". (Burnet, HIV counsellor)*

5.3.3.2.3.3 Feelings that the books will support positive health behaviours

Primary caregivers and community leaders reported that the books would promote children living with HIV to undertake health behaviours and autonomy over treatment. Some primary caregiver thought that the information that children will get from the books would help them to develop some independence in taking medications without waiting to be told by parents.

> *"If the books are developed, they will guide us to inform these children about their condition. This will help the children to be in the forefront of taking the medication and If we forget to give them medication in the morning, they will be able to remind us". (Abiti Sipoko, primary caregiver)*

5.3.3.2.3.4 Feelings that the books will improve relationship among teachers, children, and primary caregivers

Community leaders and teachers thought the books would improve the relationship with all stakeholders involved in disclosure of HIV status, which would help them to work together when conducting disclosure to a child.

> *"These books will not only help children or parents or teachers, but the big issue is that they will help us to work together. Because if we work together, then we will be assured of having positive outcomes from the books". (Mr Bande, HIV support group leader)*

5.3.3.2.3.5 perspectives that the books may promote stigma

One of the interviewed nurses who supported the development of books felt that the books could promote stigma towards people living with HIV. She thought that the promotion activities of the books once they are developed would make people associate HIV with anyone found with the books. She suggested that the best option to prevent stigma associated with the books would be to keep the books at the health facility so that children and their primary caregivers could use them when they visit the health facility. *"I think that when the books are distributed, people will know that these books have been produced because of this problem, which may lead to stigma" (Grace, nurse).*

5.3.3.2.3.6 Perspectives about what should or should not be included in the books

The majority of healthcare workers, teacher, primary caregivers and community leaders shared their views regarding what they would want to be included in the books. Less than a quarter of primary caregivers, healthcare workers and teachers thought that the books should contain information about the importance of the child eating nutritious food. While primary caregivers thought that the books should contain general information on the importance of nutrition, healthcare workers and teachers thought that the books should also contain information about the types of nutritious food to give to the child because they felt that the primary caregivers lacked such knowledge.

> *"You can also add an issue about nutrition; you have to emphasize that children are supposed to eat nutritious food because some parents do not know what type of food to give to these children". (Janet_nurse)*

Some primary caregivers, teachers, healthcare providers and community leaders thought that it would be important to include information about the importance of taking the drugs as recommended by the doctors as well as the consequences of not taking drugs as directed by the medical personnel. Teachers and healthcare workers suggested the inclusion of pictures of two children, one showing the positive outcomes of taking recommended drugs while another showed the negative outcomes of not taking recommended drugs*. "The books would have pictures that show us the positive outcomes of taking HIV medication and also the consequences of not taking the medication" (Lesinati, primary caregiver).*

Most of the participants thought that the books should encourage the children to engage in healthy behaviours such as exercise. A quarter of the primary caregivers thought that the books should have information and pictures that demonstrate the importance of physical exercise to children living with HIV. Some teachers thought that while it was important to encourage children living with HIV to engage in sports, it was also important to specify the type of sports because some of the exercises can have a negative impact on their lives.

> *"There is need to specify the type exercise that these children are supposed to do. Because some of the exercises might be harmful to them, they can do the exercise but might end up being taken to the hospital". (Mr Bamusi, teacher)*

Adolescent living with HIV felt that inclusion of sports in the books would encourage children to join HIV clubs, which could promote HIV disclosure. In addition, adolescents living with HIV thought that it was important to emphasize in the books that if children engage in healthy behaviours, they could live longer, get educated and act as role models to other children living with the virus.

> *"You should encourage children living with HIV to participate in sporting activities. For instance, I like netball, and there are other youths who like pool, others like dancing. Such activities encourage children to join HIV support groups. So if these issues are included in the books, I am sure that many children would take part in the process of HIV disclosure." (Agness, adolescent living with HIV)*

In addition, the majority of the participants felt that the books should contain basic information about HIV such as mode of transmission and prevention as well as what to do if one was found to be HIV positive. The participants felt that the books should indicate the things that children who are living with HIV should be doing in order to be healthy and the things that they should avoid. *"You can include issues such as the definition of HIV, mode of transmission of HIV, mode of prevention and also how to deal with it when you are found with the virus" (Grace, nurse).*

Participants also made suggestions regarding the outlook and layout of the book. Some teachers felt that the books should contain colourful pictures and interesting stories that would arouse interest among children to read or to recommend the books to their friends. In addition, they also thought that the book series should be made in such a way that the children would be interested to read all the books in the series, as explained in the quote below.

> *"I also think that the books should also have issues that will cultivate interest among children living with HIV to learn more for instance in the books you can be talking about a story and then you can leave it in suspense and tell them that the story will continue in the next book, this will motivate students to read all the books that will be developed". (Salikoko, teacher)*

Participants also made suggestions regarding issues which they thought should not be included in the books. Healthcare workers thought the books should not contain pictures that show emaciated children. *"Avoid putting pictures of children who are very thin. Just include pictures of children with normal weight" (Janet, nurse).* On the other hand, teachers felt that the books should not contain pictures that could frighten children. One of the teachers gave an example of the previous HIV books that contained scary pictures.

> *"Previously there were some books of HIV and those books were frightening to everyone; they had pictures of HIV, which had frightening features like something that will attack a person and kill him on the spot. So the way things are now, I hope the books will not have such type of threatening pictures." (Catherine, teacher)*

More than half of healthcare workers, primary caregivers, community leaders and teachers thought that the books should not contain nude pictures or pictures of people having sex because they feared that it could promote risky sexual behaviours. They also thought that it was against their culture.

> *"So you as people who will be developing such books should make sure that nude pictures should not be included in the books. Nude pictures can promote risky sexual behaviours". (Makose, traditional chief)*

On the other hand, some teachers felt that it was not important to hide any information from the children because most of them already know about sexual issues because they are taught at school. In addition, the teachers felt that the mode of transmission of HIV warrants that the children should be given all the information without hiding anything.

> *"Complete provision of information to the child is very important. The main mode of transmission of HIV is through sexual intercourse, so if you do not explain that to a child, how will he or she know that sexual intercourse is if a picture is not included in the books?" (Mrs Gama, teacher)*

5.3.3.2.3.7 Feelings about the need for disclosure training

Primary caregivers felt that the proposed disclosure books were the best tool to help children learn about their condition. However, they thought that training the children on how to use the books could not only help the children to get the best out of them but also to get motivated to use the books.

> *"It will be important that if you develop the books, you should train these children on how to use them you can have a two days' workshop with the children on how to use the books and showing them cartoons in the books, this will encourage them to read the books" (Samuel, primary caregiver)*

Three-quarters of the community leaders and more than half of the teachers felt that they lacked knowledge of HIV disclosure. Community leaders especially the chiefs reported that for them to effectively motivate people in their communities to disclose HIV to children living with HIV, they needed training to acquire the knowledge and skills related to disclosure.

> *"I think the first thing is for the chiefs to be trained in this issue of HIV disclosure to children. This could help them to gain more knowledge about HIV as a result they might be able help to teach people in their villages about disclosure of HIV status to children" (Salijeni, traditional chief)*

On the other hand, teachers reported that even though their curriculum had an HIV subject, the information they were teaching was just general and could do little to help them in taking part in the disclosure process. Teachers felt that they needed training on how to handle children undergoing the disclosure process

> *"In our training as teachers, we have never been taught issues about HIV in particular on how we can be involved in this process of telling children about their HIV status. Some of the lessons of HIV like life skills have just been included in the curriculum and. we did not have this in the past. So it is very difficult for us to be effectively incorporated in this process unless we go for training". (Sikoka, teacher)*

With regard Healthcare workers, most of them reported that they needed disclosure training to gain knowledge and skills regarding the steps to follow when disclosing HIV status to a child.

> *"As a healthcare worker, I need disclosure training to gain knowledge and skills on the steps to follow when disclosing HIV to a child. The training is also important as it promotes uniformity among healthcare workers on how disclosure is conducted considering that when there is a training everyone knows that during disclosure I have to follow ABCD, and when I reach this level then I can disclose to the child". (Grace, ART nurse)*

In addition, some healthcare workers also thought that disclosure training would help healthcare workers to provide consistent information about the disclosure process to primary caregivers and their children in ART clinics in Malawi. Burnet, the ART counsellor said:

> *"There is also need for training on disclosure to children with HIV so that as healthcare workers we can provide consistent information to children and their primary caregivers. The training can also help to provide standard information to children living with HIV and their primary caregivers"*

5.3.3.3 Theme one summary

Participants expressed willingness to meet and talk about disclosure of HIV status to children, however they reported that this was not happening because of the complexity of the process of HIV disclosure and potentially negative consequences of HIV status disclosure to the child and family. There was consensus among all participants that these barriers needed to be broken down and that this would involve them working together.

5.3.4 Theme two: Open communication

The second theme ‘Open communication’ emerged after many participants expressed the need for all groups of stakeholders to freely share or express ideas to one another (two-way communication) regarding the child’s HIV status, disclosure and care. Participants reported that open communication could lead to free flow of information among stakeholders that can facilitate disclosure as well as support for children undergoing the disclosure process. Nonetheless, majority of the participants expressed concern about lack of openness among the stakeholders to discuss the child’s HIV status and issues regarding disclosure of HIV status. They characterised their communication as closed as opposed to open. There were disagreements among the members regarding a discussion about HIV disclosure to a child. Majority of healthcare workers, teachers and community leaders reported that primary caregivers were not open to discuss issues related to disclosure. Madalitso, a teacher, said that: “*Most parents are not comfortable to discuss this issue with us”.* More than half of the healthcare professionals reported that many primary caregivers were opposed to disclosure of HIV to a child, and that they were not open to give reasons for their decision. Mr Mbewe, a counsellor, said that: “*There are certain parents who tell us to say ……. you are not supposed to tell him. They have got their own reasons for that……. So we give them time to think about it*”.

On the other hand, some primary caregivers reported that healthcare workers were not giving them time to discuss issues regarding HIV disclosure, instead they were just told to administer medications to the child. Chifundo commented that “*The healthcare workers just tell us about how the child should be taking the medication but do not have time to discuss with us how we are supposed to tell the children about their HIV status*”. A number of primary caregivers reported that they wished they had discussions on safe HIV disclosure with health workers.

5.3.4.1 Barriers to open communication

While many participants wished they had more open communications between them, some pointed out that the hierarchical relationships and the perception of a lack of knowledge and understanding about HIV among the primary caregivers were major deterrents.

5.3.4.1.1 *Hierarchical relationships*

Although, no participant spoke directly about hierarchical relationships, this pattern was clearly identified from their comments. Most healthcare workers, teachers, and community leaders expressed the belief that, due to their superior knowledge about HIV and health generally, they were at the top of the hierarchy, and that, due to their lack of education and knowledge, primary caregivers were at the bottom. Mr Salijeni, a grade four teacher said that, *"Parents just hear issues about HIV while teachers read about them, so teachers have more HIV knowledge than parents, so that if involved in the process of disclosure they can assist the child to understand about his condition"*.

Indeed, some healthcare workers were of the view that primary caregivers should follow what they were told to do. Ephraim, a counsellor reported that "*Parents lack necessary knowledge and skills to disclose…they are supposed to closely follow what we tell them regarding disclosure so that they can assist the child to understand about his/her condition"*. Another healthcare worker reported that they instruct primary caregivers to initiate the disclosure process first before they are fully involved in the process. Janet, a nurse, nurse commented that "*When we find that the child is not yet told about his HIV status, we tell the parents to disclose and then hand them over to us for counselling and teaching about HIV medications".* Reinforcing this hierarchical relationship, most primary caregivers indicated that they complied with the instructions of healthcare workers, acknowledging the latter's expertise. Sayinatu said that "*For us to give proper guidance to a child so that he or she can understand about his or her HIV condition, we need to follow what the doctors say"*

5.3.4.1.2 *Perceptions of knowledge*

There was general agreement among all participants that healthcare workers were most knowledgeable about HIV, followed by teachers, community leaders, and then primary caregivers. As such, there was a view that parents were supposed to listen and do what they were told by healthcare workers, teachers, and others. Thumbiko, a teacher reported that "*Parents do not know the approach that they can use to tell the child that he is HIV positive that is why healthcare workers should teach them how to disclose*., This was also supported by a nurse "*Some parents are not educated, as such they do not know the best way to tell the child about his HIV status"*.

5.3.4.1.3 *Misunderstandings*

Participants reported that there were often misunderstandings among them regarding disclosing HIV status to the child. Healthcare workers reported that it was difficult to comprehend that despite repeating the need to disclose to the child, parents were reluctant to do so. "*We keep on reminding them to disclose to the child, but they do not see the need for the child to know so we give them time to decide when they are ready to disclose*". On the other hand, many primary caregivers reported that healthcare workers did not seem to understand why they had problems disclosing to their child. Meliya, the mother of a 12-year-old child explained "*Healthcare workers always ask us why we have not disclosed but they do not understand what it is like to have a child with HIV and to have your neighbours talk about yo*u". Then again, many teachers stated that they did not understand why primary caregivers were not open to discuss the child's HIV status with their teacher despite being told by their healthcare workers to do so.

5.3.4.2 Breaking down barriers

Throughout the interviews and focus group discussions many participants expressed their wish for open communication among those involved, thereby creating an environment where everyone would feel welcome, building trust, and improving relationships. Siyambota, a community leader, summed up the need for open communication among the people involved in the care of a child: *"I think that if healthcare workers and all the stakeholders can meet and discuss how best this issue can be tackled, then I am sure we can have a good plan on how to assist children in knowing about their condition".*

5.3.4.2.1 Feeling welcome

Many healthcare workers reported that some primary caregivers and their children were avoiding hospitals near their home and going to distant hospitals where they felt welcome to receive medication. Mercy, a nurse reported that:

> *"There are even some families who are coming from places which are very far from this hospital, but they have a health facility near their home and but if you tell them to get a transfer so that they can register and start receiving medication from the health facility near their home, they answer by saying "no we are used to getting medication here".*

A few primary caregivers reported that they knew of friends whose children had HIV who were not taking their child to the hospital because they thought that they would not be welcomed there. "*Some parents avoid public hospitals because they are not sure how they will be treated, but we still encourage them to go the hospital to get help".*

5.3.4.2.2 Trust

Trust was proposed by some participants as an important component of a relationship that would ensure open communication among the members. Some healthcare workers thought that primary caregivers did not trust them to support their children. Janet, a nurse, commented that *"Some primary caregivers are not comfortable to let healthcare workers to disclose HIV status to their children because they do not know how we will conduct the disclosure process"*.

One teacher, Sikawa, stated that all stakeholders needed to trust each other if they were to provide an effective HIV disclosure *"For the whole process of HIV disclosure to be possible, then parents, healthcare workers, teachers and leaders need to trust each other*". Chiona, one of the traditional leaders, also alluded to this by saying*: "Parents need to trust us chiefs, by discussing with us the problems that they are facing in the community, otherwise it is difficult for us to know if parents are not open with us."*

5.3.4.2.3 Good relationships

All the participants expressed the importance of a good relationship if they were to freely discuss issues related to the child's HIV status. Some primary caregivers reported that it was important to have a good relationship with teachers and healthcare workers so that they can help to take care of their children. Jasimini said that *"We need to get along very well with teachers and healthcare workers because they help in caring for our children".* A number of healthcare workers said that a good relationship with primary caregivers could facilitate disclosure of HIV to the child. A counsellor, Nyirenda, commented that "*It also depends on the relationship between the healthcare worker and the primary caregiver, if there is a good relationship between the two groups, discussion about HIV disclosure is not difficult"*. Some primary caregivers reported that they had an open discussion with their child's teacher regarding ways the teacher could assist their child and that this was helpful. Eluby, the mother of a 12-year-old child explained that:

> *"When my child started getting HIV medication, some of her friends were bullying her at school, I had a friend who was teaching at the same school and was also HIV positive, I discussed this with her and she helped my child by talking to the other children to stop their behaviour".*

5.3.4.3 Theme two summary

Participants reported that closed communication as opposed to open communication was common among them. While most participants expressed their wish to be able to discuss HIV and disclosure much more openly, they reported that hierarchical relationships were a major obstacle and that there was a perception that primary caregivers lacked knowledge and understanding regarding HIV. The emerging theme was the need for open communication through the establishment of trust and good relationships.

5.3.5 Theme three: Shared responsibility

Participants recognised that children who are living with HIV needed care and services provided by many groups of people, including their parents, healthcare workers, teachers, and traditional leaders. The participants felt that through shared responsibility, children living with HIV can be assisted to achieve good health and developmental outcomes. While most participants expressed the wish that there was shared responsibility, they thought that each group was working in isolation and there was little attempt to share responsibility for care.

5.3.5.1 Defined roles

There was a general agreement that for disclosure to continue taking place there was a need for all the people involved to take part in the process. Each of the stakeholders of HIV disclosure had a role to play in the promotion of HIV disclosure.

5.3.5.1.1 Primary caregiver

Most participants expressed the belief that each stakeholder had a specific role to play in the care of a child. They were of the view that primary caregivers had the main responsibility for caring for the child. Esime, explained that "*I as a parent, have that main responsibility of providing care that a child needs every day because I am the one who has raised him".* This was supported by one of the nurses, Janet, who commented that "*the parent has the main responsibility of providing care to child including giving the child HIV medications".* In addition, primary caregivers from all the six focus groups acknowledged that only giving the child ART was not enough. Parents thought that children living with HIV needed nutritious food to complement the drugs they were taking to strengthen their body immunity. Despite acknowledging the need to provide nutritious food to the child, almost half of the primary caregivers reported that they were having difficulties in providing adequate food to the children because of poverty. *"A child with this condition needs food that gives him energy but because of poverty; I am failing to find food for my child" (Esnart, primary caregiver).* In addition to promotion of drug adherence, primary caregivers also thought that they had a role in encouraging children to join support groups. More than a quarter of primary caregivers thought that HIV support groups helped children to stop worrying about their condition and to live a happier life. They also reported that the support groups could help to improve their knowledge about HIV and promote resilience towards stigma and discrimination. *"The child should be encouraged to meet with others in groups so that can be advised not worry that he is the only person with this problem?" (Febbi, primary caregiver)*

5.3.5.1.2 Healthcare workers

Participants went further to discuss the roles that a healthcare can play to support a child living with HIV. Although most of the healthcare workers perceived HIV disclosure as the primary responsibility of primary caregivers, they acknowledged that most primary caregivers lacked knowledge about the disclosure process. As such, they thought that they had the responsibility for guiding and supporting the disclosure of HIV to the child. *"Some of the parents are not educated, as such they do not know how they can effectively disclose HIV to the child" (Mercy, nurse).* The healthcare workers felt that since they had knowledge and expertise on HIV, their role was to teach primary caregivers on how to effectively disclose to a child. "*Primary caregivers should be informed and taught how to gradually tell the child about his or her HIV status" (Fabiano, clinician)*. Also, most of the healthcare workers felt that they were required to support children who were undergoing disclosure of HIV status by providing psychological care to enable them to accept their condition. In addition, they also indicated that they were helping the children to prepare for their future.

> *"We provide psychological support and encouragement to children with HIV to continue with their education. We inspire them that they can achieve their goals in life because having HIV is not the end of life". (Grace, nurse)*

Six of the seven primary caregivers who were interviewed indicated that their clinics had formed an HIV support group for the children known as Teen Club. The Teen Club was formed for older children who were undergoing the disclosure process. The aims of the club were to encourage children living with HIV to understand that they were not alone in their situation, to assist them to know more about their condition, to encourage them to adhere to medication and to improve their social life.

> *"We have a Teen club here at the hospital that helps children with HIV to know more about their health. Children from the age of 12 or 13 can join the club. Children meet every week on Saturday, and they discuss various issues related to their condition". (Janet, nurse)*

5.3.5.1.3 Teachers

With regard to teachers, parents, healthcare workers, teachers, and community leaders acknowledged the need for teachers to be involved. A quarter of healthcare workers felt that sometimes teachers could also take part in the disclosure of HIV status especially those who have a good relationship with primary caregivers or children living with HIV. "*There is a certain teacher who is also living with HIV. She helped me to disclose HIV to my daughter" (Abiti Mereka, primary caregiver).* In addition, many participants felt that teachers had a responsibility of protecting the child from stigma at school, supporting the child to attend hospital appointments, providing additional teaching support and assisting with disclosure. Mr Mbewe, a teacher commented *that "We also guide these children and discourage other children who have no HIV from stigmatising or discriminating against these children*".

Furthermore, more than three-quarters of teachers expressed the need for teachers to be involved in HIV disclosure. Teachers felt that they stayed with the children for a greater part of the day than parents. In addition, they thought that children listen to teachers more than to their parents.

> *"From experience, we have observed that the child listens more from us teachers than parents. The child normally follows what a teacher says compared to what other people say. So it is important that teachers should take part in telling children about their HIV status". (Mr Phiri, teacher).*

Teachers also acknowledged that children living with HIV often miss classes because of illness. They thought that there was a need to help them by organising extra classes to teach them what they had missed the time they were absent. Teachers, however, said that this was only possible when they were aware that the child who missed a class was living with HIV, and that they had missed classes because of illness or a hospital appointment.

> *"If a teacher is aware of the child's HIV status, he can even arrange for extra classes for such a child if he or she misses class because of illness but sometimes we do not bother because we do not know why the child is missing classes. The least we do is to tell students that when you are absent, you have to send a note to the teacher to inform him or her about your problem". (Mr Jere, teacher)*

Participants also acknowledged that children living with HIV need to go to the hospital periodically to collect their HIV medication. Teachers reported that if the child or parents inform them about the hospital appointment date, they would remind the child of the appointment date

> *"Sometimes the child does confide in the teacher to say that I want to let you know that on this date, I do go to the hospital with my mother. On that particular day, sometimes the pupil will excuse himself and go to the hospital or sometimes the teacher can remind him or her about the hospital appointment". (Merita, teacher)*

5.3.5.1.4 Community leaders

Community leaders have the responsibility of educating the people in community about disclosure and encouraging parents to send their children to support groups. Adna, a support group leader said that:

> *“As a support group we can ensure that once children are disclosed to are not stigmatized or discriminated through organising campaign in the villages and we can invite people living with HIV and those without to educate them on negative effects of stigma and discrimination. This can change people’s attitudes and behaviour towards children or people living with HIV”.*

Adolescents living with HIV reported that through support groups the leaders were helping allay the fears of children living with HIV. Four of the five adolescents who were interviewed reported that support groups helped to reduce their fears related to HIV. The adolescents said that their meeting with their friends made them feel that they were not alone. in addition, the adolescents felt that at the support groups leaders encouraged them to express their worries and fears. *“I used to go the support group where my fears were slowly disappearing” (Alinafe, adolescent living with HIV).*

5.3.5.2 Blame game

The lack of shared responsibility among primary caregivers led to a ‘blame game’ among healthcare workers, teachers, primary caregivers and community leaders. Each group blamed the other groups for failing to take responsibility for caring for children living with HIV. Martha, a nurse commented that primary caregivers do not disclose to their child after being given an explanation as to why they should do so: *“Many children are not aware of the reason they are taking ART medications, we do explain to parents that they should disclose the condition to the child but most of them they have not yet done that* “. Many primary caregivers, on the other hand, felt that healthcare workers were not helping them to effectively disclose to the child. Elida, a grandmother, said that.” *The healthcare workers just tell us about how the child should be taking the drugs but not how we are supposed to tell them about their HIV status*“. This statement was supported by one of the teachers, Sande, who said, “*The healthcare workers should also take the responsibility of disclosing the condition to the child, they should not just tell parents that this is a secret”.*

5.3.5.3 Teachers and leaders not told

Teachers and community leaders reported that although they wanted to take part in the disclosure process, their hands were tied because it was difficult for them to identify children who were HIV positive in order to take part in the disclosure process as most often primary caregivers were not telling them about their child’s HIV status. Wanangwa, a teacher’ said that

> *“Parents are not free to give information to the school to say these children are sick. So it is difficult for teachers to know that the child is HIV positive. It is important that teachers should be informed about the child’s HIV status”.*

5.3.5.4 Breaking down barriers

Most participants pointed out that shared responsibility had many benefits and there was need to identify factors that can promote shared responsibility among the members. The majority of primary caregivers felt that shared responsibility would help to ensure continuity of care and appropriate disclosure of HIV status to children. Sayinatu, the mother of an 11 year old child said that:

> *"When the child started taking HIV medicine, I went to school to inform his teacher that this child is sick. So sometimes he might be late for school, it is because I try to make sure that he should eat first before coming to school. If you see that he has a fever you should be giving me a call so that I can come and take him to the hospital".*

Rhoda, a teacher went on to say that:

> *"What matters to us most is that primary caregivers should be free with us, to tell us if their children are HIV positive in that way we teachers and parents can work together to assist the child and even at school when other pupils want to call them names they will be afraid of us because we will put in place measures to protect such children"*

5.3.5.4.1 Support groups

A number of participants suggested that the formation of support groups for children living with HIV was a good way of facilitating shared responsibility. Fabiano, a clinician, said that *"We have a Teen Club here at the hospital that helps children with HIV to know more about their health. Children from the age of 12 or 13 can join the club."* Semati, the parent of a 14 years child reported that "*It is important that the children should be going to a support group so that they are encouraged and not to be worried that they are the only ones with HIV".* Some community leaders reported that although the support groups were beneficial to children living with HIV, some primary caregivers were not sending their children to these groups. Mercy, a community-based leader, commented that:

> *"There is a need for sensitization because there are many people including children who tested positive for HIV in the villages but have not yet joined the support group. They do not understand what it means to have HIV in their body. Many of them just stay at home they do not want to come to the group and interact with their friends".*

Many of the adolescents living with HIV who took part in the study reported that they were extremely anxious when they were told that they had HIV, and that their attendance at a support group helped them to accept their HIV status and adopt healthy behaviours. Alinafe, a 15-year-old adolescent living with HIV narrated that:

> *"When I joined the support group at FPAM, I met children of my age and my fears went away because I thought why should I be worried when my fellow friends are also living with the same condition. I realised that having HIV is not the end of your life".*

5.3.5.4.2 Disseminating information about disclosure

Many participants expressed the view that there was a need for them to share responsibility for disseminating information about HIV disclosure. Some suggestions for dissemination were: holding campaigns in the communities, using the radio and other media, talking about HIV at church gatherings, and putting up posters in hospital departments. For example, one of the counsellors, Burnet, said that:

> *"Our tradition demands that we respect the chiefs, so I think the best way is to sensitise the chiefs on this issue, informing them on how stigma and discrimination are negatively impacting on disclosure of HIV status to children and asking them for permission to educate people to stop stigma and discrimination against people living with HIV. So the way of teaching them should be in such a way that the people should be involved in finding ways of stopping the practice."*

Mr Phiri, the leader of a community-based organisation, added that:

> *"I have a drama group, we can publicise to the community for people to come and watch the performance by the drama group, and healthcare workers can use the opportunity to educate people about disclosure of HIV status to children".*

More than half of the healthcare workers who were interviewed acknowledged the need for healthcare workers to be involved in educating people about the importance of HIV disclosure to children. Healthcare workers thought that the best way to provide such education was through the use of popular media. *"Messages on the importance of disclosure should be aired out by different radio stations" (Fabiano, clinician).* The healthcare workers also thought that all the departments at the hospital had a responsibility to educate people. In addition, one of the healthcare workers thought that healthcare workers could take advantage of the social gatherings such as church and wedding ceremonies to provide information related to disclosure of HIV status to people.

> *"We can reach out to parents at OPD. Every department in the hospital should take responsibility to educate people on the importance HIV disclosure to children living with HIV. In the community we have Health Surveillance Assistants who can go the chiefs and ask for permission to sensitize the community on this issue, still in the communities there are HIV/AIDS support groups which are free and can easily engage the community on this issue. Even at church we can ask one healthcare worker to provide a talk on HIV disclosure. We have so many social gatherings here in Malawi, and we can just ask the MC [master of ceremonies] to briefly explain this issue to the people". (Grace, nurse)*

Some participants suggested that there was a need to set up a meeting to plan how they could work together through shared responsibility. Janet, the nurse, explained that

> *"Healthcare workers and all the stallholders need to meet and discuss how best this issue can be undertaken, then….we can have a good plan on how to assist children know about their condition".*

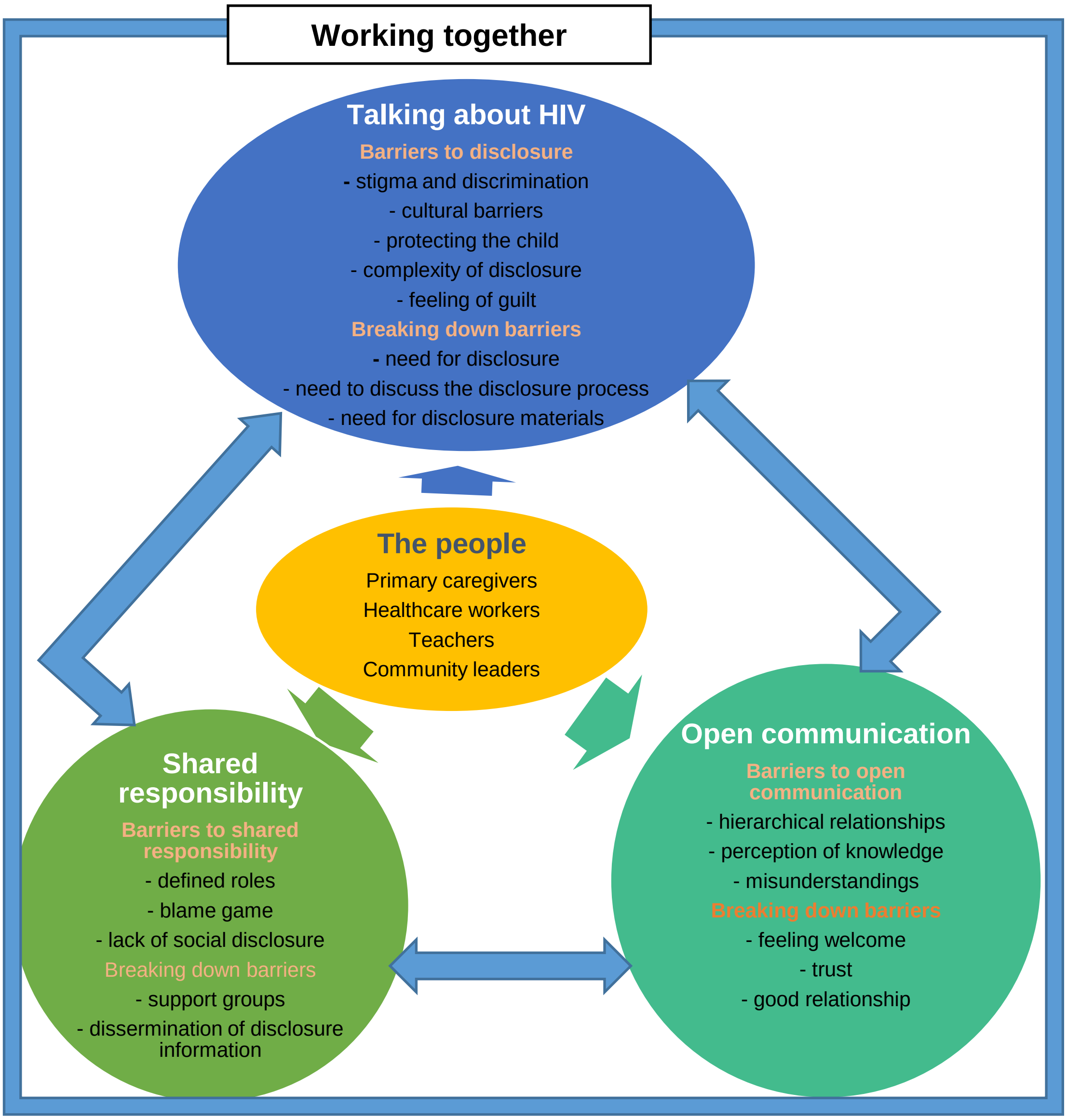
5.3.5.5 Theme three summary

Many participants expressed the necessity for shared responsibility in order to meet the needs of children living with HIV. Nonetheless, the majority reported that this was not happening because each group was working in isolation. Participants defined the roles that each group was supposed to play. The failure of each group of people caring for children to carry out their roles resulted in a 'blame game'. Some participants reported that they would be more likely to share responsibility if there were more support groups and if positive messages about HIV were disseminated more widely.

5.3.6 Working Together conceptual model

A conceptual model was constructed based on the data emerging where participants emphasised the need for all stakeholders to work together in order to promote the practice of effective HIV status disclosure to children (see Figure 5.1). There was a great deal of discussion related to working together among the study participants. Primary caregivers, healthcare workers, teachers, and community leaders all felt that the disclosure of HIV status to children was not well coordinated because each of the stakeholders was working in isolation instead of working as a team. The participants expressed the need for them to work together in talking about HIV and disclosure, sharing the responsibility to ensure that the process of HIV disclosure was conducted in a coordinated way and ensuring that there was open communication as they carried out their respective tasks (see Figure 5.1). These three themes are described in detail below.

Figure 5.1: The Working Together conceptual framework



The model is presented inside a frame with a heading 'Working Together' on top signifying that whatever is encompassed within the frame is about working together in the disclosure of HIV status order to help children living with HIV and their families achieve the best possible health outcomes and well-being (see Figure 5.1). At the centre of this model are stakeholders that study participants identified as indispensable in the process of HIV disclosure. These are primary caregivers of children living with HIV, healthcare workers, teachers, and community leaders. From the centre, three arrows emerge, one leads to the theme talking about HIV, the second one leads to the theme open communication and the last one leads to the theme shared responsibility. Meaning that there is a need for the stakeholders to work together in all the three themes if positive results are to be achieved. A bi-directional arrow connects Talking about HIV and shared responsibility; another bi-directional arrow connects shared responsibility and open communication, and the third bi-directional arrow connects open communication and talking about HIV meaning that the three themes are linked and activities within the three themes occur simultaneously.

The first theme ‘talking about HIV’ was identified through participants’ expression of the need for all stakeholders to talk about HIV. It was evident through the analysis of the transcript that participants wanted to talk more about HIV in order to promote disclosure of HIV to children aged between six and twelve years and to reduce the negative consequences of HIV disclosure. Importantly, under this theme, primary caregivers, healthcare workers, teachers, and community leaders had different views regarding HIV disclosure to children. Some participants thought that it was important to disclose HIV status to children aged between 6 to 12 years with the ultimate goal of promoting the children’s health behaviours. On the other hand, some participants felt it was not good to disclose HIV status to children because of the negative consequences of HIV status disclosure. Under this theme, participants expressed that although they wanted to talk more about HIV, but they were constrained by the complexity of the process of HIV disclosure and potentially negative consequences of HIV status disclosure to the child and family. There was consensus among all participants that these barriers needed to be broken down and that this would involve them working together.

The second theme ‘open communication’ emerged from participants’ transcripts that called the need for stakeholders to have an open communication regarding disclosure of HIV status to the child. Nonetheless, the participants described their communication as closed as opposed to open. Hierarchical relationships, perception among stakeholders that primary caregivers lacked knowledge of HIV and misunderstandings were reported as barriers to open communication. Participants expressed that these barriers could be broken down through creation of an environment where everyone will feel welcome as well as through the development of trust and good relationship among the members.

The last theme ‘shared responsibility’ was expressed by the majority of the participants. The participants felt that disclosure of HIV status was more than primary caregivers’ responsibility. Participants looked at disclosure of HIV to children as a shared responsibility, they felt that each stakeholder had a role to play not only to ensure that disclosure of HIV status was taking place, but also that it was taking place in an effective way that could help children living with HIV and their families to meet their physical, social, psychological, nutritional, academic, and health needs. They thought that each group was working in isolation and there was little attempt to share responsibility for care. Participants reported that they could promote shared responsibility through HIV support groups and dissemination of HIV messages.

Having presented the findings of the study, the following chapter will discuss these results in the context of relevant literature. The discussion will be guided by the emergent Working Together model.

6 CHAPTER 6: DISCUSSION

6.1 INTRODUCTION

The aims of the study were to assess the current status of disclosure of HIV status to children living with HIV in Malawi and to evaluate the need and acceptability of story books intended to help with the disclosure process. The research aims were addressed through three studies namely primary caregivers' survey, healthcare workers' survey and a qualitative study. Each study had its own research questions. The primary caregiver survey was guided by the following research questions: (1) What are the knowledge and practice of primary caregivers in Malawi with regards to HIV status disclosure to their children living with HIV? (2) What are their views regarding the need, acceptability and benefits of the proposed children's story books for guiding the process of informing their children about their HIV status? (3) How does their decision to disclose HIV status to their children differ by demographics, child and family psychosocial factors, and child health factors? (4) How do their reports of emotional and behavioural problems of their children living with HIV in Malawi differ by demographics, child and family psychosocial factors, and child health factors? The healthcare workers' survey had the following research questions: (1) What are the healthcare workers' responses regarding knowledge and practice of HIV status disclosure to children living with HIV in Malawi? (2) What are their views regarding the need, acceptability and benefits of the proposed children story books intended to guide the process of telling children about their HIV status in Malawi? (3) How does their decision to disclose HIV status to children differ by demographics in Malawi? The qualitative study addressed the following research questions: (1) What are the thoughts of primary caregivers, healthcare workers, teachers and community leaders regarding the importance and process of disclosing HIV status to children living with HIV? (2) What are their views regarding their involvement in the process of disclosing HIV status to children? (3) What are their barriers and facilitators to their involvement in disclosure of HIV status to children? (4) What are their views regarding the need, acceptability and contents of story books intended to guide the process of disclosing HIV status to children.

In this chapter, the findings of the three studies are discussed in the context of relevant published literature and in terms of their implications for practice, policy and future research. The discussion will also be guided by the "Working Together" framework that was conceptualised from the qualitative findings. The chapter starts with a brief summary of the key quantitative findings that are not related to the Working Together framework, followed by a summary of the Working Together framework and integrated findings of both qualitative and quantitative analyses. The findings are then discussed in the context of relevant published literature. Next, the strengths and limitations of the study are identified and discussed. Following this the implications of the study findings, including the development and piloting of the story books and other recommendations for future practice, are presented. The chapter ends with a conclusion.

6.2 SUMMARY OF KEY FINDINGS

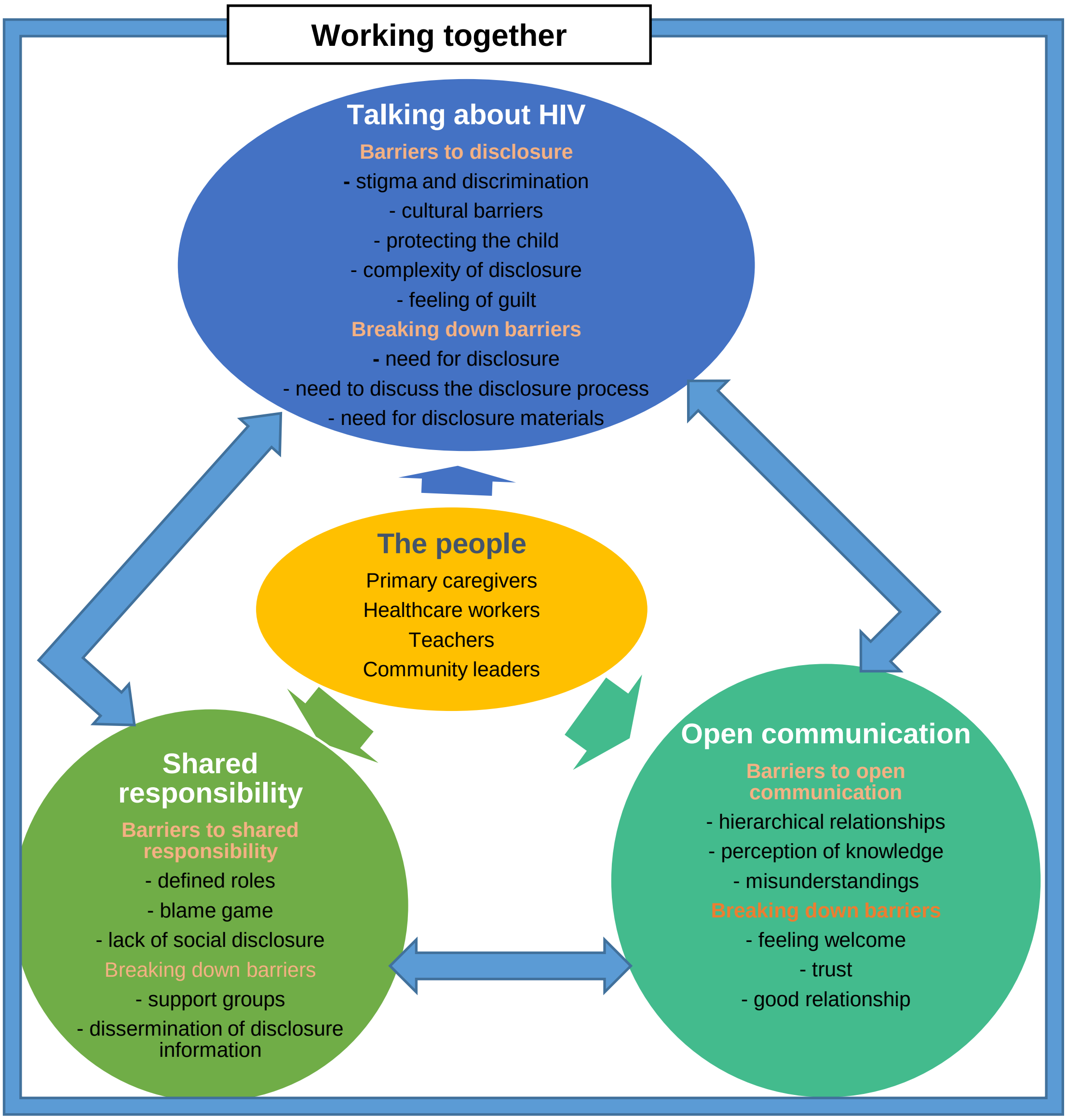
6.2.1 Key quantitative findings not related to the Working Together framework

The overall response rate for the questionnaire survey was 99 per cent with almost 600 questionnaires collected. Higher scores for emotional and behavioural problems were identified in 31 per cent of the children. In addition, significant and serious levels of impact of the illness on the family were identified in three-quarters of study participants. Factors that independently predicted emotional and behavioural problems in children were primary caregivers' young age, low level of education, and lack of employment, as well as their report of a substantial impact of the illness on the family and a low level of functional support.

6.2.2 Summary of the Working Together framework and integrated findings

While the survey data provided useful information about the prevalence of HIV disclosure, barriers to disclosure, characteristics related to non-disclosure as well as the need and acceptability of the story books, the qualitative study provided a deeper understanding of these factors. For this reason, the Working Together framework which was developed from thematic analysis of qualitative data, will be used to guide the discussion that follows (see Figure 6.1).

Figure 6.1: The Working Together conceptual framework



The conceptual framework emerged after participants expressed the need to work together in promoting effective disclosure of HIV status to children. The framework has the following three themes: talking about HIV, open communication, and shared responsibility. A brief summary of findings related to these three themes is presented below.

6.2.2.1 Talking about HIV

The principal components of this theme were barriers to disclosure and breaking down barriers. Participants expressed a willingness to meet and talk about disclosure of HIV status to children, however, they reported that this was not happening because of the complexity of the process of HIV disclosure and the potential negative consequences of HIV status disclosure to the child and family, inadequate knowledge about HIV disclosure, the lack of a standard tool for disclosure, and the lack of training on disclosure. The high rate of non-disclosure was evident in the questionnaire data, where caregivers reported that 64 per cent of children were unaware of their HIV status and more than half of healthcare workers reported that the rate of HIV disclosure in their health facilities was 25% or less. Reasons for non-disclosure reported in the quantitative part of the study were very similar to those reported in the qualitative part of the study. Primary caregivers who were engaged in farming, from the Yao or Lhomwe tribes, or living with two or fewer children older than 12 years had a higher likelihood of having children who were not aware of their HIV status. In addition, non-disclosure of HIV status was more likely to happen to children who were younger, in stage one of the WHO HIV clinical stage, had normal weight, and those who were not asking their primary caregiver the reasons for taking ART. Female gender and the lack of training on disclosure were independently associated with never having disclosed HIV status to children among healthcare workers. None of the child or family psychosocial factors were associated with non-disclosure. Neither was family wealth or parents' level of education. There was a consensus among all participants that the barriers to disclosure needed to be broken down and that this could happen only if the stakeholders involved became much more engaged in discussing the disclosure process. Nonetheless, most participants acknowledged their lack of knowledge and confidence in disclosing. They reported that the availability of story books would help to enhance their knowledge and skills in the disclosure of HIV diagnosis to children.

6.2.2.2 Open Communication

The principal components of this theme were barriers to communication and breaking down barriers. Participants reported that closed or hierarchical communication as opposed to open communication was common among them. While most participants expressed their wish to be able to discuss HIV and disclosure much more openly, they reported that hierarchical relationships were a major obstacle and that there was a perception that primary caregivers lacked knowledge and understanding about HIV. Findings from the questionnaire data revealed a lack of cooperation between primary caregivers and healthcare workers. The majority of participants reported that the establishment of trust and good relationships between the members was necessary for open communication.

6.2.2.3 Shared responsibility

The principal components of this theme were barriers to shared responsibility and breaking down barriers. Many participants expressed the necessity for shared responsibility in order to meet the needs of children living with HIV but that this was not happening because each group was working in isolation. The failure of each group of people caring for children to carry out their respective roles resulted in a ‘blame game’. This was also reflected in the questionnaire data, which showed that a considerable proportion of healthcare workers reported that primary caregivers were not willing to disclose HIV to their children. On the other hand, more than half of the primary caregivers reported that healthcare workers were not guiding them to successfully disclose to children.

6.3 DISCUSSION OF INTEGRATED FINDINGS IN RELATION TO LITERATURE

As stated in previous paragraphs, the discussion of integrated findings is mostly guided by the working together framework. The Working Together framework has three main themes: talking about HIV, open communication and shared responsibility. Within this framework, the findings are organised and presented in relation to the published literature. This sub-section of the discussion begins with a focus on psychological and social problems experienced by children and families living with HIV because the literature surrounding these topics does not easily fit within the conceptual framework.

6.3.1 Psychological and social problems experienced by children and families living with HIV

Overall, the levels of emotional and behavioural problems (31%) found in this study are similar to those found in a study in Zambia (29.1%) (Menon et al., 2007) but higher than in a study in Tanzania (13.7%) (Dow et al., 2016). The difference with the Tanzanian study (Dow et al., 2016) could be due to the differences in age groups of the children. While this study targeted 6 to 12 years old children, the Tanzanian study involved youths aged between 12 to 24 years. In addition, our study used the parent-report version of the Strengths and Difficulties Questionnaire (SDQ), while the Tanzanian study used the self-report version. It is common for adolescents to report their experience of symptoms differently to their parents (Arman, Amel, & Maracy, 2013; Van Roy, Groholt, Heyerdahl, & Clench-Aas, 2010). For example, the authors of a cross sectional study who compared the parent report and child self-report of the SDQ between 1934 adolescents aged 11 to 14 years in Iran, reported discrepancies between the two report forms with parents over-reporting and children under-reporting emotional and behavioural problems (Arman, Amel, & Maracy, 2013).

While the authors of a study conducted in Ghana among children orphaned by HIV reported higher scores of total difficulties (52%) (Doku, 2009), the level of difficulties among children living with HIV identified in this study was higher than those reported in studies conducted in Spain (24.5%) (Medin et al., 2016) and the UK (27.1%) (Melvin et al., 2007). The difference with the Ghanaian study could be explained by the fact that losing one or both parents is a stressful life event that children struggle to cope with

(Rotheram-Borus, Weiss, Alber, & Lester, 2005). Moreover, there is great deal of evidence that shows that the loss of one or both parents is associated with mental health problems among children (Cerel, Fristad, Verducci, Weller, & Weller, 2006; Dowdney, 2005; Luecken & Roubinov, 2012; Stikkelbroek, Bodden, Reitz, Vollebergh, & van Baar, 2016). The death of a parent frequently results in the loss of social and economic support to the child (Cerel et al., 2006; Chi & Li, 2013; Stikkelbroek et al., 2016). The prevalence of mental health problems among children living with HIV in this study suggests that a significant proportion of children in Malawi are at risk of engaging in high risk behaviours such as non-adherence to ART, which may have a significant impact on their health and development (Amzel et al., 2013; Li et al., 2008). Early childhood mental health services targeting these children are therefore needed in order to reduce the impact that mental health problems can have on these children.

Primary caregivers who were younger and had a low level of formal education were more likely to report that their child had a mental health problem. Similar findings were reported in a study conducted in India (Banerjee & Grover, 2007). In the current study, primary caregivers who had no formal employment and were engaged in home duties were also more likely to report that their child had a mental health problem. In Malawi, primary caregivers who are primarily engaged in home duties may spend more time with their child and thus be more likely to observe changes in the child’s behaviour compared to those who are employed or doing business. A study conducted in the Netherlands reported that unemployed parents were more likely to report more emotional or behavioural problems in their children compared to those who were employed (Harland, Reijneveld, Brugman, Verloove-Vanhorick, & Verhulst, 2002). The negative psychosocial well-being associated with parental unemployment may also affect the child’s mental health status which in turn affects their relationship with their parents (Kendall et al., 2009).

Three-quarters of all primary caregivers reported significant or very serious levels of impact of the child’s condition on the family. It has previously been documented that caring for a child living with HIV in Malawi is related to families great financial, physical and psychosocial hardship (Nyando, 2014). In addition to the usual care, caregivers of children living with HIV must administer medications daily, take the child to hospital clinic appointments regularly, and buy nutritious food that can be costly and in short supply (Nyando, 2014; Sefasi, 2010). Over the life course, these children are also more likely to be hospitalised, which places a further strain on the family (Sefasi, 2010). Caregivers must also cope with the stress and anxiety associated with knowing that their child has HIV, a potentially life-threatening illness (Mandalazi et al., 2014). Coupled with this, caregivers frequently experience stigma and discrimination (Nyando, 2014). Finally, caregivers must manage the complexity of disclosure of HIV status to the child and issues such as the right age to disclose and the potential for disclosure to affect the psychological wellbeing of their child (Mandalazi et al., 2014). Primary caregivers who reported significant or very serious levels of impact of illness were respectively three and nine times more likely to report that their child had an emotional or behavioural problem. This finding is in accordance with substantial evidence that childhood mental health problems are more prevalent in families that experience psychosocial difficulties (McLoyd, Jayaratne, Ceballo, & Borquez, 1994; Murphy & Fonagy, 2012; Sheehan, 2017; Tallon, Kendall, Priddis, Newall, & Young, 2017). More specifically, there is evidence that families coping with the stress of a child's chronic illness are at substantially increased risk of developing dysfunctional patterns of behaviour that can, in turn, impact on the child's emotional and behavioural outcomes (Malhotra & Singh, 2002; Murphy & Fonagy, 2012; Tallon et al., 2017).

Children whose primary caregiver reported that they had a low level of functional support were also more likely to have a mental health problem than those whose caregivers reported a high level of functional support. A high level of functional support helps the primary caregiver with human and financial resources to cope with the demands of caring for a child living with a chronic illness (Boyd, 2002). In Rwanda, an intervention that promoted improved relationships and communication between primary caregivers and their children living with HIV helped to reduce mental health problems among children (Betancourt et al., 2014). The Rwandan intervention study involved trained counsellors visiting families affected by HIV to provide psychosocial support, promote resilience, strengthen problem-solving skills, and assist in getting other forms of social support (Betancourt et al., 2014). The intervention improved parenting skills, child prosocial behaviour, caregiver social support as well as children's mental health.

6.3.2 Talking about HIV

Due to the focus of existing literature on either parents and caregivers or healthcare workers the following discussion is organised with a sub-section focusing on primary caregivers, followed by a sub-section focusing on healthcare workers. It finishes with a sub-section about ways of breaking down barriers to talking about HIV.

6.3.2.1 Focus on primary caregivers

6.3.2.1.1 Prevalence of HIV disclosure

The majority of primary caregivers in both qualitative and quantitative parts of the study reported that HIV disclosure was the exception rather than the rule. The prevalence of non-disclosure of HIV status to children living with HIV identified in the survey data was 64 per cent. This finding is similar to those reported in studies conducted in Tanzania

(Nzota et al., 2015), Zambia (Menon et al., 2007), and South Africa (Skeen et al., 2014), and lower than those reported in two studies conducted in Kenya where the non-disclosure rates were 89 per cent (Turissini et al., 2013) and 74 per cent (Vreeman et al., 2014) respectively and an Ethiopian study where the rate was 83 per cent (Biadgilign et al., 2011). While both the current study and the Kenyan study conducted by Turissini and colleagues (2013b) were cross-sectional and targeted children in a similar age group, data for the Kenyan study were collected from only one hospital and thus may not have been representative of all hospitals in Kenya. In addition, whereas the current study used data from primary caregivers to determine the rate of non-disclosure, Vreeman and colleagues (2014) in Kenya, and Biadgilign and colleagues (2011) in Ethiopia used data collected from caregiver-child dyads to determine the rate of non-disclosure. The authors of two studies conducted in sub-Saharan Africa found that caregivers tend to underreport non-disclosure compared to children (Biadgilign et al., 2011; Namasopo-Oleja M et al., 2015).

On the other hand, the estimated prevalence of non-disclosure in our study is higher than those reported in two studies conducted in Uganda, where the non-disclosure rate was found to be 49 per cent (Kajubi et al., 2014) and 44 per cent (Namasopo-Oleja M et al., 2015). As with the study conducted by Turissini and colleagues (2013) in Kenya, data for the Ugandan studies were collected at a limited number of sites and thus may not have been representative of the population. Furthermore, the foci of both the Ugandan studies were disclosure among children up to 18 years of age. The finding that children aged nine to 12 years in our study were more likely than their younger counterparts to be aware of their HIV diagnosis supports this evidence that older children are more likely than younger children to be told that they have HIV (Turissini et al., 2013; Vreeman et al., 2014).

The prevalence of HIV non-disclosure in the current study was also much higher than in the US where a non-disclosure rate of 30 per cent was reported in one study (Santamaria et al., 2011). However, the US study targeted older children between the ages of 9 to 16 years. While the variation in the age groups of children living with HIV in the two studies might explain the difference in the rate of non-disclosure, the more likely reason is that developed countries have proactive measures and resources for disclosing HIV status to children (McCleary-Sills et al., 2013; O'Malley et al., 2014). The high proportion of children who are unaware of their HIV status in Malawi are likely not to adhere to ART medications (Brown et al., 2011; Hejoaka, 2009; Vreeman et al., 2010b), adopt unhealthy behaviours (Gyamfi et al., 2015), and have accidental HIV disclosure in unsupported environment (McCleary-Sills et al., 2013), which might negatively impact on their physical and emotional wellbeing (Mehta et al., 2016; Mutwa et al., 2013). Primary caregivers in

Malawi need support to help them understand the importance of children knowing their HIV and how age appropriate disclosure can be conducted. Healthcare workers are well placed to take up this role given that they are in regular contact with primary caregivers. In Malawi, primarycaregivers of children living with HIV are supposed to visit the ART clinic to collect medication for their children once every two to three months. Healthcare workers can use these visits to provide health literacy related to the importance and process of HIV status disclosure to children to primary caregivers.

6.3.2.1.2 Reasons and factors associated with non-disclosure

The main reasons for non-disclosure were: concerns about the child's ability to cope with the news about his/her HIV status, concerns about the child's age, a lack of confidence about how to disclose appropriately, fear of stigma and discrimination, cultural barriers, guilt, and fear of family disharmony. These reasons concur with those found in other studies from sub-Saharan Africa, where primary caregivers failed to tell children about their HIV status because of lack of disclosure knowledge, concerns that children may not understand about their infection, and fear that children may tell others about their diagnosis who may in turn stigmatise and discrimate against them (Madiba & Mokwena, 2012; Mburu et al., 2014a; McCleary-Sills et al., 2013; Vaz et al., 2008). While many primary caregivers are concerned that HIV disclosure will cause their child to experience psychological distress, the literature reveals that most children with HIV understand the seriousness of the condition long before he or she is told (Domek, 2010; Spinetta & Maloney, 1975). Moreover, although many parents are worried that children might have emotional and behavioural difficulties when they are told about their HIV status, research has shown that these difficulties are usually short lived and resolve with time (Mburu et al., 2014a).

As to concerns about the child's age, there is evidence that primary caregivers perceive younger children to lack the emotional and cognitive maturity to cope with the knowledge of their HIV status (McCleary-Sills et al., 2013). Primary caregivers in the current study reported that they disclosed when the child was asking questions about their HIV medications. This finding is consistent with those of a study from Rwanda, where children who engaged in conversation with their primary caregivers about their condition were 15 times more likely to be told about their HIV status compared to those who did not engage in such conversation (Binagwaho et al., 2012). Also, older children are more likely to ask questions and engage adults in conversation. For example, Madiba (2016) found that caregivers in Botswana and South Africa interpreted children's frequent questions about their condition as a sign of maturity, that they are ready to be told about their HIV status (Madiba, 2016).

Conversely, recent studies conducted in Burkina Faso, Uganda, and The Democratic Republic of Congo found that despite children's curiosity to know about their disease, primary caregivers felt that they were too young to be engaged in conversation about their HIV status and instead opted for deception and threats as a way of protecting the children from the perceived negative consequences of disclosure (Hejoaka, 2009; Kajubi, Whyte, Kyaddondo, & Katahoire, 2016; Kiwanuka et al., 2014; Vaz et al., 2011a). There is a great deal of evidence that delay in telling children about their HIV status has negative implications for future health and wellbeing. For example, poor medication adherence can result in low virological suppression and the virus becoming drug resistant (Mburu et al., 2014a), the child unknowingly transmitting the virus to others (Santamaria et al., 2011), and failure of the child to assume independence and responsibility in HIV treatment and care (Santamaria et al., 2011). Moreover, recent evidence shows that people living with HIV who adhere to ART achieve and maintain undetactable viral load, which consequently reduce the risk of sexually transmitting the virus to a partner (Grulich et al., 2015; Rodger et al., 2016). Thus, disclosure of HIV status can help to prevent the transmission of HIV from the child to others.

With regards to HIV stigma and discrimination, three qualitative studies conducted in Malawi show that these are still major problems despite the increased coverage of health promotion campaigns against such practices (Mandalazi et al., 2014; Nyando, 2014; Pindani et al., 2014). According to Pindani and colleagues (2014), people in Malawi living with HIV are discriminated against because many people believe that those with HIV have been involved in socially unacceptable practices, such as sex work, are not moral, are infectious, and are incurable (Pindani et al., 2014). Furthermore, it has been found that stigma and discrimination are directed at all members of families affected by HIV, including children (Mandalazi et al., 2014). Children living with HIV in Malawi who face stigma and discrimination are at risk of poor mental health, school dropout, social isolation and reduced health seeking behaviours (Amzel et al., 2013; Cluver, Gardner, & Operario, 2007). Participants in this study proposed several ways of discouraging stigma and discrimination against people living with HIV. First, participants proposed the use of HIV support groups to educate people in the community about the negative impact of stigma and discrimination against people living with HIV. Second, members proposed holding joint campaigns against stigma and discrimination within the community through the use of drama, radio and other media outlets. Third, traditional leaders proposed giving a fine to people within their community who stigmatise or discriminate against people living with HIV. Fourth, teachers proposed educating pupils in schools not to discriminate their fellow learners who are living with HIV. While these are promising interventions, it is important for the Government and donors to support the implementententation of these interventions through funding and policies.

Many participants reported that primary caregivers failed to disclose because they were afraid that they would be blamed for transmitting the virus to the child which could consequently lead to family disharmony. This finding is similar to what is reported by a qualitative study conducted in Malawi, where parents of children living with HIV reported that they failed to disclose HIV status to their children because they were afraid of being confronted by their chidren for infecting them with the virus (Mandalazi et al., 2014). This finding is not unique to Malawi alone but also other sub-Saharan countries (Kiwanuka et al., 2014; Mutwa et al., 2013). For example, authors of qualitative study in Uganda failed to disclose because they felt responsible for transmitting the infection to the child and were afraid that disclosure would damange their relationship with the child (Kiwanuka et al., 2014). In Rwanda, authors of another qualitative study conducted with adolescents living with HIV, reported that adolescents held their parents responsible for transmitting the virus to them (Mutwa et al., 2013). This finding underscores the importance of supporting primary caregivers with knowledge and skills on how to disclose in order to reduce the impact that discosure can have on their relationship with their children.

Primary caregivers' lack of confidence in their ability to disclose appropriately is another major barrier to HIV disclosure that has been reported in previous studies (Alemu et al., 2013; Madiba & Mokgatle, 2016; Mahloko & Madiba, 2012). These findings highlight the crucial need for healthcare workers to support primary caregivers appropriately through the disclosure process. It is difficult for primary caregivers to implement the WHO recommendation about gradual disclosure in an age-appropriate manner without a great deal of support from healthcare workers (Madiba & Mokgatle, 2015; O'Malley et al., 2014; World Health Organisation, 2011a). Within the context of a trusting relationship, it is essential for primary caregivers to understand why it is important to disclose and to develop the skills necessary to do so in a safe and effective manner.

The finding that primary caregiver's farming occupation was independently associated with non-disclosure is in contrast to the findings of two recent studies conducted in Tanzania and Rwanda, where farming occupation of parents was not significantly associated with non-disclosure of HIV status to children (Binagwaho et al., 2012; Nzota et al., 2015). In Malawi, majority of farmers live in rural areas and have a low level of education, which might affect their understanding of the importance of disclosure of HIV status to children (Short & Goldberg, 2015; Tchale, 2009). In addition, it was found in the current study that living with fewer than three children older than 12 years was associated with non-disclosure. In Malawi, as in South Africa, older children are becoming a source of social support to their siblings and primary caregivers in families affected by HIV (Sharer, Cluver, Shields, & Ahearn, 2016). Since having older siblings in the family may increase support for the child living with HIV, the primary caregiver may disclose to the child with the expectation that this additional support will be available. Also, children who were in WHO HIV clinical stage one or of normal body weight were more likely to be unaware of their HIV status compared to those in stage four or those who were underweight. Both WHO HIV stage one and normal body weight signify early asymptomatic disease where parents may be reluctant to cause distress or worry to apparently healthy children (Ubesie et al., 2016; Vreeman et al., 2015). A study conducted in Kenya reported no association between malnutrition and HIV disclosure to children (Vreeman et al., 2014). With regard to the relationship between severity of symptoms and disclosure, previous findings are mixed (Mellins et al., 2002; Sirikum et al., 2014; Ubesie et al., 2016; Vreeman et al., 2015). While on one hand, authors of two cross-sectional studies conducted in Nigeria and Kenya and one cohort prospective study conducted in Thailand reported that children who had mild symptoms of HIV infection were likely to be told their HIV status (Sirikum et al., 2014; Ubesie et al., 2016; Vreeman et al., 2015), on the other hand, in a UK cross-sectional study, children were likely to be told their HIV status if they had severe clinical signs of HIV infection (Mellins et al., 2002).

The current study is one of the few in sub-Saharan Africa where the association between psychosocial factors and non-disclosure of HIV status to children was assessed (Menon et al., 2007; Vreeman et al., 2014). Similar findings were reported in a study in the United States, which found no difference in terms of the prevalence of emotional and behavioural problems in children who knew their HIV status and those who did not (Mellins et al., 2002). In contrast to these findings, the authors of a study in Zambia found that children who were unaware of their HIV status were twice as likely to experience concerning levels of emotional difficulties compared to those who knew their HIV status (Menon et al., 2007). The younger age range of the children in the current study may account for the difference in HIV disclosure between the two studies. The focus of the Zambian study was mental health problems among older children between 11 and 15 years of age. Older children are likely to suspect that something is wrong especially when they have frequent hospital appointments and are told to take medications – such suspicions may affect their emotional wellbeing (Domek, 2010). In addition, rates of anxiety and depression are known to increase dramatically, especially for females, during adolescence (Andersen & Teicher, 2008). To the researcher’s knowledge, this is the first study in sub-Saharan Africa that has assessed the association between non-disclosure of HIV status to children and family stressful life events, the burden of the illness on the family, and functional family support. While no association between these factors and HIV disclosure was found, future studies should continue to include these measures because there is ample evidence that the psychosocial functioning of the family exerts a powerful influence on children’s health and developmental outcomes and that serious childhood illness has a major impact on families (Maggi, Irwin, Siddiqi, & Hertzman, 2010; Tallon, Kendall, & Snider, 2015).

6.3.2.2 Focus on healthcare workers

Almost all healthcare workers in the current study reported that it was important to disclose HIV status, with more than half stating that disclosure should be a shared responsibility between healthcare workers and primary caregivers. However, a significant proportion reported that they had never disclosed HIV status to a child and that only a quarter or less of the children at their facility knew their HIV status. Consistent with these results, a recent South African study of 206 healthcare workers found that 89 per cent felt it was important to disclose HIV to a child living with HIV (Madiba & Mokgatle, 2015). Similar findings were also reported in a study conducted in Ethiopia (Woldemariam, 2012). There is evidence that healthcare workers support disclosure because of its benefits, such as helping the child to understand about their condition (Flanagan-Klygis, Ross, Lantos, Frader, & Yogev, 2001; Pfaff, 2004; Sariah et al., 2016), improved drug adherence (Beima-Sofie et al., 2014; Madiba & Mokgatle, 2015; Sariah et al., 2016; Woldemariam, 2012), protecting the child from re-infection or others from the infection (Madiba & Mokgatle, 2015; Rujumba et al., 2010b), and empowering the child to take responsibility for their own health (Gyamfi et al., 2015).

The literature from other countries indicates there are conflicting opinions by healthcare workers regarding whose responsibility it is to disclose to the child. The authors of a study conducted in Zimbabwe reported that the majority of healthcare workers and community leaders they surveyed indicated that healthcare workers were the best people to disclose HIV status to children (De Baets et al., 2008). On the other hand, three South African studies found that healthcare workers thought it was the primary caregiver’s responsibility to disclose to their child and that the healthcare workers’ responsibility was mainly to assist the primary caregiver with information and to provide emotional support to the child (Heeren et al., 2012; Madiba & Mokgatle, 2015; Moodley et al., 2006). The authors of another recent South African study reported that counsellors and nurses considered that their role was to provide psychosocial support rather than to disclose to the child, while doctors deemed that it was principally the doctor’s role to disclose to the child (Watermeyer, 2015).

However, consistent with the findings of the current study, recent studies conducted in Kenya and Zimbabwe have found that healthcare workers reported that it is best for them to work with primary caregivers in disclosing HIV status to children (Beima-Sofie et al., 2014; Gyamfi et al., 2015). However, they also noted the unwillingness of primary caregivers as a potential barrier to disclosure. Recent research in Malawi has shown that parents are unwilling to have a conversation about HIV with their child as it is not culturally appropriate to talk to children about sexual issues (Mandalazi et al., 2014). They are concerned that discussing HIV with their child might have a negative impact on the child's wellbeing (Mandalazi et al., 2014; Nyando, 2014), and stigma and discrimination directed at parents and children living with HIV are still common (Nyando, 2014).

This highlights the need for healthcare workers to recognise the challenges primary caregivers face regarding disclosure. In the researcher's experience, in Malawi, the nurse – patient relationship is more likely to be hierarchical where the nurse tells the patient what to do and the patient is expected to do as they are told, rather than empowering them in a relationship that is more equal and supportive. While psychology and sociology are taught in nursing degree programs in Malawi, many nurses continue to be influenced by community sanctioned patterns of social behaviour and, perhaps, most importantly they are too busy providing medications and other essential medical care. This hierarchical framework of care is also evident among medical doctors, with counsellors possibly being the only healthcare group who provide emotional support based on a more equal working relationship (Kalumbi, Kumwenda, & Chidziwisano, 2014).

This scenario is not unique to the care of children with HIV in sub-Saharan African countries. Quite some time ago in the United States, healthcare workers were implored by child health experts to view children with HIV and their families as a unit of treatment and to appreciate their cultural background instead of adhering to a hierarchical framework of care (Meyers & Weitzman, 1991). Another suggestion is for healthcare workers to assess cultural, religious, psychosocial, family, as well as community factors that can affect the disclosure of HIV to children (Flanagan-Klygis et al., 2001). Continuous communication between healthcare workers and caregivers can provide an enabling environment on which preparation for disclosure can be made possible (Pfaff, 2004). Once the challenges related to disclosure have been identified, healthcare workers are in a better position to work with caregivers to find possible solutions and develop age appropriate disclosure plans (American Academy Paediatrics, 1999; Lesch et al., 2007).

Given that the prevalence of disclosure reported by primary caregivers in sub-Saharan African countries ranges from 11 to 34 per cent (Biadgilign et al., 2011; Nzota et al., 2015; Skeen et al., 2014; Turissini et al., 2013; Vreeman et al., 2013; Vreeman et al., 2014), it is not surprising that a significant proportion of healthcare workers in this study reported that they themselves had never disclosed HIV status to a child and that the rate of HIV disclosure at their facility was also very low. Similar to the findings of the primary caregivers' survey, healthcare workers in this, and other studies, have reported inadequate knowledge on HIV disclosure, the lack of a standard tool for disclosure, and the lack of training on disclosure as barriers to disclosure of HIV to children. More than three-quarters of healthcare workers participating in a study conducted in South Africa reported that they had not received any formal training in disclosure and they lacked resources, such as practice manuals and printed materials for families (Madiba & Mokgatle, 2015). A lack of training and disclosure resources was also reported as hindering healthcare workers' involvement in HIV disclosure in qualitative studies conducted in Tanzania, Ethiopia, and Uganda (Beima-Sofie et al., 2014; Rujumba et al., 2010b; Sariah et al., 2016; Woldemariam, 2012).

The finding in the current study that male healthcare workers were more likely to disclose to children compared to their female counterparts is identical to a study conducted in Zimbabwe (De Baets et al., 2008). In most African cultures a man is considered to be the head of his family and is given responsibility to make critical decisions regarding the health of family members (Govender & Penn-Kekana, 2008; Ngubane, 2010). Sociological literature shows that healthcare institutions not only reflect but also maintain, societal norms and values (Govender & Penn-Kekana, 2008). In addition, there is some evidence that female healthcare workers are generally more empathetic in their provision of care to patients than males (Govender & Penn-Kekana, 2008). On average, the female healthcare workers in this study might have chosen not to disclose because they were more concerned with the negative impact of HIV disclosure on the child than their male counterparts.

6.3.2.3 Breaking down the barriers to talking about HIV

While the majority of participants acknowledged that disclosure of HIV status to children was rarely done, most of them felt that it was important to break down the barriers by talking about disclosure and its process, as well as having materials to guide the disclosure materials.

6.3.2.3.1 Need for disclosure

Many primary caregivers, healthcare workers, teachers and community leaders acknowledged the need for disclosure of HIV status to a child because of the benefits of such disclosure for the child and family. Similar findings have been reported in both high and low-income countries. In the US, parents of children talked about HIV with their child who was living with the virus because they felt that doing so will help to identify social support and protect the child from misinformation (Edwards, Reis, & Weber, 2013). Authors of a systematic review conducted in Sub-Saharan Africa reported that talking about HIV disclosure helped to promote ART adherence and retention in care (Aderomilehin, Hanciles-Amu, & Ozoya, 2016). While most participants reported that they wanted to increase the conversation around HIV disclosure, they were hindered by stigma and discrimination, feelings of guilt for transmitting the virus to the child, cultural factors, and the complexity of the disclosure process. HIV disclosure is a sensitive issue to talk about in Malawi because of the stigma and discrimination directed towards people living with HIV (Mandalazi et al., 2014; Nyando, 2014; Pindani et al., 2014). Addressing the significant barriers to HIV disclosure to children can be the first step in promoting discussion about HIV and disclosure. The authors of previous studies have reported ways of overcoming barriers to disclosure, which include: providing HIV disclosure training to all stakeholders (Heeren et al., 2012), developing disclosure materials (Beima-Sofie et al., 2017; Hornschuh et al., 2014; Nelms & Zeigler, 2008; O'Malley et al., 2014; Simoni et al., 2015), having, laws that discourage stigma and discrimination (Williamson, Wondergem, & Amenyah, 2014) and encouraging HIV literacy in families and communities (Heeren et al., 2012).

6.3.2.3.2 Need to discuss the disclosure process

Many participants expressed the need to discuss the disclosure process, including the best age and person to disclose, as well as how the disclosure process should be conducted. The most appropriate age to disclose HIV status to children remains contentious in sub-Saharan African countries despite the widely disseminated WHO guidelines. Sixty-four per cent of healthcare workers in a recent South African study identified 11 to 14 years as the best age for HIV disclosure(Madiba & Mokgatle, 2015), while the majority of participants in this study and a recent study conducted in Tanzania recommended 6 to 12 years (Mumburi, Hamel, Philemon, Kapanda, & Msuya, 2014). In the current study, the participants indicated that within the age range of 6-12 years, children can begin to understand their condition and keep it secret.

In terms of how disclosure of HIV status should be conducted, most of the participants thought that disclosure of HIV should be a gradual process as opposed to a one-time event. This is consistent with the recommendation for a gradual disclosure process in the WHO guidelines for paediatric HIV disclosure (World Health Organisation, 2011a). Gradual disclosure of HIV status is crucial because it gives a child time to process the information, thereby leading to a positive cognitive and emotional adjustment to the diagnosis (Lesch et al., 2007; Saunders, 2012). According to literature, disclosure of HIV status should be conducted in line with the child’s level of emotional and cognitive development (Lesch et al., 2007; Saunders, 2012). Simple terms should be used in initial stages with more complex terms added as the child develops (Koopman et al., 2004; Lesch et al., 2007). Similar to the findings of the current study, the authors of a study conducted in Botswana reported that children were told about their HIV status through a gradual process (Lowenthal et al., 2014). On the other hand, primary caregivers in a cross-sectional study conducted in the Democratic Republic of Congo reported that disclosure was conducted as a one-time event (Vaz et al., 2011a). However, despite Vaz and collegues reporting that HIV disclosure was conducted as one-time event, they did not report adverse effects resulting from such type of disclosure (Vaz et al., 2011a).

Although the majority of the participants reported that primary caregivers should have the primary role of initiating the disclosure process, many participants acknowledged the positive contribution of healthcare workers, teachers and community leaders in disclosing HIV to the child and supporting the child to adjust positively to the condition. WHO has recommended that parents seek support from, and share the disclosure process with, teachers, healthcare workers, and community leaders (World Health Organisation, 2011). There is evidence that health outcomes for children are enhanced when their medical and psychosocial care is shared with supportive adults (Wattradul & Sriyaporn, 2014). Unfortunately, the care these children typically receive is fragmented and the adults involved seldom get the opportunity to work together to meet the child's needs (Allison & Siberry, 2015; Campbell et al., 2016; Wolf et al., 2014).

6.3.2.3.3 Need for disclosure materials

Most primary caregivers, healthcare workers, teachers and community leaders reported that there was a great need for resources to help guide the disclosure process. The idea of providing children with story books was widely welcomed and almost all participants reported that they would use the books if they are developed. This finding supports those of recent studies conducted in sub-Saharan Africa where primary caregivers and healthcare workers reported a lack confidence and skills to appropriately disclose HIV status to children (Alemu et al., 2013; Kidia et al., 2014; Mahloko & Madiba, 2012) as well as a lack of disclosure materials to guide the disclosure process (Madiba & Mokgatle, 2015; McCleary-Sills et al., 2013). The use of disclosure materials has been found to have many benefits which include: guiding the disclosure process (Beima-Sofie et al., 2017; Nelms & Zeigler, 2008; O'Malley et al., 2014; Simoni et al., 2015), improving the rates of HIV disclosure (Nicastro et al., 2013), improving drug adherence (Lowenthal et al., 2014), promoting the psychosocial wellbeing of children (Lowenthal et al., 2014; O'Malley et al., 2014; Simoni et al., 2015), and improving efficacy of disclosure of HIV status to children (O'Malley et al., 2014; Simoni et al., 2015).

Despite the many benefits of disclosure materials, there are only a few studies globally that have reported on the development, availability and use of such materials (Beima-Sofie et al., 2017; Lowenthal et al., 2014; Nelms & Zeigler, 2008). Of these few studies, one reported on the development of a brochure to assist primary caregivers to assist with disclosure (Nelms & Zeigler, 2008), another reported on the use of a cartoon book to help healthcare workers to disclose to children and to assist primary caregivers on how to disclose HIV to children (O'Malley et al., 2014) and three reported about providing training sessions to primary caregivers and healthcare workers on how to disclose (Beck-Sagué et al., 2015; Lowenthal et al., 2014; Simoni et al., 2015). Out of the four studies, only two were conducted in sub-Saharan Africa (Lowenthal et al., 2014; O'Malley et al., 2014). The other studies, one was conducted in the US (Nelms & Zeigler, 2008) while the the other one was conducted in both Haiti and Dominican Republic (Beck-Sagué et al., 2015) .

In addition to these accounts of the development and use of disclosure materials in the academic literature, there are a number of resources described in the grey literature that provide age appropriate HIV information for children living with HIV. The resources are written materials and a video covering different HIV topics that include children and family experience of livng with HIV, myths about HIV, information to guide with the disclosure process, and stories about children living with HIV talking to their peers with the same condition. While these resources are helpful in guiding the disclosure process, it is important that a rigorous process should be used in developing and evaluating these materials if they are to be effective (Jensen et al., 2014; Kennedy et al., 1999). Failure to evaluate these materials can result in providing misleading and inaccurate information to the targeted population (Nduati & Kiai, 1997). Besides, the lack of involvement of potential prospective users of the materials in the planning, development and evaluation of the materials my reduce the likelihood of their acceptability and appropriate use (Nduati & Kiai, 1997; Rudd, 2011).

Currently, in the absence of standard disclosure materials in Malawi, primary caregivers and healthcare workers rely on their judgement and experience to disclose HIV to children. This is likely to result in confusion among children and their families due to inconsistencies in the information provided to them (Sariah et al., 2016). Although many participants suggested the need for a training in using the story books, the researcher envisages that the story books will be developed in such a way that they would be cost effective and user friendly. The books will be self explanatory and would require minimal level of assistance or training to understand (Crawley et al., 2012). Moreover, the books will have specific instructions for the primary caregivers, healthcare workers, teachers and community leaders, which is in line with principles of developing effective education materials for children (Absolom et al., 2004; Doak et al., 1996; Feldman-Stewart et al., 2007). In addition, intervention mapping principles will also be used to develop the discosure materials (Eldredge et al., 2016).

The involvement of primary caregivers, healthcare workers, teachers, community leaders and adolescent living with HIV in the process of developing story books is an important step in ensuring that the books to be developed are widely accepted and culturally appropriate (Fourney & Williams, 2003; Jensen et al., 2014; Kennedy et al., 1999) . Experts in education recommend the involvement of end users of materials in the development and implementation such materials to ensure that the resources are developed to meet the educational needs of the people they are intended for (Jensen et al., 2014; Kennedy et al., 1999; Rudd, 2011). Besides, the involvement of these stakeholders would ensure that children going through a disclosure process are well supported to deal with the negative impact of HIV disclosure. Nonetheless, despite the importance of these stakeholders in HIV disclosure to children, they are rarely included in studies that inform the development of education materials (World Health Organisation, 2011a).

6.3.3 Open communication

The majority of participants identified the importance of openness among the stakeholders to discuss the child's HIV status and issues regarding the disclosure of HIV status. However, they characterised their communication as closed or hierarchical as opposed to open. The benefits of open communication as reported in previous studies include: the promotion of team work (Gilley, Morris, Waite, Coates, & Veliquette, 2010; West & Lyubovnikova, 2013), the identification of social support (Pejtersen, Kristensen, Borg, & Bjorner, 2010), improved productivity, and positive mental health outcomes of team members (Eklof & Ahlborg Jr, 2016; Netterstrøm et al., 2008). The lack of open communication among adults who are involved in the care of children living with HIV is likely to affect the level of support these children receive. Furthermore, with closed communication, it is difficult for adults to identify the strategies that are required to address barriers to HIV disclosure. While many participants reported that they wished they had more open communication, it was pointed out that the hierarchical relationships between healthcare workers, teachers and primary caregivers, and the perception of a lack of knowledge and understanding about HIV among primary caregivers, was a major deterrent. The following paragraphs will discuss these barriers to open communication and will also provide strategies for addressing them.

6.3.3.1 Barriers to open communication

The following paragraphs will discuss the barriers to open communication as highlighted in the previous paragraph.

6.3.3.1.1 Hierarchical relationships

An important finding in the current study was that relationships of unequal power prevented open communication. In Malawi power is exercised through a variety of hierarchies that include bureaucracy, tradition and educational attainment (Norwegian Agency for Development Cooperation, 2013). The power of healthcare workers and teachers is based on their high level of education and their status as professionals. They are respected and regarded as important people in the community (Norwegian Agency for Development Cooperation, 2013). The majority of primary healthcare users are women with low socioeconomic status and lower social status than men. This constrains their engagement with healthcare workers as well as participation in healthcare programs (Norwegian Agency for Development Cooperation, 2013).

In addition to their low social status, women who care for children living with HIV are often treated rudely by healthcare workers, with little choice about the clinics they can attend, and they are powerless to complain. There are few private healthcare facilities in the rural areas where most families reside, and the great majority of women would not be able to afford private care in any case. As such, healthcare workers in public facilities are in high demand. They sometimes exercise their authority by providing or withdrawing services or resources from the people they serve (Norwegian Agency for Development Cooperation, 2013). Inappropriate or rude actions usually go unpunished (Norwegian Agency for Development Cooperation, 2013). The unequal power between healthcare workers and the people they serve is highlighted in many studies conducted in Malawi (Hoffman et al., 2012; Kumbani, Chirwa, Odland, & Bjune, 2012; Munthali et al., 2014; Roberts et al., 2015). For example, the authors of two studies in Malawi that assessed women’s perception of antenatal care found that health care workers treated women who came for antenatal care as though they were children, they were shouted at and ordered not to complain otherwise they would be sent back home (Kumbani et al., 2012; Roberts et al., 2015). In another study, family members who were giving basic care to very sick relatives reported that healthcare workers were disrespectful toward them and that they were often chased away from the wards where their relatives were patients (Hoffman et al., 2012). In a related study, patients reported that they were sometimes slapped and swore at by healthcare workers (Roberts et al., 2015). In a final example, in a recent study about healthcare utilisation in Malawi, the authors found that the poor behaviour of healthcare workers was one of the reasons why some people decided to stop using public services altogether (Munthali et al., 2014). This issue is not specific to Malawi, it is prevalent in all sub-Saharan countries (Abiola, Udofia, & Abdullahi, 2014; Campbell, Scott, Madanhire, Nyamukapa, & Gregson, 2011; Gourlay et al., 2014) and also not that unusual in resource-rich settings (Worthington & Myers, 2003).

While it would be easy to blame healthcare workers for this lack of open communication and occasionally inappropriate behaviour, it is important to acknowledge that the healthcare workers, themselves, are neither the true cause of, nor ultimate solution to, the problem (Maluwa, Andre, Ndebele, & Chilemba, 2012). The underlying cause is a chronic lack of financial, physical and human capital resources in the healthcare system

(Maluwa et al., 2012; World Health Organisation Africa, 2016). The services that are available are free and largely financed by the Government, however, due to the global economic downturn, the Government currently provides even less funding for healthcare services than in the past (World Health Organisation Africa, 2016). For example, in 2014 the government provided US$11 per person for basic health services instead of the US$86 that was recommended for Malawi (Mamaye, 2015). In addition to a lack of physical resources, such as hospitals and equipment, there has been inadequate investment in human resources. For example, the ratio of professional healthcare workers to the population is 0.2 per 10,000 and 3.4 per 10,000 for doctors and nurses respectively (Schmiedeknecht et al., 2015). The nurse to population ratio is only a third of what WHO recommends (Schmiedeknecht et al., 2015). Inadequate funding has resulted in exceptionally heavy workloads and very low salaries for healthcare workers in Malawi (Chimwaza et al., 2014; Schmiedeknecht et al., 2015). Because of the workloads, healthcare workers have reported feeling exhausted and failing to discharge their duties professionally (Bradley et al., 2015; Sun & Rau, 2017). Studies from both low and high income countries have reported work related stress, unequal power, and organisational politics as challenges to open communication in healthcare settings (Eklof & Ahlborg Jr, 2016; Grill, Ahlborg Jr, & Wikström, 2014; Grill, Ahlborg Jr, Wikström, & Lindgren, 2015; Sun & Rau, 2017).

It has been suggested that ensuring equal power and trusting relationships between primary caregivers and other stakeholders is an important step towards providing a safe environment for HIV disclosure (Ward, 2017). The building of trust promotes engagement between community members and healthcare workers (Gilson, 2003; Okello & Gilson, 2015; Ward, 2017). Patients, or members of the public, need to trust healthcare workers before they engage them in any important health interventions (Okello & Gilson, 2015). Trust in the healthcare system improves patients' health outcomes and satisfaction with care (Birkhäuer et al., 2017). It is, therefore, essential for healthcare workers to create a conducive environment where primary caregivers can trust them to discuss their concerns regarding disclosure of HIV status (World Health Organisation, 2011a). This sounds ideal, and yet the reality is that it is very difficult for healthcare workers in Malawi to make the time, and have the composure required to communicate effectively with primary caregivers about HIV disclosure.

6.3.3.1.2 Perception of a lack of knowledge and understanding about HIV among the primary caregivers

There was general agreement among all participants that healthcare workers were most knowledgeable about HIV, followed by teachers, community leaders, and then primary caregivers. As such, there was an expectation that parents should listen to and do what they were told by healthcare workers, teachers, and others. Authors of a related study in Malawi reported that some patients were mistreated by doctors when they tried to express their views about their condition (Munthali et al., 2014). In addition, authors of a qualitative study in Malawi reported that the primary caregivers of patients admitted to the hospital reported having arguments with healthcare workers because of poor communication (Hoffman et al., 2012). The primary caregivers wished that doctors could explain the conditions of their patients and hospital policies to them so that they could understand what their family members were suffering from (Hoffman et al., 2012). Moreover, patients reported that they were afraid to ask questions because healthcare workers could shout at them (Hoffman et al., 2012). The attitudes of some doctors in Malawi have resulted in some people not wanting to go to the hospital when they are sick (Munthali et al., 2014). Similar findings have been reported by the authors of a study in South Africa where healthcare workers considered primary caregivers to be lacking in knowledge about HIV (Heeren et al., 2012).

6.3.3.1.3 Misunderstandings

Participants reported that there were often misunderstandings between healthcare workers and primary caregivers regarding the disclosure of HIV status to the child. On one hand, primary caregivers reported that healthcare workers did not seem to understand why they had problems disclosing to their child. On the other hand, healthcare workers reported that it was difficult to comprehend why parents were still reluctant despite repeating the need to disclose to the child. With closed communication, it is difficult for primary caregivers in Malawi to discuss with healthcare providers the factors that constrain them to disclose HIV to their child. Whereas, with open communication, an atmosphere is created where there is a willingness from both parties to listen to each other and ask questions without prejudice (Goldsmith & Domann-Scholz, 2013). A thematic analysis of 28 focus group discussions conducted among people livng with HIV in the US, Puerto Rico and Botswana revealed that the participants preferred to see healthcare workers who respected and engaged them in conversation regarding their care rather than just telling them what to do (Dawson-Rose et al., 2016).

6.3.3.2 Breaking down barriers to the lack of open communication

Participants reported that open communication among the stakeholders could be made possible through the creation of an environment where everyone would feel welcome. They talked about building trust and improving relationships among the stakeholders. The following paragraphs will discuss these factors in the context of existing literature.

6.3.3.2.1 Feeling welcome

The findings of this study have shown that some primary caregivers are likely to speak openly with healthcare workers if they feel welcomed. Moreover, a number of healthcare workers reported that they were aware of some primary caregivers going to distant hospitals where they felt welcomed to receive care. Moreover, they said that healthcare workers need to be approachable. It is difficult for primary caregivers to share their concerns if they think that they are going to be shouted at or mistreated by healthcare workers. However, as mentioned previously, the working conditions of healthcare workers in Malawi are far from ideal. A great deal of literature highlights the critical role healthcare organisations and managers play in determining the level of care provided by staff (Glickman, Baggett, Krubert, Peterson, & Schulman, 2007; Kabene, Orchard, Howard, Soriano, & Leduc, 2006; Slipicevic & Masic, 2012). It is important to establish clear policies and guidelines for communication in health facilities that encourage patients to engage in therapeutic conversations with healthcare workers (Wong & Talmi, 2015).

6.3.3.2.2 Building trust and relationship

The establishment of trust is one of the most important steps in ensuring open communication among partners. Trust between healthcare workers and patients entails that the healthcare workers will act in the best interest of the patient (Thom, Hall, & Pawlson, 2004) and can lead to better treatment compliance (Thom et al., 2004). Moreover, trust was found to be a strong predictor of service usage among people living with HIV in a study conducted in the US (Altice, Mostashari, & Friedland, 2001). Primary caregiver’s trust cannot be won in in a single day, It is a process that takes time and effort (Lynn-sMcHale & Deatrick, 2000; Thom et al., 2004). Thus, it is important that primary caregivers continue to see the same healthcare workers as this can help build up trust.

There are several ways in which trust can be gained, some of them include; taking time to listen attentively to what a primary caregiver is saying (Mitchell et al., 2012), showing understanding about what the patient is saying (de Negri, Brown, Hernández, Rosenbaum, & Roter, 1997; Kourkouta & Papathanasiou, 2014), and promoting dialogue with the primary caregiver (Kourkouta & Papathanasiou, 2014). Other issues to consider are frankness and honesty in communication, and reducing power differences (Chaar, 2017; Thom et al., 2004). Further to this, authors of a recent longitudinal qualitative study involving 21 participants conducted in the US reported the following as important in building trust between healthcare providers and patients; providing reassurance to patients, showing patients lab results and explaining what they mean and avoiding language and behaviours that are judgemental (Dang, Westbrook, Njue, & Giordano, 2017). In addition, authors of an interventional study in the US that involved medical assistants providing health coaching on procedures, safe management skills and social support to patients with type-2 diabetes mellitus over a period of one year revealed increased in trust by twofold in patients in the treatment group compared to those in the control group after one year of follow-up (Thom et al., 2014).

Building a good relationship is an important element of open communication because it facilitates the transmission of important information as well as expression of concerns regarding the care of the patient (Kourkouta & Papathanasiou, 2014; Moussas, Karkanias, & Papadopoulou, 2010). A good relationship follows after the development of trust between the people involved. Differences in values and beliefs make relationships difficult between healthcare workers and patients, nonetheless, healthcare workers must show acceptance and a non-judgemental attitude to make the relationship work (Lynn-sMcHale & Deatrick, 2000). To maintain a good relationship, healthcare workers must ensure that patients and their families are treated with respect and dignity (Chaar, 2017). In paediataric practice, primary caregivers' autonomy needs to be upheld through shared decision making regarding care of their child (Chaar, 2017). In the study conducted in the US and Botswana mentioned previously, participants reported that they felt good if healthcare workers treated them as equals and allowed them to be in charge of their own care, while at the same time providing them any support needed (Dawson-Rose et al., 2016).

6.3.4 Shared responsibility

Many participants reported the importance of shared responsibility among the stakeholders to meet the needs of children living with HIV. It was suggested that the four groups of stakeholders make a disclosure plan together and develop strategies to protect the child from any negative consequences of disclosure. Fostering shared responsibility between key adults is crucial to ensure that children living with HIV not only receive comprehensive supportive care but also feel secure as they go through the disclosure process (Conway, 2005). By working in partnership, caring adults are better able to address gaps in knowledge and the many challenges associated with disclosure of HIV status (Dobia & O'Rourke, 2011). Each group builds on the experience and strengths of the others to provide effective care (International HIV/AIDS Alliance, 2007). It is especially important for stakeholders to work together when disclosure is a gradual and continuous process (World Health Organisation, 2011). Yet, research undertaken in sub-Saharan Africa and elsewhere has focused almost exclusively on the role of specific groups of adults in the HIV disclosure process, and the perspectives of each group have been interpreted independently in isolation from other stakeholders.

The findings of this study have shown that while most participants expressed the wish for a shared responsibility, they thought that each group was working in isolation and there was little attempt to collaborate and share responsibility for care. Lack of defined roles was seen as the main barrier to lack of shared responsibility.

6.3.4.1 Defined roles

Virtually all participants expressed the belief that each stakeholder had a specific role to play in the care of a child living with HIV. They were of the view that primary caregivers had the main responsibility for caring for the child. The literature also recognises the rights of parents to decide whether to disclose to their child or not, and if they choose to disclose, they have the right to make decisions regarding when, how, where and who is the best person to disclose (Moodley et al., 2006). In reality, the majority of parents do not disclose to their child because of concerns about the child's capacity to understand and their emotional readiness to cope with the diagnosis (Kiwanuka et al., 2014; Vreeman et al., 2014). Further, they have concerns about bringing stigma and discrimination to the family (Mburu et al., 2014a), and concerns about lack of support from healthcare workers (Kidia et al., 2014).

The majority of participants were also of the view that healthcare workers had the responsibility of assisting and providing support to primary caregivers to effectively care for their child. Indeed, it has been suggested that healthcare workers are the most appropriate people to coordinate supportive care for children because HIV is a focus of their practice (Wattradul & Sriyaporn, WHO, 2006). Healthcare workers have knowledge about HIV and technical skills that the other groups lack (WHO, 2011). Healthcare workers are the first people to learn of the HIV diagnosis and they have the responsibility of sharing this confidential information with the child's parents (Amzel et al., 2013). They can use their communication skills to help parents disclose to their children and share their knowledge and understanding of the condition with teachers and community leaders (Amzel et al., 2013). Continuous interaction between healthcare workers and children living with HIV has been shown to facilitate children's acceptance of the condition, as well as improve their resilience (Abubakar et al., 2008; Amzel et al., 2013). While many healthcare workers expressed the need for shared responsibility among stakeholders, they had closed communication with primary caregivers. They expected primary caregivers to follow whatever they were told because of the unequal balance of power between the two groups. It is unlikely that shared responsibility could be achieved without treating primary caregivers as equal partners in the disclosure process. While the participation of healthcare workers in the disclosure process is essential, the authors of recent sub-Sahara African studies have revealed that many are reluctant to do so because of the unwillingness of parents to disclose (Kidia et al., 2014; Rujumba et al., 2010b), a lack of training (Madiba & Mokgatle, 2015; McCleary-Sills et al., 2013); inadequate knowledge and skills, and a lack of disclosure materials (Madiba & Mokgatle, 2015; McCleary-Sills et al., 2013).

Many participants, including teachers themselves, felt that teachers had a responsibility of protecting the child from stigma at school, supporting the child to attend hospital appointments, providing additional teaching support and assisting with disclosure. In addition to healthcare workers, school teachers and administrators play a role in helping children to adapt to HIV and achieve good academic outcomes (Ebersöhn & Ferreira, 2011; UNESCO, 2008). Research has shown that making schools HIV friendly is one of the best ways to provide children living with HIV a safe, protective, caring, and supportive environment (Conway Magda, 2015). According to UNESCO (2008), schools should provide education, counselling, psychosocial support, and assist children to access adequate nutrition and healthcare services. This is crucial because children living with HIV face a number of challenges at school, including stigma and discrimination from other students, absenteeism due to sickness, lack of the privacy required for taking HIV medications, and difficulty obtaining permission to attend hospital appointments when teachers are not aware of their HIV status (Campbell et al., 2016; Campbell et al., 2014; Mutwa et al., 2013; Punpanich et al., 2012; UNESCO, 2008). Ideally, school teachers do need to know when children have HIV because the HIV infection can affect motor and neurocognitive development, thereby impacting on academic performance (Abubakar et al., 2008). While schools are supposed to be safe, protective, and caring environments, this is not always the case as children are exposed to stigma and bullying, as revealed by research in Malawi, Kenya, and Zimbabwe (Campbell et al., 2014; Kendall & O'Gara, 2007).

Many participants identified community leaders as having an important role in educating the people in the community about disclosure and encouraging parents to send their children to support groups. Literature shows that the communities where children and their families live are an important source of psychosocial support for children living with HIV in sub-Saharan Africa (Mburu et al., 2014a; Petersen et al., 2010). Religious leaders, traditional village headmen, the leaders of community-based organisations, and the leaders of support groups can all play an important role in mobilising communities to support children living with HIV (Mupambireyi et al., 2014). Community leaders can assist in raising awareness of HIV, disseminating information, providing pastoral support to children and their families living with HIV, and promoting the sustainability of their care (World Health Organization, 2008). In addition, community leaders can advocate for the rights of people living with HIV and help to fight against stigma and discrimination (International Center for Research on Women and London School of Hygiene & Tropical

Medicine, 2010). Nonetheless, despite the significant role community leaders are able to play in mobilising community support, they are rarely involved to any great extent (Allison & Siberry, 2015).

6.3.4.2 Working together

For stakeholders to work together there is a need for them to have a common language and a mutual understanding which can be possible through more open channels of communication (Dobia & O'Rourke, 2011; Durch, Bailey, & Stoto, 1997). Shared responsibility ensures accountability among stakeholders since each member is aware of the boundaries of his or her responsibility and that of others in the team (Dobia & O'Rourke, 2011). It also ensures the continuity of care since a channel of communication is established to ensure the flow of information regarding the care that the child is receiving and the next plan of care (Dobia & O'Rourke, 2011).

According to Durch, Bailey, and Stoto (1997), in the context of health promotion, the first step to shared responsibility is for the key stakeholders to acknowledge that all the stakeholders have the responsibility of improving the health of a particular population. The second step involves assigning specific tasks to each group of stakeholders. Each stakeholder should be held accountable for the assigned task. Successful performance should be rewarded, and failures be subjected to review by the stakeholders. The assignment of tasks helps to develop a “round table” approach rather than a top-bottom approach (Durch et al., 1997, p. 75). In addition, shared responsibility should be built on inclusion, trust, respect relationships, and equality among all members (Collard et al., 2005). The team members need to put in place a clear guideline on how the partnership will work and identify which channel of communication team members will follow (Dobia & O'Rourke, 2011). The members will also need to choose active and effective team leaders to coordinate the activities, as often partnerships with passive leaders do not last long (Alexander, Comfort, Weiner, & Bogue, 2001).

It is important to recognise what each member is bringing to the project and building on the strengths and working on the challenges (Burke et al., 2013). Furthermore, there is a need for an equitable and equal power in all phases of an intervention (Burke et al., 2013; De Marco et al., 2014; Middleton, Henderson, & Evans, 2014). The members of the partnership need to build the capacity of the partners through workshops and training (De Marco et al., 2014; Middleton et al., 2014). This ensures that all the partners learn and develop skills necessary for successful implementation and sustainability of the project (Burke et al., 2013; Ferreira, Ebersöhn, & Mbongwe, 2015). Another important principle is the creation of relationships between partners which are essential for the establishment of norms, values and trust among the members which can lead to an effective partnership (Ferreira et al., 2015; Middleton et al., 2014). Furthermore, it is important to have a strong leadership and well laid out goals of the program from the outset of the program and this should be well known to all the members (Middleton et al., 2014). Also, shared responsibilities towards the intervention should be well known to all members and measures should be put in place to promote accountability from the members (Middleton et al., 2014). The lack of defined roles resulted in a “blame game” among the stakeholders in this study. Each group blamed the other groups for failing to take responsibility for caring for children living with HIV. This is discussed in the next paragraph.

6.3.4.3 Blame game

In this study, teachers and community leaders reported that they could not adequately support children living with HIV because primary caregivers did not inform them about their HIV status. Similar findings were reported in a study from Zimbabwe, where teachers reported that they were not told about the HIV status of the pupils who were living with HIV, which made it difficult to identify them and provide the necessary support (Campbell et al., 2016). The failure of primary caregivers to inform their child’s teacher of their HIV status is not confined to sub-Saharan Africa. The authors of a recent cross-sectional study from the UK reported that the primary caregivers of 89% of children living with HIV did not inform the school about their child’s HIV status which made it difficult for teachers to support the children (Conway Magda, 2015).

6.3.4.4 Social disclosure

The most important part of ensuring shared responsibility and a workable partnership to support children living with HIV is *social disclosure*. According to the WHO, social disclosure entails that the primary caregiver identifies and shares the child’s HIV status with other people in his/her social network who may assist in the disclosure process and provision of other related issues (World Health Organisation, 2011). For this to be possible mutual trust and understanding among the team members is important (Arnott, 2013). Primary caregivers need assurance that shared information will be kept confidential and that their child will be protected from the negative consequences of disclosure (Chamla et al., 2016). As they mature emotionally and cognitively, children themselves need to become involved in the process so that they are aware of the kind of support they can receive from each member of the team (World Health Organisation, 2011). There is a great deal of literature that shows that the prevalence of social disclosure is sub-Saharan region is very low. For example, authors of four cross sectional studies conducted among adolescents aged between 10 and 18 years who were living with HIV and knew their HIV status in Kenya, South Africa, Uganda, Ivory Coast and Zambia reported that less than 40% had disclosed to their sexual partners or others (Madiba, 2016; Nöstlinger et al., 2015; Toska et al., 2015; Vreeman et al., 2015).

Although most of the adolescents had positive views about social disclosure, they reported the following as barriers to social disclosure: fear of stigma and discrimination (Madiba & Mokgatle, 2016; Toska et al., 2015; Vreeman et al., 2015), maintaining relationships with their partners (Mburu et al., 2014a; Toska et al., 2015) and discouragement from parents (Mburu et al., 2014a; Mburu et al., 2014b).

6.3.4.5 Breaking down barriers to the lack of shared responsibility

Many participants had the view that support groups and dissemination of information about disclosure could promote their collaboration.

6.3.4.5.1 Support groups

Participants suggested that one way of sharing responsibility was providing care to children through support groups. Adolescents reported that joining a support group was a key strategy that facilitated their acceptance of HIV. Moreover, the support group helped them to develop resilience to stigma and discrimination and adopt a healthy lifestyle. Similar findings are reported in five cross sectional studies conducted in Zimbabwe, Botswana, and Zambia (Kidia et al., 2014; Lowenthal et al., 2014; Mburu et al., 2014a; Mburu et al., 2014b; Mupambireyi et al., 2014). Other benefits of support groups for children as reported by the authors of recent studies include: helping children to understand their illness (Kidia et al., 2014); regain their confidence (Mupambireyi et al., 2014); and receive support related to education, skill building, stigma, healthy living, and love (Lowenthal et al., 2014). Moreover, authors of a quasi-experimental study conducted among 196 Thai adolescents living with HIV, compared adolescents who were participating in children support group activities and those who were not (Chokephaibulkit et al., 2015). The results showed that those who were were participating in support group activities were more likely to score higher in self-esteem compared to those who were not (Chokephaibulkit et al., 2015).

The findings of the current study have also revealed that although support groups were identified as an important resource for children living with HIV, some adolescents who were leading some of the support groups reported lacking materials to help them provide accurate information about HIV to their peers. Authors of a recent nationally representative demographic health survey in Malawi have reported that despite decades of HIV existence in Malawi, less than 45% of both male and female youths have adequate knowledge of HIV related to unsafe sex, knowing that a healthy looking person can still have HIV and common myths about HIV (Malawi National Statistical Office & ICF International, 2017). This is worrisome, considering that inaccurate information about HIV among children can prevent them from engaging in protective health behaviours which may lead to poor health outcomes (Guilamo-Ramos et al., 2012; Tsala Dimbuene

& Kuate Defo, 2011). It is not surprising that adolescents recruited in the current study supported the development of the story books to address this gap in knowledge. The proposed story books will therefore provide a valuable resource for the children to understand their condition and deal with the adverse effects of living with HIV.

6.4 APPLICATION OF THE BIOECOLOGICAL FRAMEWORK TO THE STUDY FINDINGS

Bronfenbrenner's Bioecological approach provide a good framework of understanding factors associated with non-disclosure of HIV status to children at microsystem, mesosystem exosystem and macrosystem levels. At microsystem (the immediate environment in which the individual interacts with) and mesosystem (interaction between two or more microsystems) levels, the following factors were barriers to disclosure: child's young age, being underweight and having a mild HIV infection, stigma and discrimination, and fear among primary caregivers that the child will be teased, rejected and called hurtful names by their peers. At exosystem level (environment in which the individual is not actively involved), non-disclosure was common among children whose primary caregivers were farmers or had a low-level education. At a macro-system (consists of the larger societal structures such as social, cultural, and political structures) level, lack of disclosure materials and training, lack of a good working relationship between primary caregivers and other stakeholders involved in the care of a child living with HIV as well as cultural factors were some of the reasons for non-disclosure.These findings suggest the need to consider the child's environment when planning, developing, implementing, and evaluating disclosure programs. This will ensure that the interventions target specific factors across the child's environment.

At a microsystem and mesosystem levels, there is need to identify policies, tools and programs that could help to reduce stigma and discrimination, provide support to primary caregivers to effectively disclose, provide mental health services to children and their primary caregivers deal with the psychosocial impact of HIV disclosure. Psychosocial support programmes identified in literature include: individual counselling sessions, support and training for primary caregivers, children support groups, family centred care and peer mentorship programmes for children (Amzel et al., 2013; Kanesathasan et al., 2011). When developing HIV disclosure programs, special attention should be paid to children who are younger, underweight, and in stage one of HIV infection.

At exosystem level, there is need to identify programs that empower primary caregivers to disclose HIV status and adequately support their children to understand HIV infection. When developing and implementing such programmes, special attention should be paid to primary caregivers who are farmers and those with low level education. The support programmes could be in form of training and educational sessions which are developed to match primary caregivers level of literacy (WHO, 2011). In addition, programmes that encourage adult literacy could help primary caregivers to understand information about the importance and process of disclosure of HIV status to children (WHO, 2011). Furthermore, programmes that can financially support primary caregivers through soft loans to enable them start small scale businesses could help them to have adequate resources to support children to fully understand their disease.

At a macrosystem level, programs in form of age appropriate disclosure materials, disclosure trainings and HIV policies and guidelines that discourage stigma and discrimination and promote disclosure of HIV status to children living with HIV are warranted. For the disclosure materials to be effective they need to be adapted to fit the cultural context of the target population (Amzel et al., 2013). Training healthcare workers, teachers, community leaders and primary caregivers on how to conduct an age appropriate disclosure may help to increase the prevalence of disclosure. In addition, Malawian ART clinics do not have mental health workers to support children and their families deal with the emotional impact of HIV and disclosure, yet there is a considerable proportion of psychiatric nurses working in general medical wards. Restructuring the ART clinics to include atleast one mental health worker could help to improve the mental wellbeing of children and their families. Lastly, the Government and donors have a role to play in identifying and providing funding for HIV disclosure programmes and research.

Having discussed the findings of the study in relation to the available literature and conceptual frameworks, the next section will discuss the strengths and limitations of the study.

6.5 STRENGTHS AND LIMITATIONS OF THE STUDY

The following paragraphs highlight the strengths and limitations of the study.

6.5.1 Strengths

The study has a number of strengths. First, to the best of the candidate's' knowledge, this is the first study to be conducted in Malawi and sub-Saharan Africa to assess the involvement of key stakeholders in the disclosure of HIV status to children. The study aimed to address gaps in knowledge about HIV disclosure to children that had been identified by WHO (World Health Organisation, 2011a). It is anticipated that the study findings will bring the issue to the attention of people throughout the world and make a significant contribution to the practice and development of policies and materials related to paediatric HIV care not only in Malawi but also in other sub-Saharan African countries. Second, the study recruited participants from all regions in Malawi which are diverse in terms of culture and socioeconomic status. This resulted in strongly representative data as people from different cultural and socioeconomic backgrounds were represented.

Third, data collection involved questionnaire data, as well as interviews and focus group discussions. This triangulation enabled both data depth and richness and strengthened the validity of the study findings. Moreover, the large numbers of interviews and focus groups meant that data saturation was easily reached. Fourth, this is the first study to be conducted in Malawi to assess healthcare workers' perspectives about HIV disclosure to children and also the first of its type in sub-Saharan Africa to estimate the proportion of healthcare workers who do disclose. The findings would, therefore, fill in the knowledge gap in this area. Fifth, this is also the first study in Sub-Saharan Africa to rigorously evaluate the feasibility and acceptance of a proposed HIV disclosure intervention before its development and implementation. The findings of this study will, therefore, help to develop a culturally appropriate intervention which addresses challenges of HIV disclosure to children not only in Malawi but other sub-Saharan Africa countries as well. Sixth, this is one of the few population-based studies conducted in Sub-Saharan Africa that assessed behavioural and emotional problems among children living with HIV and their relationship with the impact of illness on the family. It is anticipated that the findings will inform mental health policy and the formulation of guidelines for children living with HIV and their families in Malawi as well as the whole of sub-Saharan Africa.

6.5.2 Limitations

While the primary caregiver survey used stratified random sampling in recruiting participants from the regions and districts of Malawi, data analysis did not take into account the district and regional differences. Ideally multilevel modelling would have been the method of choice of data analysis. However, this was not done because the researcher achieved the same purpose of analysis that multilevel modelling could have achieved with the current data analysis method. For example, bivariate analysis did not show any relationship between demographic characteristics and non-disclosure of HIV status, as such using multilevel modelling could have not yielded different results.

Another limitation of the study is that only primary caregivers of children who were receiving care at the ART clinic were recruited in the study. This means that primarycaregivers of children who were not yet in care were missed. However, this is likely to be a small proportion given the high coverage of ART among children living with HIV in Malawi (Malawi Government, 2015).

This study had a high response rate. While this may be seen as a strength, it may also be a limitation given the overly compliant of participants which may be due to unequal power relationship, courtesy bias and the compensation that participants received after participating in the study (Banwell, Ulijaszek, & Dixon, 2013; Johnson & Van de Vijver, 2003). However, the researcher believe that the compensation may have had a little effect in influencing potential participants to participate in the study, given that the participants were not told about the compensation until after they had completed responding to the questionnaire. Moreover, participants were approached to participate in the study soon after arrival to the ART clinic before they had a chance to look around and see other participants coming out of the interview room with the compensation. High response rate is also common in other studies conducted in sub-Saharan African (Gultie, Genet, & Sebsibie, 2015; Vold, 2015).

Another limitation of the study is that a convenient sample was used to recruit healthcare workers in Tertiary and District hospitals but did not include participants in rural areas. Healthcare workers in rural health facilities may have had characteristics that could have enriched the findings of the study if they were included. Moreover, the senior officials in the hospitals assisted with distribution and collection and of questionnaires from the participants and this could have resulted in courtesy bias due to power relationship (Banwell et al., 2013; Johnson & Van de Vijver, 2003). Nonetheless, the research explained to the senior officials the importance of following data collection protocol and participants were asked not to include their names on the questionnaire.

In addition, few clinicians were available for interviews and no medical doctor participated. This just reflect how the health system in Malawi is. There are very few doctors in Malawi and most of them working in highly specialised areas such as Intensive care unit and theatre, while those in District hospitals tend to assume managerial role and are not available to treat people in ART clinics as such their involvement could have not made any big difference.

Furthermore, due to the nature of qualitative part of the study, bias related to researchers engaging with the research process and participants cannot be ruled out (Tong, Sainsbury, & Craig, 2007). However, this was prevented through the following ways: 1) research assistants who had no working relationship with the participants were employed to assist with recruitment of participants and data collection; 2) prior to the interviews and focus group discussion, the study participants were assured that their responses would not affect the type of care they receive at the clinic even if they decide to withdraw from the study; 3) interviews and focus groups took place in a quiet and private room, and only study participants were allowed in the room; and 4) the process of data analysis involved a group of experts with a wide range of expertise who reviewed and identified themes and this helped to validate and improve the credibility of the study findings (Schmiedeknecht et al., 2015).

Finally, while the findings of this study are relevant to other Sub-Saharan African countries because of the many similarities they share, they may not be generalizable to these countries because the sample was not representative of this region.

6.6 RECOMMENDATIONS

The findings of this study will change the way disclosure of HIV status to children is managed in Malawi and will ultimately increase the prevalence of the effective disclosure of HIV status. The following recommendations, based on key study findings, address issues related to the disclosure of HIV status to children living with HIV in Malawi in the context of the family, school, community, country, and world.

First, it is evident from the study that despite participants recognising the need for disclosure of HIV status to children, the rate of disclosure is still low. The lack of disclosure materials, knowledge and confidence are major factors associated with non-disclosure in Malawi. Healthcare workers, teachers and community leaders would benefit greatly from training in working together with families living with HIV and, specifically, training in the disclosure process. They also require resources, in the form of books and other educational materials, to help explain HIV and effective management to children and families. Thus, it is critically important that the story books to be developed should take into account the recommendations made by participants if they are to have a positive impact.

Second, undoubtedly, children could have better health and developmental outcomes if all adults involved in the care and education of children living with HIV work together to support the children. It is time that a strong partnership of these adults should be established and promoted in Malawi. Healthcare workers are better placed to initiate this collaboration given the influence they have in Malawian society. For this collaboration to work it is important for healthcare workers and teachers to acknowledge the power imbalance that exists between them and primary caregivers and see primary caregivers as equal partners rather than recipients of care. This is going to be difficult to implement because of the hierarchical relationships that exist in Malawian healthcare setting, high workloads, and limited resources available. Incorporating principles of effective partnership in undergraduate curricula and syllabi of healthcare workers could help to standardise this framework of care. Within the context of a trusting relationship and partnership, it is essential for primary caregivers to understand why it is important to disclose and to develop the skills necessary to do this in a safe and effective manner. The Government, non-Government organisations, and international donors have a responsibility to support the establishment of these partnerships through adequate funding and the formulation of policies and guidelines.

Third, this study has also demonstrated that stigma and discrimination are still common in Malawi despite years of health campaigns to end the practice. The impact of stigma and discrimination on the child and family is devastating. Eradication of these practices will require greater collaboration between Government, non-Government organisations, and all stakeholders involved in the care of children through the following ways: 1) the Government can formulate policies that protect children and their families from stigma and discrimination; 2) the Government and other non-Government organisations can increase funding for the development of evidence-based interventions that discourage stigma and promote tolerance of people living with HIV in Malawi; 3) and perhaps most importantly, primary caregivers, healthcare workers, teachers and community leaders need to work together in providing a safe environment for the children living with HIV and their families.

Fourth, majority of primary caregivers of children living with HIV in Malawi are women, thus policies that help to empower women through education and employment opportunities will, in turn, improve the health and developmental outcomes of children living with HIV. HIV places a considerable burden on families. More psychological and social support for families is required. Again, this will help reduce emotional and behavioural problems that are, in turn, associated with poor school performance, and diminished life chances for these children. Better support for families will also result in better health and developmental outcomes for mothers, fathers, siblings and other extended family members. Furthermore, it will reduce the general burden of disease and optimise the human capital of the population that is critical for Malawi’s future economic development.

Fifth, limited family resources and a lack early childhood services increase children’s vulnerability to poor health and developmental outcomes. As much as possible, the Government and non-Government organisations in Malawi should direct scarce healthcare resources to the care of women during pregnancy and to services that support families during the earliest years of children’s lives. Policies that promote the protection of families of children living with HIV, early child development, and children’s access to healthcare services and education can have a big impact on the developmental trajectories of these children.

Sixth, future research is warranted, including both longitudinal studies to better understand the disclosure process that takes place over time, and intervention studies that begin by asking primary caregivers and healthcare workers to identify the kinds of resources they require to help them effectively disclose. Further research on the effectiveness of the Working Together framework is warranted, specifically, longitudinal studies that evaluate the health and developmental outcomes of children receiving care in an environment where there is partnership among stakeholders involved are needed.

In addition to these more general recommendations, the researcher believes that sufficient evidence has been presented to support the further development of the proposed disclosure materials. The final paragraphs outline the ongoing development of the proposed intervention: a series of story books about HIV that are suitable for children of all ages.

Planning for the development of the disclosure books started in the design phase of the study through consultation with members of the steering committee and stakeholders. The established committee has academic members from Curtin University and the University of Malawi with expertise in Nursing, Public Health, Psychology, and Education. It includes senior officials in the Malawi Ministry of Health, the WHO in Geneva and Malawi, UNICEF, the United States Agency of International Development (USAID), and Baylor College of Medicine Children's Foundation in Malawi. In addition, it includes primary caregivers who represent the families of children living with HIV. The steering committee members are all keen to support the development and implementation of the story books that are seen to have great potential in Sub-Sahara African region. Preliminary discussions have taken place with representatives of the well-known publisher McGraw-Hill Education Company, who have indicated that they will assist with the development of the children's books using suitable authors from both Malawi and Australia, and their printing.

The development and implementation of the story books will be guided by the steering committee using the Working Together framework. The first step will involve outlining the content of the books using the information garnered from the study findings and review of literature, and expert advice from steering committee members. The second step will involve the writing of a series of three books suitable for children aged six and seven, eight to 10, and 11 and 12, by Malawian and Australian children's authors and illustrators. The books will be reviewed by steering committee members as many times as necessary to ensure they are appropriate before they go into production. The books will be published in both English and Chichewa. A protocol will be developed by the researcher in collaboration with members of the steering committee in which all steps and processes involved in the appropriate use of the story books will be documented. The proptocol will be suitable for healthcare workers and teachers to share with primary caregivers and community leaders.

It is anticipated that the books and associated resources will help to: 1) provide HIV information for children of different age groups; 2) answer questions that children may have related to their condition; 3) promote resilience among children; 4) prepare caregivers for long- and short-term emotional reactions; 5) include information for children, health workers, primary caregivers, community leaders and teachers on how to develop a disclosure plan and the roles of each member of the disclosure team; 6) provide information about provision of supportive care to children undergoing the disclosure process; 7) develop a plan for the caregiver and children to disclose to others; and 8) provide a culturally appropriate disclosure.

The next phase will be to pilot the books among selected children in Malawi. The pilot study will be guided by the Working Together framework and principles of intervention mapping (Eldredge et al., 2016). Process and impact evaluation data will be collected at baseline, six months, and 12 months to finalise the books and process of implementation, as well as to establish their effectiveness. Measures related to acceptability, user friendliness, and rates of HIV disclosure will be the main outcomes of the study. The outcomes of the pilot study will determine whether the intervention should be scaled up or not. If the outcomes are positive, then the coverage of the intervention will be increased. All further stages of implementation will be supported by evaluation research.

6.7 CONCLUSION

The findings of this study demonstrated that the rate of HIV non-disclosure among affected children in Malawi is high. The study has shown that the process of HIV disclosure to children is a complex issue with stakeholders facing a range of barriers and constraints to effective disclosure. The study identified the need for developing guidelines and materials that have been rigorously evaluated prior to dissemination. The involvement of all stakeholders from planning to implementation is important in this process. Based on the results of this study, it is anticipated that the proposed children books will be well accepted by the majority of stakeholders. The children’s books will be an important resource for children to understand about their diagnosis and to develop resilience to HIV diagnosis. The material will also help to simplify and standardise the disclosure process as well as promote collaborative HIV status disclosure among primary caregivers, healthcare workers, teachers and community leaders. While the proposal to develop and pilot the disclosure story books may seem to be a relatively straightforward goal, it will be a challenging task in Malawi where healthcare budgets are already stretched and have to cater for numerous competing health priorities. A multi-lateral consortium of governments and international aid organisations will be asked to provide resources and expertise to better support these children living with HIV and their families.

The study results call for a collaborative approach to HIV status disclosure to children living with HIV to ensure that children receive a well-coordinated biopsychosocial support and continuity of care. This is in line with Bronfenbrenner’s Bioecological framework, which emphasises the importance of the children’s environment in determining the developmental trajectory across the lifespan. Factors associated with non-disclosure should be examined from the Working together and bioecological perspectives to ensure that disclosure interventions are well targeted and coordinated across individual, family, community, school and health facility settings. Furthermore, support systems that discourage stigma and discrimination and promote resilience among children living with HIV should be promoted in these settings. The findings of this study will inform the next phase of the intervention, which is to develop and pilot the children books. Further inquiries are also warranted to develop and test interventions, policies and tools that promote disclosure of HIV status to children through reduction of stigma and discrimination and promotion of resilience among children living with HIV.

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APPENDICES

Appendix A: Basic Logic model development

Resources	Activities	Output	Short and long-term outcomes	Impact
• Committed Steering committee • Primary caregivers of children living with HIV • Teachers • Community leaders • Healthcare workers • Funds • Antiretroviral therapy clinic • Terms of reference for steering committee	• Consultation with steering committee • Review of available • Needs assessment survey • Development of the disclosure resource • Refining of the disclosure resource • literature • Publication of the resource	• Steering committee comments or suggestions • Results from the needs assessment survey • HIV disclosure resource	• Increase in confidence and knowledge about disclosure among primary caregivers, health care workers, teachers and community leaders • Increase in disclosure rate of HIV status to seropositive children • Good psychosocial adjustment of children to HIV • Increase in ART drug adherence among children living with HIV • Improved team work among healthcare workers, primary caregivers, teachers and community leaders • Inclusion of the HIV resource in the guidelines and policies related to disclosure of HIV to seropositive children in Malawi	• Improved psychosocial health of children living with HIV and their families • Improved physical health for children living with HIV • Improve academic performance of children living with HIV • Improved family, school and community support for children living with HIV • Reduced stigma and discrimination for children living with HIV and their families • Provision of standard HIV status disclosure to children living with HIV

Appendix B: Primary caregiver survey information sheet

Study Title: Psychosocial and health system factors in disclosure of HIV status to children living with HIV in Malawi: Needs assessment and formative evaluation of a disclosure resource.

Research Team: Fatch Kalembo, Dr Garth Kendall, Dr Mohammed Ali

My name is Fatch Kalembo, and as part of my university studies (PhD) with Curtin University in Western Australia, I am carrying out a study about how parents and guardians tell their children who are living with HIV about their HIV status.

The aims of the study are to understand the current situation on how children are told about their HIV status in Malawi and to make books for children, that can help them accept their illness, encourage them to take their medicine, and follow other important advice given by their doctor. We also hope that the books can guide parents and guardian on the best way to help children deal with problems in the community that appear because of their condition, and respond to questions that children may have about their HIV status.

We would like to invite you to take part in the study. I will ask you questions related to your knowledge, attitudes, and practices about telling your child that he/she has HIV*;* problems associated with telling your child that he/she has HIV; and your views on the need for books to guide the way children are told about their HIV status. This interview will take about 30 to 45 minutes.

Before you agree to participate, it is important for you to understand that:

- Participation is completely voluntary. Your participation will in no way impact the quality and type of services you may be getting now or may get in the future from any partners/agencies/organisations linked with this study. There will be no impact on treatment for you or your child if you choose not to participate or withdraw from the study

- **You can choose not to answer individual questions.** If you do not wish to answer any of the questions asked, you do not have to. You can speak with the interviewer about any fears or questions you may have.

- **You may choose to stop the interview at any time**. If you wish to stop the interview, you can do so at any time with no impact on the services you are using now or in the future from any partners/agencies/organisations linked with this study.

- **All information collected as part of this study will be kept confidential**. Only research assistants and the researcher will view the responses you have given. All responses will be kept strictly confidential and will not be shown to any other persons. We will not write down your name or personal information (such as addresses) when we report the results. Code numbers will be used to protect your identity. All the information related to the study will be stored in a locked cabinet at Curtin University

- The results of this research may be published or shared in international medical journals and in the form of a thesis. **Neither your name nor any**

personal information that may identify you will be used in any published material.

This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number HR 186/2014). The Committee is comprised of members of the public, academics, lawyers, doctors and pastoral carers. If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University, GPO Box U1987, Perth, 6845 or by telephoning +6189266 2784 or by emailing hrec@curtin.edu.au.

The research has also been approved by the Malawi National Health Sciences Research Committee (Approval Number: NHSRC 1347.). If you have any ethical concerns related to this study, you are free to contact the Chairman, National Health Sciences Research Committee, Ministry of Health (Research Department, P.O. BOX, 30O377, Lilongwe 3, Malawi (Phone: +26 560 1726422).

If you have questions or if you need clarifications related to the research, feel free to contact the researcher by phone or email.

Researcher: Fatch Kalembo

Email: kalembofatch@yahoo.com

Mobile contact: +265998260623.

Appendix C: Primary caregiver survey consent form

STUDY SITE ………………………ID NO……………………

Study Title: Psychosocial and health system factors in disclosure of HIV status to children living with HIV in Malawi: Needs assessment and formative evaluation of a disclosure resource.

Research Team: Fatch Kalembo, Dr Garth Kendall, Dr Mohammed Ali

I have been given clear written information and understand the intentions of this study.

I have taken the time to consider participation in this study.

I have had the opportunity to ask questions and had them answered to my satisfaction.

I understand that in the event of this work being published, as a participant, I will not be in any way identifiable.

I understand that I may choose to withdraw from the study at any time or not to participate without any impact on treatment for me and my child.

I am also aware that in the event of having any complaints regarding this study, I can contact the Chairman, National Health Sciences Research Committee, Ministry of Health (Research Department, P.O. BOX, 30O377, Lilongwe 3, Malawi (Phone: +2651726422).

Participant Statement

I……………………………………………………………….. (Print full name)

Understand the intentions of the study and know that I have the opportunity to ask questions at any time.

I agree to complete a questionnaire.

I understand that my participation in this study is voluntary and I can withdraw at any time without any consequences.

Signature/thumb print ……………………………………………… Participant

Signature ……………………………………………………….... Researcher

Date ………………………………………………………

Appendix D: Primary caregiver questionnaire

Curtin University

Study title: Psychosocial and health system factors in disclosure of HIV status to children living with HIV in Malawi: Needs assessment and formative evaluation of a disclosure resource.

The purpose of this questionnaire is to obtain information about you, your partner, your child, household, finances, occupation, and disclosure of HIV status to the child, need for development of HIV status disclosure resource, child's physical and emotional health, life stress, social support and impact of the child's illness on the family.

The questionnaire will take 30 to 45 minutes to complete. Please respond to all questions with honesty, completeness and accuracy. You are free to withdraw from participating in this study at any time without penalty. All answers you give will be confidential. Please use the pen to complete the questionnaire.

Tick the box that corresponds to your answer and write clearly where required. For example: How old is your child

6 years ☒ 1

7 years ☐ 2

8 years ☐ 3

9 years ☐ 4

10 years ☐ 5

11years ☐ 6

12years ☐ 7

If your answer is 6 years, then tick the box next to 6 years with a pen as indicated above.

PART A: SOCIO-DEMOGRAPHIC DATA.

A1.	**What is your relationship with the child?**		
		Mother ☐	Uncle ☐
		Father ☐	Grandparent ☐
		Aunt ☐	Sibling ☐
			Legal guardian ☐
	Other (please specify)…		

A2.	**What is your age?**		
		Below 15 years ☐	36-40 years ☐
		15- 20 years ☐	41-45 years ☐
		21-25 years ☐	46-50 years ☐
		26-30 years ☐	Over 50 years ☐
		31-35 years ☐	

A3.	**What is your gender?**		
		Male ☐	Female ☐

A4.	**What is your current marital status?**		
		Married ☐	Widowed ☐
		Single ☐	Divorced ☐

A5.	**What is the highest level of formal education you have completed?**		
		None ☐	College ☐
		Primary ☐	University ☐
		Secondary ☐	

A6.	**What is the highest level of formal education your spouse has completed?**		
		None ☐	College ☐
		Primary ☐	University ☐
		Secondary ☐	Not applicable ☐

A7.	**How many children 12 years of age or younger live in your home?**		
		1-2 ☐	6-8 ☐
		3-5 ☐	9-12 ☐

A8.	**How many children over 12 years of age live in your home?**		
		0 ☐	6-8 ☐
		1-2 ☐	9-12 ☐
		3-5 ☐	
A9	**Which of the following would you describe your tribe as?**		
		Chewa ☐	Ngoni ☐
		Yao ☐	Tonga ☐
		Tumbuka ☐	Sena ☐
		Lomwe ☐	Nkhonde ☐
	Other (please specify)…………………………………………………………		

A10.	**Does your household have any of the following (tick all that apply) ?**		
	Electricity	Yes ☐	No ☐
	Koloboyi	Yes ☐	No ☐
	A paraffin lamp other than a koloboyi	Yes ☐	No ☐
	A radio?	Yes ☐	No ☐
	A television	Yes ☐	No ☐
	A cellular phone	Yes ☐	No ☐
	A telephone (landline)	Yes ☐	No ☐
	A bed with a mattress	Yes ☐	No ☐
	A sofa set?	Yes ☐	No ☐
	A table and chair(s)	Yes ☐	No ☐
	A refrigerator?	Yes ☐	No ☐
	A bicycle	Yes ☐	No ☐
	Motorcycle or scooter	Yes ☐	No ☐
	An oxcart	Yes ☐	No ☐
	A car	Yes ☐	No ☐

A11.	**What is the main source of drinking water for members of your household?(Tick only one)**	
	Piped water	**Water from spring**
	Piped into dwelling ☐	Protected spring ☐
	Piped to yard or plot ☐	Unprotected spring ☐
	Public taps/standpipe ☐	Rain water ☐
	Borehole ☐	Surface water ☐
	Dug well	Bottled water ☐
	Protected well ☐	
	Unprotected well ☐	
	Other (please specify….……..……………………………………………………………………..	

A12.	**What kind of toilet facility is used by members of your household?**	
	Flush toilet ☐	Compositing toilet ☐
	Ventilated improved latrine ☐	Bucket toilet ☐
	Pit latrine with a slab ☐	No facility/bush/field ☐
	Pit latrine without a slab/one pit ☐	

A13.	**What type of fuel is used for heating by your household?**	
	Electricity ☐	Wood ☐
	Natural gas ☐	Straw/shrubs/grass ☐
	Kerosene ☐	Animal dung ☐
	Coal ☐	No food cooked in household ☐
	Charcoal ☐	
	Other (please specify………………………………………………………………………………………	

A14.	**What is the main material of the floor of your house**		
		Earth/sand ☐	Broken bricks ☐
		Dung ☐	Ceramic tiles ☐
		Wooden planks ☐	Cement ☐
		Palm/Bamboo/grass ☐	
	Other (please specify)…………………………………………………………………………………..		

A15.	**What is the main material of the roof of your house?**		
		No roof ☐	Iron sheets ☐
		Thatch/palm leaf ☐	Wood ☐
		Palm/bamboo/grass ☐	Cement ☐
		Wood planks ☐	Ceramic tiles ☐
		Cardboard ☐	
	Other (Please specify………………………………………………………………………………...........		

A16.	**What is the main material of the exterior walls of your house?**		
		No walls ☐	Cement ☐
		Cane/palm/trunks ☐	Stone with lime/cement ☐
		Bamboo/tree trunks with mud ☐	Burnt bricks ☐
		Stone with mud ☐	Unburnt bricks ☐
		Plywood ☐	Cement blocks ☐
		Cardboard ☐	Wood planks ☐
	Other (please specify) …………………………………………………………………………………		

A17.	**Does your household own any livestock, herds, other farm animals, or poultry?**		
		Yes ☐	No ☐ Go to A19

A18.	**How many of the following animals does your household own? (Specify number)**		
		Goats.....................	Chickens……………
		Pigs........................	Ducks………………
		Cattle.....................	Pigeons……………
	Other (please specify) …………………………………………………………………………….....		

A19.	**Does any member of your household own any agricultural land?**		
	Yes ☐		No ☐ Go to A21

A20.	**How much agricultural land do members of your household own? (Specify number)**		
		Acres ………………….	Football pitches………..
		Hectares……………….	I don’t know ☐

A21.	**In the last 7 days, how many main meals did your household have per day?**		
		1 ☐	3 or more ☐
		2 ☐	

A22.	**In the last year, did your household have sufficient food?**		
		Yes ☐	No ☐

A23.	**What do you currently spend most of your time doing? (Please mark only one answer, unless two, or more, answers apply equally)**	
	Full-time or part-time job (salary or own business) ☐	Recovering from injury / illness ☐
	Farming ☐	Caring for an ill person ☐
	Looking for work ☐	Studying ☐
	Home duties / caring for children ☐	

A24.	**What does your spouse currently spend most of his/her time doing? (Please mark only one answer, unless two, or more, answers apply equally)**	
	Full-time or part-time job (salary or own business) ☐	Recovering from injury / illness ☐
	Farming ☐	Caring for an ill person ☐
	Looking for work ☐	Studying ☐
	Home duties / caring for children ☐	Not applicable ☐

PART B: ABOUT YOUR CHILD OR THE CHILD YOU ARE CARING FOR. THIS SECTION, ASKS ABOUT YOUR OLDEST CHILD WITH HIV WITHIN THE AGE RANGE OF 6-12 YEARS.

B1.	**What is your child’s age?**	
	6 years ☐	10 years ☐
	7 years ☐	11 years ☐
	8 years ☐	12 years ☐
	9 years ☐	

B2.	**What is your child’s gender?**	
	Female ☐	Male ☐

B3.	**What is your child’s WHO clinical staging of HIV disease? (Obtain from the child’s health profile book)**	
	Stage 1 ☐	Stage 3 ☐
	Stage 2 ☐	Stage 4 ☐

B4.	**What are your child’s anthropometric measures? (Please measure)**	
	Height …………………(M)	Weight……………(Kg)

B5.	**Does your child have now, or has your child had in the last year, any of the following health professional diagnosed medical conditions or health problems? (***Please tick all that apply)*		
	Fever	Yes ☐	No ☐
	Diarrhoea	Yes ☐	No ☐
	Pneumonia	Yes ☐	No ☐
	Tuberculosis	Yes ☐	No ☐
	Skin disease	Yes ☐	No ☐
	Undernutrition	Yes ☐	No ☐
	Other (please specify) ………………………………………………………………………………		

B6.	**Is your child currently taking HIV medicine?**	
	No ☐	Yes ☐

B7.	**If yes, for how long has your child been on the HIV medicine?**	
	Less than 6 months ☐	4 to 5 years ☐
	6 months to 1 year ☐	More than 5 years ☐
	2 to 3 years ☐	

PART C. DISCLOSURE OF HIV STATUS TO YOUR CHILD.

C1.	**Does your child know that he/she has HIV?**	
	Yes ☐	No ☐ (Go to C7)

C2.	**Who disclosed the HIV status to your child? (Tick all that apply)**	
	Parents ☐	Aunt ☐
	Healthcare worker ☐	Grandparent ☐
	Uncle ☐	Legal guardian ☐
	Other (please specify) ……………………………………………………………………………	
C3.	**Were HIV related issues such as causes, transmission and treatment, discussed with the child prior to disclosure of HIV status?**	
	Yes ☐	Not sure ☐
	No ☐	

C4	**How was your child told about his/her HIV status?**	
	As a one-time event ☐	Not sure ☐
	As a gradual process ☐	

C5.	**How old was your child when his/her HIV status was first disclosed?**	
	Less than 6 years ☐	9 years ☐
	6 years ☐	10 years ☐
	7 years ☐	11 years ☐
	8 years ☐	12 years ☐

C6.	**Which of the following statements best describes the reason for telling your child his HIV status? (Tick all that apply)**		
	The child is old enough to understand his condition	Yes ☐	No ☐
	The healthcare worker insisted that the child should be told of his/her condition	Yes ☐	No ☐
	The child asked about his illness	Yes ☐	No ☐
	The child did not want to take medicines because he/she did not know why he/she was taking them	Yes ☐	No ☐
	The child's condition got worse	Yes ☐	No ☐
	The parent's health condition got worse	Yes ☐	No ☐
	Other (please specify)…………………………………………………………………………………		

C7.	**Please answer the following general questions about HIV disclosure**			
	Does the child know that he /she is taking medicines for HIV?	Yes ☐	No ☐	Not sure ☐
	Does the child ever ask questions about why he /she is taking medicine?	Yes ☐	No ☐	Not sure ☐
	Does the child ever refuse to take medicines that he or she is supposed to take?	Yes ☐	No ☐	Not sure ☐
	Do you ever not give medicines to the child because you do not want to give them in front of other people?	Yes ☐	No ☐	Not sure ☐
	Do you ever have problems with giving the medicines because the child does not know why he/she taking them?	Yes ☐	No ☐	Not sure ☐
	Does the child ever have problems taking the medicines on time or taking them every day?	Yes ☐	No ☐	Not sure ☐
	Do other children avoid playing with the child because of his/her HIV status?	Yes ☐	No ☐	Not sure ☐
	Do other children tease or call the child hurtful names because of his/her HIV status?	Yes ☐	No ☐	Not sure ☐
	Has your child been rejected by friends or family because of his illness?	Yes ☐	No ☐	Not sure ☐
	Does your child seem to have little pleasure in doing things lately?	Yes ☐	No ☐	Not sure ☐
	Has your child been feeling down, depressed or hopeless?	Yes ☐	No ☐	Not sure ☐

C8.	**Who do you think is the best person to disclose HIV status to children living with HIV?**		
		Primary caregiver ☐	Healthcare worker ☐
		Teacher ☐	Church minister ☐
	Other (please specify) ………………………………………………………………………………		

C9.	**Do you think you have adequate knowledge on how to disclose HIV status to your child?**		
		Yes ☐	Not sure ☐
		No ☐	

C10.	**Which of the following statement best describes the reason that prevent you from telling your child about his/her HIV status? (Tick all that apply) (If disclosed go to Question C11)**		
	Fear of children’s inability to handle the news (mental immaturity)	Yes ☐	No ☐
	Fear of stigma and discrimination	Yes ☐	No ☐
	Lack of support from the healthcare workers	Yes ☐	No ☐
	Lack of knowledge on how to disclose	Yes ☐	No ☐
	Feeling of guilty or shame	Yes ☐	No ☐
	Because the child is not showing signs of sickness	Yes ☐	No ☐
	Other (please specify)………………………………………………………………………………		

C11.	**We are planning to develop an HIV status disclosure resource that will be in form of books, developed according to children’s emotional and physical maturity. The resource will use pictures, stories, and songs in Chichewa to convey HIV disclosure messages to children. I am going to read some statements about this resource. For each statement I read please tell me whether at the present time you would strongly disagree, disagree, neither agree nor disagree, agree or strongly agree with the statement (*Please circle appropriate numbers)***					
		Strongly disagree	**Disagree**	**Neither Agree nor Disagree**	**Agree**	**Strongly Agree**
	It is a good idea to develop such type of a resource	1	2	3	4	5
	I will be able to use the resource with my child	1	2	3	4	5
	The resource will help to improve my knowledge in HIV status disclosure to children	1	2	3	4	5
	The resource will help to improve my confidence in HIV status disclosure to children	1	2	3	4	5
	The resource will help to reduce my worries on HIV status disclosure to children	1	2	3	4	5

PART D. CHILD DEVELOPMENT

D1. For each item, please mark the box for Not True, Somewhat True or Certainly True. Please give your answers on the basis of your child's behaviour over the last six months

	Not true	**Somewhat True**	**Certainly True**
Considerate of other people's feelings	○	○	○
Restless, overactive, cannot stay still for long	○	○	○
Often complains of headaches, stomach-aches or sickness	○	○	○
Shares readily with other children (treats, toys, pencils etc.)	○	○	○
Often has temper tantrums or hot tempers	○	○	○
Rather solitary, tends to play alone	○	○	○
Generally obedient, usually does what adults request	○	○	○
Many worries, often seems worried	○	○	○
Helpful if someone is hurt, upset or feeling ill	○	○	○
Constantly fidgeting or squirming	○	○	○
Has at least one good friend	○	○	○
Often fights with other children or bullies them	○	○	○
Often unhappy, down-hearted or tearful	○	○	○
Generally liked by other children	○	○	○
Easily distracted, concentration wanders	○	○	○
Nervous or clingy in new situations, easily loses confidence	○	○	○
Kind to younger children	○	○	○
Often lies or cheats	○	○	○
Picked on or bullied by other children	○	○	○
Often volunteers to help others (parents, teachers, other children)	○	○	○
Thinks things out before acting	○	○	○
Steals from home, school or elsewhere	○	○	○
Gets on better with adults than with other children	○	○	○
Many fears, easily scared	○	○	○
Sees tasks through to the end, good attention span	○	○	○

D2. Overall, compared to other children of the same age, do you think that your child has difficulties in one or more of the following areas: emotions, concentration, behaviour or being able to get on with other people?

No (Go to Part E)	○	Yes, moderate difficulties	○
Yes, minor difficulties	○	Yes, severe difficulties	○

If you have answered "Yes", please answer the following questions about these difficulties:

D3. How long have these difficulties been present?		
Less than a month	○	○ 6-12 months
1-5 months	○	○ Over a year

D4. Do the difficulties upset or distress your child?	
Not at all	○
Only a little	○
Quite a lot	○
A great deal	○

D5. Do the difficulties interfere with your child's everyday life in the following areas?

	Not at all	Only a little	Quite a lot	A great deal
Home life	○	○	○	○
Friendships	○	○	○	○
Classroom learning	○	○	○	○
Leisure activities	○	○	○	○

D6. Do the difficulties put a burden on you or the family as a whole?	
Not at all	○
Only a little	○
Quite a lot	○
A great deal	○

PART E. FAMILY LIFE AND IMPACT OF THE CHILD’S ILLNESS

E1. In the last year, have any of the following happened to you? (Tick all that apply)	Yes	No
Pregnancy problems	○	○
Separation or divorce	○	○
Marital problems	○	○
A close family friend or another relative (e.g. aunt, cousin, grandparent) died	○	○
Problems with your children	○	○
Your own job loss (not voluntary)	○	○
Your own job loss (not voluntary)	○	○
Money problems	○	○
Insufficient food	○	○
Other *(please describe)*………………………………………...		

E2. I am going to read some statements that people have made about living with an ill child. For each statement, please indicate at the present time if you would strongly agree, agree, disagree or strongly disagree (*Please circle appropriate numbers)*

Strongly agree		**1**			
Agree			**2**		
Disagree				**3**	
Strongly disagree					**4**
		1	**2**	**3**	**4**
a.	The illness is causing financial problems for the family	**1**	**2**	**3**	**4**
b.	Time is lost from work because of hospital appointments	**1**	**2**	**3**	**4**
c.	I am cutting down hours I work to care for my child	**1**	**2**	**3**	**4**
d.	Additional income is needed in order to cover medical expenses	**1**	**2**	**3**	**4**
e.	I stopped working because of my child’s illness	**1**	**2**	**3**	**4**
f.	Because of the illness we are not able to travel out of the city	**1**	**2**	**3**	**4**
g.	People in the neighbourhood treat us specially because of the my child’s illness	**1**	**2**	**3**	**4**
h.	we have got little desire to go out because of my child’s illness	**1**	**2**	**3**	**4**
i.	It is hard to find a reliable person to take care of my child	**1**	**2**	**3**	**4**
j.	sometimes we have to change plans about going out at the last minute because of my child’s state	**1**	**2**	**3**	**4**
k.	We see family and friends less because of the illness	**1**	**2**	**3**	**4**
l.	Because of what we have shared we are a closer family	**1**	**2**	**3**	**4**
m.	Sometimes I wonder whether my child will be treated “specially” or the same as a normal child	**1**	**2**	**3**	**4**
n.	My relatives have been understanding and helpful with my child	**1**	**2**	**3**	**4**
o.	I think about not having more children because of the illness	**1**	**2**	**3**	**4**
p.	My partner and I discuss my child’s problems together	**1**	**2**	**3**	**4**
q.	we try to treat my child as if he/she were a normal child	**1**	**2**	**3**	**4**
r.	I don’t have much time left over for other family members after caring for my child	**1**	**2**	**3**	**4**
s.	Relatives interfere and think they know what’s best for my child	**1**	**2**	**3**	**4**
t.	Our family gives up things because of my child’s illness	**1**	**2**	**3**	**4**
u.	Fatigue is a problem for me because of my child’s illness	**1**	**2**	**3**	**4**
v.	I live from day to day and I don’t plan for the future	**1**	**2**	**3**	**4**
w.	Nobody understands the burden I carry	**1**	**2**	**3**	**4**
x.	Travelling to the hospital is a strain on me	**1**	**2**	**3**	**4**
y.	Learning to manage my child’s illness has made me feel better about myself	**1**	**2**	**3**	**4**
z.	I worry about what will happen to my child, in the future	**1**	**2**	**3**	**4**
aa.	Sometimes I feel like we live on a roller coaster: in crisis when my child is acutely ill, OK when things are stable	**1**	**2**	**3**	**4**
bb.	It is hard to give much attention to the other children because of the needs of my child	**1**	**2**	**3**	**4**
cc.	having a child with an illness makes me worry about my other children’s healthy	**1**	**2**	**3**	**4**

PART F: FAMILY SUPPORT

F3. This scale includes different types of assistance that people sometime find helpful. This questionnaire asks you to indicate how much you need help in each of these areas. Please circle the response that best describes your needs. Please answer all questions.

To what extent do you feel a need for any of the following types of help or assistance	**Never**	**Once in a while**	**Some times**	**Often**	**Quite often**
Someone to talk to about things that worry you	1	2	3	4	5
Someone to provide money for food, clothes and other things	1	2	3	4	5
Someone to care for your child on a regular basis	1	2	3	4	5
Someone to talk to about problems with raising your child	1	2	3	4	5
Someone to help you get services for your child	1	2	3	4	5
Someone to encourage you when you are down	1	2	3	4	5
Someone to fix things around the house	1	2	3	4	5
Someone to talk to who have similar experience	1	2	3	4	5
Someone to do things with your child	1	2	3	4	5
Someone to whom you can depend	1	2	3	4	5
Someone to hassle with agencies or businesses when I can’t	1	2	3	4	5
Someone to lend you money	1	2	3	4	5
Someone who accepts your child regardless of how he or she acts	1	2	3	4	5
Someone to relax and joke with	1	2	3	4	5
Someone to help with household chores	1	2	3	4	5
Someone to keep you going when things seem hard	1	2	3	4	5
Someone to care for your child in emergencies	1	2	3	4	5
Someone to talk to when you need advice	1	2	3	4	5
Someone to provide you and your children transportation	1	2	3	4	5
Someone who tells you about services for your child or family	1	2	3	4	5

End of questionnaire.

Thanks you for your participation in the study.

Appendix E: Healthcare worker survey information sheet

Study Title: Psychosocial and health system factors in disclosure of HIV status to children living with HIV in Malawi: Needs assessment and formative evaluation of a disclosure resource.

Research Team: Fatch Kalembo, Dr Garth Kendall, Dr Mohammed Ali

My name is Fatch Kalembo, and as part of my university studies (PhD) with Curtin University in Western Australia, I am carrying out a study about how parents and guardians tell their children who are living with HIV about their HIV status.

The aims of the study are to understand the current situation on how children are told about their HIV status in Malawi and to make books for children, that can help them accept their illness, encourage them to take their medicine, and follow other important advice given by their doctor. We also hope that the books can guide health workers, teachers, community leaders, parents and guardians on the best way to help children deal with problems in the community that appear because of their condition and respond to questions that children may have about their HIV status.

We would like to invite you to take part in the study, where you will be asked questions about your knowledge, attitudes, and practices about telling children that they have HIV; problems associated with telling children that they have HIV; and your views on the need for books to guide the way children are told about their HIV status. You will be expected to take less than 15 minutes to answer the questions related to the study.

Before you agree to participate, it is important for you understand that:

- **Participation is completely voluntary.** Your participation will in no way impact the quality and type of services you may be getting now or may get in the future from any partners/agencies/organisations linked with this study.
- **You can choose not to answer individual questions.** If you do not wish to answer any of the questions asked, you do not have to.
- **You may choose to stop the interview at any time**. If you wish to stop the interview, you can do so at any time with no impact on the services you are using now or in the future from any partners/agencies/organisations linked with this study.
- **All information collected as part of this study will be kept confidential**. Only research assistants and the researcher will view the responses you have given. All responses will be kept strictly confidential and will not be shown to any other persons. We will not write down your name or personal information (such as addresses) when we report the results. All the information related to the study will be stored in a locked cabinet at Curtin University
- The results of this research may be published or shared in international medical journals and in the form of a thesis. **Neither your name nor any personal information will be used in any published material.**

This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number HR 186/2014). The Committee is comprised of members of the public, academics, lawyers, doctors and pastoral carers. If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University, GPO Box U1987, Perth, 6845 or by telephoning +6189266 2784 or by emailing hrec@curtin.edu.au.

The research has also been approved by the Malawi National Health Sciences Research Committee (Approval Number xxxx.). If you have any ethical concerns related to this study, you are free to contact the Chairman, National Health Sciences Research Committee, Ministry of Health (Research Department, P.O. BOX, 30O377, Lilongwe 3, Malawi (Phone: +26 560 1726422) or the Secretary, Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University, GPO Box U1987, Perth, 6845 or by telephoning +6189266 2784 or by emailing hrec@curtin.edu.au If you have questions or if you need clarifications related to the research, feel free to contact the researcher by phone or email.

Researcher: Fatch Kalembo

Email: kalembofatch@yahoo.com

Mobile contact: + 265998260623

Appendix F: Healthcare worker survey consent form

Curtin University

STUDY SITE ……………………….. ID NO……………………

Study Title: Psychosocial and health system factors in disclosure of HIV status to children living with HIV in Malawi: Needs assessment and formative evaluation of a disclosure resource.

Research Team: Fatch Kalembo, Dr Garth Kendall, Dr Mohammed Ali

I have been given clear written information and understand the intentions of this study.

I have taken the time to consider participation in this study.

I have had the opportunity to ask questions and had them answered to my satisfaction.

I understand that in the event of this work being published, as a participant, I will not in be in any way identifiable.

I understand I may withdraw from the study at any time without consequence, effect or access to routine health care.

I am also aware that in the event of having any complaints regarding this study, I can contact the Secretary of the Human Research Ethics Committee, Curtin University on +61892262784.

Participant Statement

I………………………………………………………………….. (Print full name)

Understand the intentions of the study and know that I have the opportunity to ask questions at any time.

I agree to complete a questionnaire and / or participate in an in-depth interview.

I understand that my participation in this study is voluntary and I can withdraw at any time without any consequences.

Signature ……………………………………………………… Participant

Signature …………………………………………………….... Researcher

Date ………………………………………………………

Appendix G: Healthcare worker survey questionnaire

Study Title: Psychosocial and health system factors in disclosure of HIV status to children living with HIV in Malawi: Needs assessment and formative evaluation of a disclosure resource.

The questionnaire will take less than 30 minutes to complete. Please respond to all questions with honesty, completeness and accuracy. You are free to withdraw from participating in this study at any time without penalty. All answers you give will be confidential. Please use the pen to complete the questionnaire.

Tick the box that corresponds to your answer and write clearly where required. For example:

What is your gender?

Female ☐

Male ☒

If your answer is male, then tick the box next to male with a pen as indicated above.

PART A: DISCLOSURE OF HIV STATUS TO CHILDREN

A1.	**In your view, is it necessary to disclose HIV status to Children living with HIV?**	
	Yes ☐	No ☐

A2.	**Have you ever disclosed HIV status to a child?**	
	Yes ☐	No ☐ (Go to Question B6)

A3.	**Did you discuss with the child, HIV related issues such as causes, transmission and treatment, prior to disclosure of HIV status?**	
	Yes ☐	No ☐

A4.	**Did you provide follow-up emotional support to the child after disclosure of HIV status?**	
	Yes ☐	No ☐

A5.	**How would you describe the disclosure process?**	
	Happened on one occasion only ☐	Happened on 5-6 occasions ☐
	Happened on 2-3 occasions ☐	Gradual process over 6 or more occasions ☐

A6.	**In your view, at what age should a child be disclosed his/her HIV status?**	
	Below 6 years ☐	above 13 years ☐
	6-12 years ☐	I don’t know ☐

A7.	**Who do you think is the best person to disclose HIV status to the child?**	
	Primary caregiver ☐	Teacher ☐
	Healthcare worker ☐	Church minister ☐
	Primary care giver and healthcare worker ☐	Community leaders ☐
	Other (please specify)…………………………………………………………………………………………	

A8.	**At this facility, how would you rate the proportion of HIV disclosure to children living with HIV?**	
	0%☐	26-35 per cent ☐
	5-10 %☐	36-45 per cent ☐
	11-15 per cent ☐	46-55 per cent ☐
	16-20 per cent ☐	Above 55 per cent ☐
	21-25 per cent ☐	
A9.	**Have you ever received in-service training on disclosure of HIV status to children?**	
	Yes ☐	No ☐

A10.	**The following statements are factors that are known to hinder some healthcare workers from disclosing HIV status to children. For each statement, please indicate at present time if you would strongly disagree, disagree, neither agree nor disagree, agree or strongly agree (*Please circle appropriate number).***					
		Strongly disagree	**disagree**	**Neither agree or disagree**	**Agree**	**Strongly agree**
	Inadequate knowledge on how to disclose HIV status to children	1	2	3	4	5
	Lack of a standard tool to use in disclosing HIV status to children	1	2	3	4	5
	Lack of training for healthcare workers on disclosure of HIV status to children	1	2	3	4	5
	Pressure of work	1	2	3	4	5
	Lack of cooperation between healthcare workers and primary guardians	1	2	3	4	5
	Unwillingness of the primary guardian to disclose	1	2	3	4	5
	Other (please specify) ………………………………………………………………………………………...					

A11. **We are planning to develop an HIV status disclosure resource that will be in form of books, developed according to children' emotional and physical maturity. The resource will use pictures, stories, and songs in Chichewa to convey HIV disclosure messages to children. For each statement, please indicate at present time if you would strongly disagree, disagree, neither agree nor disagree, agree or strongly agree (*Please circle appropriate number).***					
	Strongly disagree	**disagree**	**Neither agree or disagree**	**Agree**	**Strongly agree**
It is a good idea to develop such type of a resource	1	2	3	4	5
I will be able to use the resource to disclose HIV status to child	1	2	3	4	5
I will be able to use the resource in helping primary caregivers to disclose HIV status to children	1	2	3	4	5
The resource will help to improve my knowledge in HIV status disclosure to children	1	2	3	4	5
The resource will help to improve my confidence in HIV status disclosure to children	1	2	3	4	5
The resource will help to increase the rate of HIV disclosure to children living with HIV	1	2	3	4	5
The resource will help to reduce my worries on HIV status disclosure to children	1	2	3	4	5

PART B: ABOUT YOU

B1.	**What is your age range?**	
	21-25 years ☐	41 to 45 years ☐
	26-30 years ☐	46-50 years ☐
	31-35 years ☐	Over 50 years ☐
	36-40 years ☐	

B2.	**What is your gender?**	
	Male ☐	Female ☐

B3	**What is your professional status?**	
	Nurse technician ☐	Counsellor ☐
	Registered nurse ☐	Medical assistant ☐
	Clinical officer ☐	Physician ☐
	Health surveillance assistant ☐	
	Other (please specify)…………………………………………………………………………………	

B4.	**For how long have you worked in the antiretroviral therapy clinic?**	
	Less than 6 months ☐	4 to 5 years ☐
	6 months to one year ☐	More than 5 years ☐
	2 to 3 years ☐	

Is there anything you would like to add?

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End of questionnaire

Appendix H: Primary caregiver focus group discussion information sheet

Study Title: Psychosocial and health system factors in disclosure of HIV status to children living with HIV in Malawi: Needs assessment and formative evaluation of a disclosure resource.

Research Team: Fatch Kalembo, Dr Garth Kendall, Dr Mohammed Ali

My name is Fatch Kalembo, and as part of my university studies (PhD) with Curtin University in Western Australia, I am carrying out a study about how parents and guardians tell their children who are living with HIV about their HIV status.

The aims of the study are to understand the current situation on how children are told about their HIV status in Malawi and to make books for children, that can help them accept their illness, encourage them to take their medicine, and follow other important advice given by their doctor. We also hope that the books can guide parents and guardian on the best way to help children deal with problems in the community that appear because of their condition and respond to questions that children may have about their HIV status.

We would like to invite you to take part in a group discussion where, you will discuss knowledge, attitudes, and practices related to telling children that they have HIV; problems associated with telling children that they have HIV; and your views on the need for books to guide the way children are told about their HIV status. The discussion will take 45 minutes.

Before you agree to participate, it is important for you to understand that:

- **Participation is completely voluntary.** Your participation will in no way impact the quality and type of services you may be getting now or may get in the future from any of partners/agencies/organisations linked with this study. There will be no impact on treatment for you or your child if you choose not to participate or withdraw from the study
- **You can choose not to answer individual questions.** If you do not wish to answer any of the questions asked, you do not have to. You can speak with the interviewer about any fears or questions you may have.
- **You may choose to stop the interview at any time**. If you wish to stop the interview, you can do so at any time with no impact on the services you are using now or in the future from any partners/agencies/organisations linked with this study.
- **All information collected as part of this study will be kept confidential**. Only research assistants and the researcher will view the responses you have given. All responses will be kept strictly confidential and will not be shown to any other persons. We will not write down your name or personal information (such as addresses) when we report the results. All the information related to the study will be stored in a locked cabinet at Curtin University.

- The results of this research may be published or shared in international medical journals and in the form of a thesis. **Neither your name nor any personal information will be used in any published material.**

This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number HR 186/2014). The Committee is comprised of members of the public, academics, lawyers, doctors and pastoral carers. If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University, GPO Box U1987, Perth, 6845 or by telephoning +6189266 2784 or by emailing hrec@curtin.edu.au.

The research has also been approved by the Malawi National Health Sciences Research Committee (Approval Number xxxx.). If you have any ethical concerns related to this study, you are free to contact the Chairman, National Health Sciences Research Committee, Ministry of Health (Research Department, P.O. BOX, 30O377, Lilongwe 3, Malawi (Phone: +26 560 1726422) or the Secretary, Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University, GPO Box U1987, Perth, 6845 or by telephoning +6189266 2784 or by emailing hrec@curtin.edu.au.

Researcher: Fatch Kalembo

Email: kalembofatch@yahoo.com

Mobile contact: +265998260623.

Appendix I: Primary caregiver focus group consent form

Study Title: Psychosocial and health system factors in disclosure of HIV status to children living with HIV in Malawi: Needs assessment and formative evaluation of a disclosure resource.

Research Team: Fatch Kalembo, Dr Garth Kendall, Dr Mohammed Ali

I have been given clear written information and understand the intentions of this study.

I have taken the time to consider participation in this study.

I have had the opportunity to ask questions and had them answered to my satisfaction.

I understand that in the event of this work being published, as a participant, I will not be in any way identifiable.

I understand that I may choose to withdraw from the study at any time or not to participate without any impact on treatment for me and my child.

I am also aware that in the event of having any complaints regarding this study, I can contact the Chairman, National Health Sciences Research Committee, Ministry of Health (Research Department, P.O. BOX, 30O377, Lilongwe 3, Malawi (Phone: +26 560 1726422).

Participant Statement

I………………………………………………………………….. (Print full name)

Understand the intentions of the study and know that I have the opportunity to ask questions at any time.

I agree to complete a questionnaire and / or participate in an in-depth interview.

I understand that my participation in this study is voluntary and I can withdraw at any time without any consequences.

Signature/thumb print ………………………………………………… Participant

Signature ……………………………………………………... Researcher

Date ………………………………………………………

Appendix J: Primary caregiver focus group moderator guide

Introduction

My name is Fatch Kalembo and I’m conducting a research project with an aim of finding the best way of telling children living with HIV about their condition. The purpose of this discussion is to learn about your thoughts on how children living with HIV can be told about their condition.

This discussion will take 45 minutes.

Before we begin I would like to ask you to write your name and sign the consent form.

It is important that before you sign the consent form, you understand that: you are fully educated about the purpose of the study, the benefits and risks of the study, your right to have questions answered to your satisfaction, and your right to have you information protected and not shared with anyone.

I will now read through the information sheet that you have been given.

Read information sheet.

Do you have any questions? Please feel free to ask.

Answer questions.

It is my role to keep the discussion focused on the topic. I may need to move the conversation along so we can cover all the items and hear from everyone present here today. I will encourage you to express your point of view, while at the same time respecting the views of others. There are no right or wrong answers; just answer as honestly as you can.

Primary caregivers' focus group discussion questions

1. What are your thoughts about telling children that they have HIV?
   Importance?
2. In your family, who would make a decision to inform your child about his or her HIV status?
   - *2.1. Prompt: Father? Mother? Both father and mother? Other significant members of the family?*
3. How should children be informed of their HIV status?
   - *3.1. Prompt: Who should disclose?*
   - *3.2. Where should it take place?*
   - *3.3. Duration of disclosure?*

   Prompt: Who should tell the children? Place? Timing?
4. What kind of support would you need to help you inform your child of his or her HIV status?
   - *4.1. Prompt: Training? Healthcare worker's support? Family support? A book to guide the disclosure process?*
5. What do you think are some of the reasons that prevent primary caregivers from disclosing HIV status to their children?
   - *5.1. Prompt: Money? Stigma? Discrimination? Lack of support? Inadequate knowledge? Age of the child? Culture?*
6. What kind of support would you need to tell your child that she or he has HIV?
   - *6.1. Prompt: help from community? Healthcare workers? Help from family members? A book that can show you the way of telling your child that she or he has HIV?*
7. We are intending to make children's books that will be used by primary caregivers of children living with HIV, healthcare workers and teachers to tell children that they have HIV. The books will contain pictures, stories, and songs about what HIV is and how it can affect people's lives. The books will be in Chichewa and will have information for primary caregivers, healthcare workers and teachers on how to use the books. What do you think about this idea?
   - *7.1. Prompt: Need? Acceptability? Usage?*
8. What issues would you want to be included in the children's books?
9. Is there anything you would like to add?

This brings the questions to an end. Thank you very much for you participation in the focus group discussion. Your views are very much appreciated.

Appendix K: Teachers focus group information sheet

Curtin University

Study Title: Psychosocial and health system factors in disclosure of HIV status to children living with HIV in Malawi: Needs assessment and formative evaluation of a disclosure resource.

Research Team: Fatch Kalembo, Dr Garth Kendall, Dr Mohammed Ali

My name is Fatch Kalembo, and as part of my university studies (PhD) with Curtin University in Western Australia, I am carrying out a study about how parents and guardians tell their children who are living with HIV about their HIV status.

The aims of the study are to understand the current situation on how children are told about their HIV status in Malawi and to make books for children, that can help them accept their illness, encourage them to take their medicine, and follow other important advice given by their doctor. We also hope that the books can guide parents, guardians, teachers, health workers and community leaders on the best way to help children deal with problems in the community that appear because of their condition, and respond to questions that children may have about their HIV status.

We would like to invite you to take part in the study, where you will be asked to have a group discussion on your knowledge, attitudes, and practices about telling children that they have HIV; problems associated with telling children that they have HIV; and your views on the need for books to guide the way children are told about their illness.

The group discussion will take 45 minutes.

Before you agree to participate, it is important for you to understand that:

- **Participation is completely voluntary.** Your participation will in no way impact the quality and type of services you may be getting now or may get in the future from any partners/agencies/organisations linked with this study.
- **You can choose not to answer individual questions.** If you do not wish to answer any of the questions asked, you do not have to. You can speak with the interviewer about any fears or questions you may have.
- **You may choose to stop the interview at any time**. If you wish to stop the interview, you can do so at any time with no impact on the services you are using now or in the future from any partners/agencies/organisations linked with this study.
- **All information collected as part of this study will be kept confidential**. Only research assistants and the researcher will view the responses you have given. All responses will be kept strictly confidential and will not be shown to any other persons. We will not write down your name or personal information (such as addresses) when we report the results. All the information related to the study will be stored in a locked cabinet at Curtin University.
- The results of this research may be published or shared in international medical journals and in the form of a thesis. **Neither your name nor any personal information will be used in any published material**.

This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number HR 186/2014). The Committee is comprised of members of the public, academics, lawyers, doctors and pastoral carers. If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University, GPO Box U1987, Perth, 6845 or by telephoning +6189266 2784 or by emailing hrec@curtin.edu.au.

The research has also been approved by the Malawi National Health Sciences Research Committee (Approval Number xxxx.). If you have any ethical concerns related to this study, you are free to contact the Chairman, National Health Sciences Research Committee, Ministry of Health (Research Department, P.O. BOX, 30O377, Lilongwe 3, Malawi (Phone: +26 560 1726422) or the Secretary, Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University, GPO Box U1987, Perth, 6845 or by telephoning +6189266 2784 or by emailing hrec@curtin.edu.au.

If you have questions or if you need clarifications related to the research, feel free to contact the researcher by phone or email.

Researcher: Fatch Kalembo

Email: kalembofatch@yahoo.com

Mobile contact: +265998260623.

Appendix L: Teachers focus group consent form

Study Title: Psychosocial and health system factors in disclosure of HIV status to affected children in Malawi: Needs assessment and formative evaluation of a disclosure resource.

Research Team: Fatch Kalembo, Dr Garth Kendall, Dr Mohammed Ali

I have been given clear written information and understand the intentions of this study.

I have taken the time to consider participation in this study.

I have had the opportunity to ask questions and had them answered to my satisfaction.

I understand that in the event of this work being published, as a participant, I will not be in any way identifiable.

I understand I may withdraw from the study at any time without any penalty.

I am also aware that in the event of having any complaints regarding this study, I can contact the Chairman, National Health Sciences Research Committee, Ministry of Health (Research Department, P.O. BOX, 30O377, Lilongwe 3, Malawi (Phone: +26 560 1726422).

Participant Statement

I………………………………………………………………….. (Print full name)

Understand the intentions of the study and know that I have the opportunity to ask questions at any time.

I agree to complete a questionnaire and / or participate in an in-depth interview.

I understand that my participation in this study is voluntary and I can withdraw at any time without any consequences.

Signature ……………………………………………………… Participant

Signature …………………………………………………….... Researcher

Date ………………………………………………………

Appendix M: Teachers focus group moderator guide

Introduction

My name is Fatch Kalembo and I'm conducting a research with an aim of finding the best way of telling children living with HIV about their condition. The purpose of this discussion is to learn about your thoughts on how children living with HIV can be told about their condition.

This discussion will take 45 minutes.

Before we begin I would like to ask you to write your name and sign the consent form. It is important that before you sign the consent form, you understand that: you are fully educated about the purpose of the study, the benefits and risks of the study, your right to have questions answered to your satisfaction, and your right to have you information protected and not shared with anyone.

I will now read through the information sheet that you have been given. *Read information sheet.* Do you have any questions? Please feel free to ask, no questions are silly. *Answer questions.*

It is my role to keep the discussion focused on the topic. I may need to move the conversation along so we can cover all the items and hear from everyone present here today. I will encourage you to express your point of view, while at the same time respecting the views of others.

I would like to assure you that the information that you will provide will be confidential. No names will be attached to any report or publications. There are no right or wrong answers; just answer as honestly as you can.   If you do not wish to sign the consent form, you are free to withdraw from the group before the discussion begins. If anyone is feeling uncomfortable with anything that we talk about at any time please feel free to leave or sit quietly and not comment.

Focus group discussion interview guide questions for teachers

1. From your experience, what are some of the problems faced by children living with HIV at school?
    1.1. Prompt: Absenteeism due to illness? Poor academic performance? Lack of concentration in class? Trouble in making friends? Rejection? Bullying?
2. What kind of support do you provide to pupils living with HIV?
    2.1. *Prompt: Counselling? Arranging extra classes? Discouraging stigma and bullying?*
3. What are your thoughts regarding telling children that they have HIV?
    3.1. Prompt: Importance? Timing? Appropriate age?
4. What are your thoughts regarding the involvement of teachers in informing children about their HIV status?
    4.1. Prompt: Importance?
5. How can teachers be prepared for for the role of telling children that they have HIV?
    5.1. Prompt: Training? Provision of a disclosure process guideline book?
6. We are intending to make children's books that will be used by primary caregivers of children living with HIV, healthcare workers and teachers to tell children that they have HIV. The books will contain pictures, stories, and songs about what HIV is and how it can affect people's lives. The books will be in Chichewa and will have information for primary caregivers, healthcare workers and teachers on how to use the books. What do you think about this idea?
    6.1. Prompt: Need? Acceptability? Usage?
7. What issues would you want to be included in the children's books?
8. Is there anything you would like to add?

This brings the questions to an end.

Thank you very much for you participation in the in-depth interviews. Your views are very much appreciated

Appendix N: Healthcare worker interviews information sheet

Curtin University

Study Title: Psychosocial and health system factors in disclosure of HIV status to children living with HIV in Malawi: Needs assessment and formative evaluation of a disclosure resource.

Research Team: Fatch Kalembo, Dr Garth Kendall, Dr Mohammed Ali

My name is Fatch Kalembo, and as part of my university studies (PhD) with Curtin University in Western Australia, I am carrying out a study about how parents and guardians tell their children who are living with HIV about their HIV status.

The aims of the study are to understand the current situation on how children are told about their HIV status in Malawi and to make books for children, that can help them accept their illness, encourage them to take their medicine, and follow other important advice given by their doctor. We also hope that the books can guide health workers, teachers, community leaders, parents and guardians on the best way to help children deal with problems in the community that appear because of their condition, and respond to questions that children may have about their HIV status.

We would like to invite you to take part in the interview. As a participant you will be asked to answer questions about your knowledge, attitudes, and practices about telling children that they have HIV; problems associated with telling children that they have HIV; and your views on the need for books to guide the way children are told about their illness. This interview will take 45 minutes.

Before you agree to participate, it is important for you to understand that:

- **Participation is completely voluntary.** Your participation will in no way impact the quality and type of services you may be getting now or may get in the future from any partners/agencies/organisations linked with this study.
- **You can choose not to answer individual questions.** If you do not wish to answer any of the questions asked, you do not have to.
- **You may choose to stop the interview at any time**. If you wish to stop the interview, you can do so at any time with no impact on the services you are using now or in the future from any partners/agencies/organisations linked with this study.
- **All information collected as part of this study will be kept confidential**. Only research assistants and the researcher will view the responses you have given. All responses will be kept strictly confidential and will not be shown to any other persons. We will not write down your name or personal information (such as addresses) when we report the results. All the information related to the study will be stored in a locked cabinet at Curtin University.
- The results of this research may be published or shared in international medical journals and in the form of a thesis. **Neither your name nor any personal information will be used in any published material.**

This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number HR 186/2014). The Committee is comprised of members of the public, academics, lawyers, doctors and pastoral carers. If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University, GPO Box U1987, Perth, 6845 or by telephoning +6189266 2784 or by emailing hrec@curtin.edu.au.

The research has also been approved by the Malawi National Health Sciences Research Committee (Approval Number xxxx.). If you have any ethical concerns related to this study, you are free to contact the Chairman, National Health Sciences Research Committee, Ministry of Health (Research Department, P.O. BOX, 30O377, Lilongwe 3, Malawi (Phone: +26 560 1726422) or the Secretary, Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University, GPO Box U1987, Perth, 6845 or by telephoning +6189266 2784 or by emailing hrec@curtin.edu.au If you have questions or if you need clarifications related to the research, feel free to contact the researcher by phone or email.

Researcher: Fatch Kalembo

Email: kalembofatch@yahoo.com

Mobile contact: + 265998260623

Appendix O: Healthcare worker interviews consent form

Curtin University

Study Title: Psychosocial and health system factors in disclosure of HIV status to children living with HIV in Malawi: Needs assessment and formative evaluation of a disclosure resource.

Research Team: Fatch Kalembo, Dr Garth Kendall, Dr Mohammed Ali

I have been given clear written information and understand the intentions of this study.

I have taken the time to consider participation in this study.

I have had the opportunity to ask questions and had them answered to my satisfaction.

I understand that in the event of this work being published, as a participant, I will not be in any way identifiable.

I understand I may withdraw from the study at any time without any penalty.

I am also aware that in the event of having any complaints regarding this study, I can contact the Chairman, National Health Sciences Research Committee, Ministry of Health (Research Department, P.O. BOX, 30O377, Lilongwe 3, Malawi (Phone: +26 560 1726422).

Participant Statement

I……………………………………………………………….. (Print full name)

Understand the intentions of the study and know that I have the opportunity to ask questions at any time.

I agree to complete a questionnaire and / or participate in an in-depth interview.

I understand that my participation in this study is voluntary and I can withdraw at any time without any consequences.

Signature ……………………………………………………… Participant

Signature ………………………………………………………. Researcher

Date ………………………………………………………

Appendix P: Healthcare worker interviews moderator guide

Introduction

My name is Fatch Kalembo and I'm conducting a research project with an aim of finding the best way of telling children living with HIV about their condition. The purpose of this interview is to learn about your thoughts on how children living with HIV can be told about their condition.

This interview will take 45 minutes.

Before we begin I would like to ask you to write your name and sign the consent form. It is important that before you sign the consent form, you understand that: you are fully educated about the purpose of the study, the benefits and risks of the study, your right to have questions answered to your satisfaction, and your right to have you information protected and not shared with anyone.

I will now read through the information sheet that you have been given. *Read information sheet.* Do you have any questions? Please feel free to ask. *Answer questions.*

It is my role to keep the discussion interview focussed on the topic. I may need to move the conversation along, so we can cover all the items. I will encourage you to express your point of view.

I would like to assure you that the information that you will provide will be confidential. No name will be attached to any report or publications. There are no right or wrong answers; just answer as honestly as you can.   If you do not wish to sign the consent form, you are free to withdraw from the interview now. If you are feeling uncomfortable with anything that we talk about at any time, please feel free to ask me to suspend our discussion.

Healthcare worker in-depth interview questions

1. What does disclosure of HIV status mean to you?
    1.1. *Prompt: The World health organisation and the Ministry of Health in Malawi recommend that children living with HIV should be completely told that they have HIV when they are within the ages of 6 to 12. What are your thoughts on this?*
2. What are your thoughts on how children living with HIV should be told about their condition?
    2.1. *Prompt: Who should disclose? How? When? Where?*
3. What kind of support should be given to a child undergoing the process of being told that she or he has HIV?
    3.1. *Prompt: counselling? Family support? Community support? Education support? Medical support?*
4. From your experience what do you think are some of the challenges to disclosure of HIV status to children?
    4.1. *Prompt: Pressure of work? Lack of training? Lack of guiding tool? Lack of support from primary guardians?*
5. From your experience what do you think are some of the facilitators of disclosure of HIV status to children?
    5.1. *Prompt: Adequate staffing? Training? Availability of disclosure materials? Cooperation from primary guardians?*
6. We are intending to make children’s books that will be used by primary caregivers of children living with HIV, healthcare workers and teachers to tell children that they have HIV. The books will contain pictures, stories, and songs about what HIV is and how it can affect people’s lives. The books will be in Chichewa and will have information for primary caregivers, healthcare workers and teachers on how to use the books. What do you think about this idea?
    6.1. *Prompt: Need? Acceptability? Usage?*
7. What issues would you want to be included in the children’s books?
8. Is there anything you would like to add?

This brings the questions to an end.

Thank you very much for your participation in the interview. Your participation is very much appreciated.

Appendix Q: Community leader's interviews information sheet

Curtin University

Study Title: Psychosocial and health system factors in disclosure of HIV status to children living with HIV in Malawi: Needs assessment and formative evaluation of a disclosure resource.

Research Team: Fatch Kalembo, Dr Garth Kendall, Dr Mohammed Ali

My name is Fatch Kalembo, and as part of my university studies (PhD) with Curtin University in Western Australia, I am carrying out a study about how parents and guardians tell their children who are living with HIV about their HIV status.

The aims of the study are to understand the current situation on how children are told about their HIV status in Malawi and to make books for children, that can help them accept their illness, encourage them to take their medicine, and follow other important advice given by their doctor. We also hope that the books can guide health workers, teachers, community leaders, parents and guardians on the best way to help children deal with problems in the community that appear because of their condition, and respond to questions that children may have about their HIV status.

We would like to invite you to take part in an interview. As participants you will be asked to answer questions about your knowledge, attitudes, and practices about telling children that they have HIV; problems associated with telling children that they have HIV; and your views on the need for books to guide the way children are told about their illness. This interview will take 45 minutes.

Before you agree to participate, it is important for you understand that:

- **Participation is completely voluntary**. Your participation will in no way impact the quality and type of services you may be getting now or may get in the future from any partners/agencies/organisations linked with this study.
- **You can choose not to answer individual questions**. If you do not wish to answer any of the questions asked, you do not have to.
- **You may choose to stop the interview at any time**. If you wish to stop the interview, you can do so at any time with no impact on the services you are using now or in the future from any partners/agencies/organisations linked with this study.
- **All information collected as part of this study will be kept confidential**. Only research assistants and the researcher will view the responses you have given. All responses will be kept strictly confidential and will not be shown to any other persons. We will not write down your name or personal information (such as addresses) when we report the results. All the information related to the study will be stored in a locked cabinet at Curtin University.

The results of this research may be published or shared in international medical journals and in the form of a thesis. **Neither your name nor any personal information will be used in any published material**.

This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number HR 186/2014). The Committee is comprised of *members of the public, academics, lawyers, doctors and pastoral carers. If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University, GPO Box U1987, Perth, 6845 or by telephoning +6189266 2784 or by emailing hrec@curtin.edu.au.*

The research has also been approved by the Malawi National Health Sciences Research Committee (Approval Number xxxx.). If you have any ethical concerns related to this study, you are free to contact the Chairman, National Health Sciences Research Committee, Ministry of Health (Research Department, P.O. BOX, 30O377, Lilongwe 3, Malawi (Phone: +26 560 1726422) or the Secretary, Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University, GPO Box U1987, Perth, 6845 or by telephoning +6189266 2784 or by emailing hrec@curtin.edu.au If you have questions or if you need clarifications related to the research, feel free to contact the researcher by phone or email.

Researcher: Fatch Kalembo

Email: kalembofatch@yahoo.com

Mobile contact: + 265998260623

Appendix R: Community leader’s interviews consent form

Study Title: Psychosocial and health system factors in disclosure of HIV status to children living with HIV in Malawi: Needs assessment and formative evaluation of a disclosure resource.

Research Team: Fatch Kalembo, Dr Garth Kendall, Dr Mohammed Ali

I have been given clear written information and understand the intentions of this study.

I have taken the time to consider participation in this study.

I have had the opportunity to ask questions and had them answered to my satisfaction.

I understand that in the event of this work being published, as a participant, I will not be in any way identifiable.

I understand I may withdraw from the study at any time without any penalty.

I am also aware that in the event of having any complaints regarding this study, I can contact the Chairman, National Health Sciences Research Committee, Ministry of Health (Research Department, P.O. BOX, 30O377, Lilongwe 3, Malawi (Phone: +26 560 1726422).

Participant Statement

I……………………………………………………………….. (Print full name)

Understand the intentions of the study and know that I have the opportunity to ask questions at any time.

I agree to complete a questionnaire and / or participate in an in-depth interview.

I understand that my participation in this study is voluntary and I can withdraw at any time without any consequences.

Signature/thumb print ……………………………………………………Participant

Signature ……………………………………………………. Researcher

Date ……………………………………………………

Appendix S: Community leader’s interviews moderator guide

Introduction

My name is Fatch Kalembo and I’m conducting a research with an aim of finding the best way of telling children living with HIV about their condition. The purpose of this interview is to learn about your thoughts on how children living with HIV can be told about their condition.

This interview will take 45 minutes.

Before we begin I would like to ask you to write your name and sign the consent form. It is important that before you sign the consent form, you understand that: you are fully educated about the purpose of the study, the benefits and risks of the study, your right to have questions answered to your satisfaction, and your right to have you information protected and not shared with anyone.

I will now read through the information sheet that you have been given. *Read information sheet.* Do you have any questions? Please feel free to ask, no questions are silly. *Answer questions.*

It is my role to keep the interview focused on the topic. I may need to move the conversation along so we can cover all the items. I will encourage you to express your point of view.

I would like to assure you that the information that you will provide will be confidential. No name will be attached to any report or publications. There are no right or wrong answers; just answer as honestly as you can. If you do not wish to sign the consent form, you are free to withdraw from the interview now. If you are feeling uncomfortable with anything that we talk about at any time please feel free to ask me to suspend our discussion.

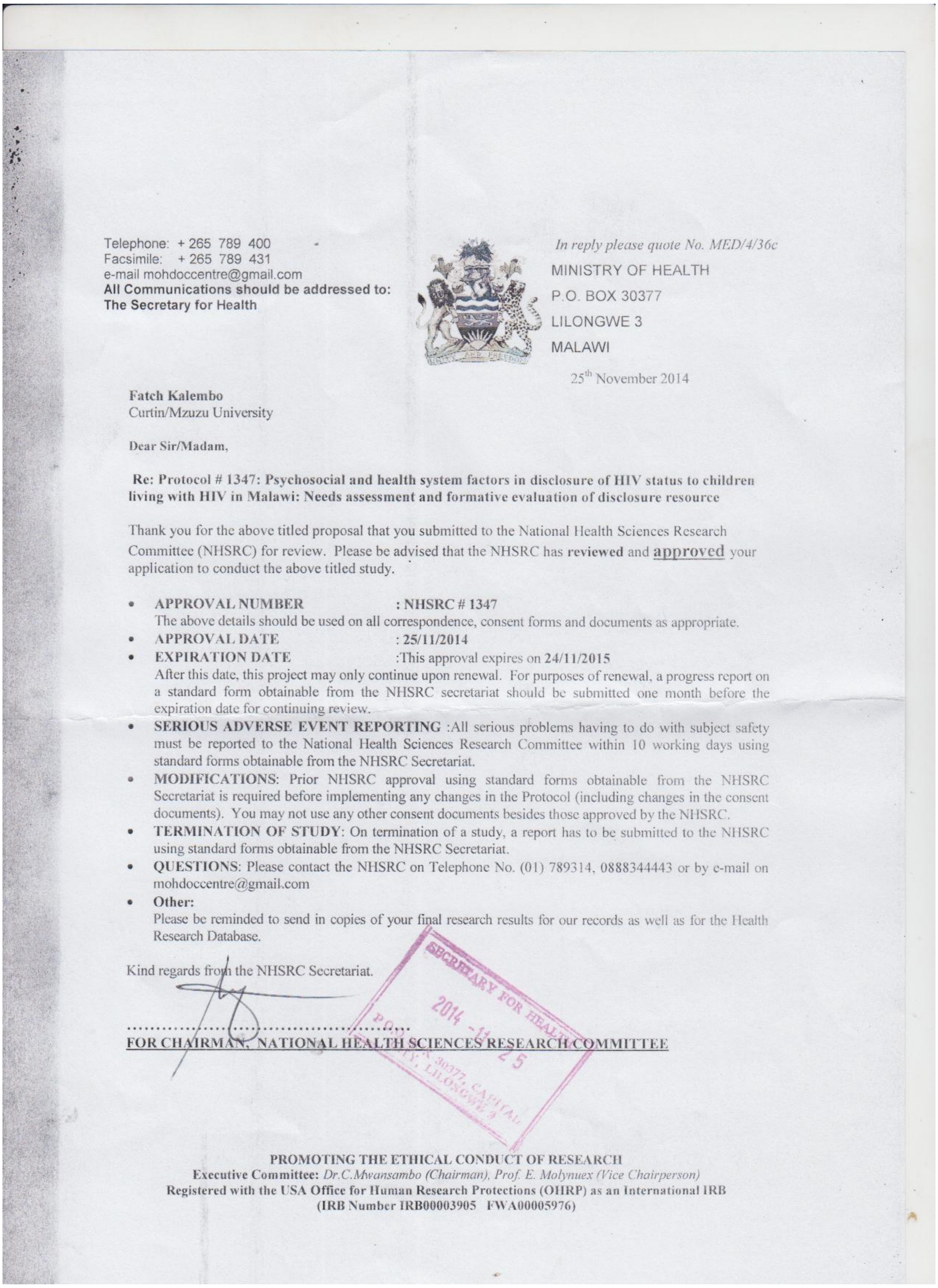
In-depth interviews for community leaders

1. What do you think are some of the problems faced by children living with HIV in the community??
    a. *Prompt: Stigma and discrimination?*
2. What are your thoughts about telling children that they have HIV?
    a. *Prompt: The Government of Malawi recommend telling children living with HIV about their condition within the ages of 6 to 12. What are your thoughts on this? Importance*
3. What are your thoughts regarding involvement of community leaders in telling children that they have HIV?
    a. *Prompt: Importance?*
4. How can community leaders promote disclosure of HIV status to children?
    a. *Prompt: Public meetings? Discouragement of stigma and discrimination?*
5. We are intending to make children's books that will be used by primary caregivers of children living with HIV, healthcare workers and teachers to tell children that they have HIV. The books will contain pictures, stories, and songs about what HIV is and how it can affect people's lives. The books will be in Chichewa and will have information for primary caregivers, healthcare workers and teachers on how to use the books. What do you think about this idea?
    a. *Prompt: Need? Acceptability? Importance?*
6. What issues would you want to be included in the children's books?
7. Is there anything you would like to add?

This brings the questions to an end.

Thank you very much for you participation in the interviews. Your views are very much appreciated.

Appendix T: Malawi National Health Science Research Committee approval letter



Telephone: + 265 789 400
Facsimile: + 265 789 431
e-mail mohdoccentre@gmail.com
All Communications should be addressed to:
The Secretary for Health

In reply please quote No. MED/4/36c
MINISTRY OF HEALTH
P.O. BOX 30377
LILONGWE 3
MALAWI

25th November 2014

Fatch Kalembo
Curtin/Mzuzu University

Dear Sir/Madam,

Re: Protocol # 1347: Psychosocial and health system factors in disclosure of HIV status to children living with HIV in Malawi: Needs assessment and formative evaluation of disclosure resource

Thank you for the above titled proposal that you submitted to the National Health Sciences Research Committee (NHSRC) for review. Please be advised that the NHSRC has **reviewed** and **approved** your application to conduct the above titled study.

- **APPROVAL NUMBER** : **NHSRC # 1347**
  The above details should be used on all correspondence, consent forms and documents as appropriate.
- **APPROVAL DATE** : **25/11/2014**
- **EXPIRATION DATE** :This approval expires on **24/11/2015**
  After this date, this project may only continue upon renewal. For purposes of renewal, a progress report on a standard form obtainable from the NHSRC secretariat should be submitted one month before the expiration date for continuing review.
- **SERIOUS ADVERSE EVENT REPORTING** :All serious problems having to do with subject safety must be reported to the National Health Sciences Research Committee within 10 working days using standard forms obtainable from the NHSRC Secretariat.
- **MODIFICATIONS**: Prior NHSRC approval using standard forms obtainable from the NHSRC Secretariat is required before implementing any changes in the Protocol (including changes in the consent documents). You may not use any other consent documents besides those approved by the NHSRC.
- **TERMINATION OF STUDY**: On termination of a study, a report has to be submitted to the NHSRC using standard forms obtainable from the NHSRC Secretariat.
- **QUESTIONS**: Please contact the NHSRC on Telephone No. (01) 789314, 0888344443 or by e-mail on mohdoccentre@gmail.com
- **Other:**
  Please be reminded to send in copies of your final research results for our records as well as for the Health Research Database.

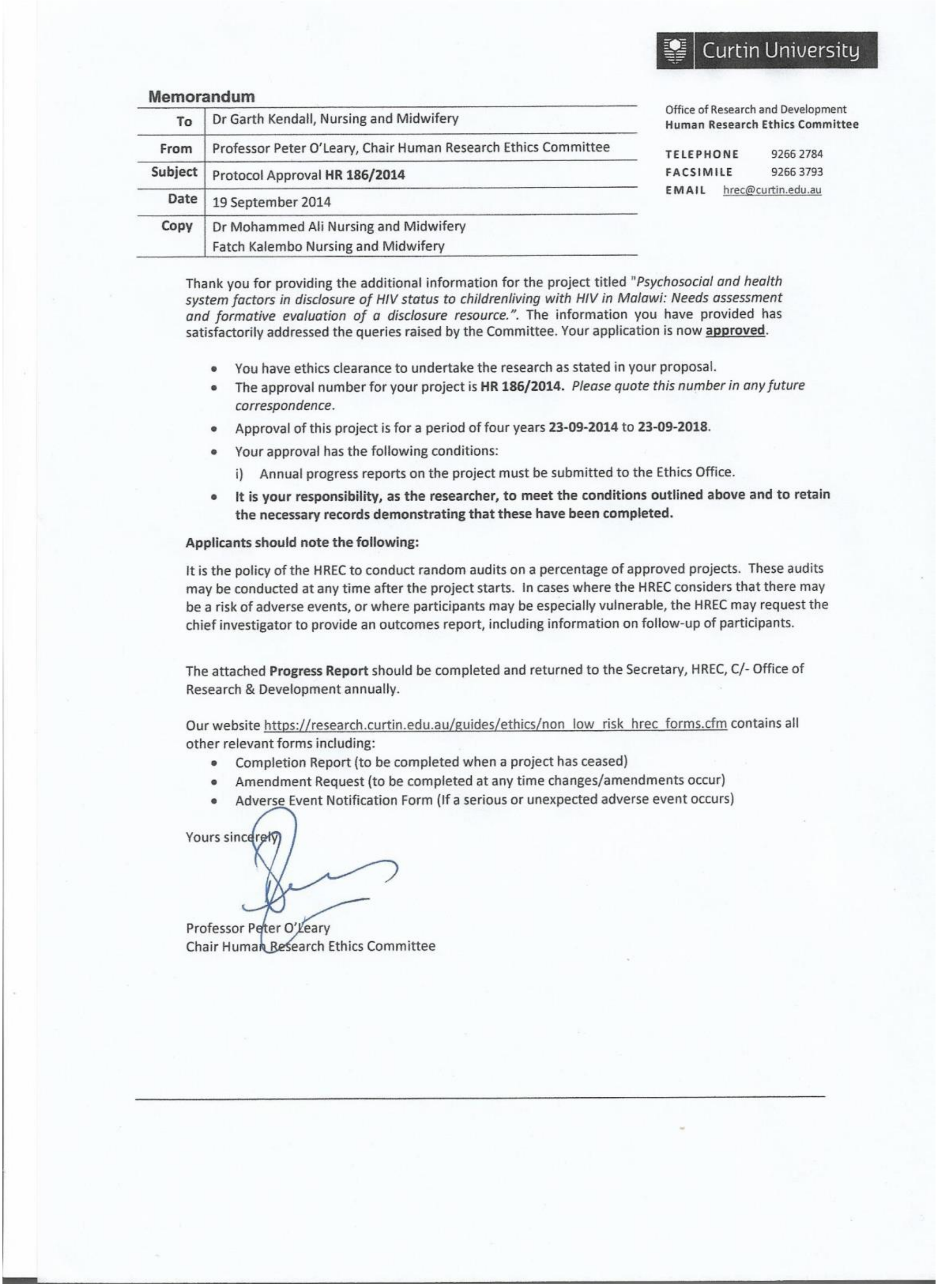
Kind regards from the NHSRC Secretariat.

……………………………………………………
FOR CHAIRMAN, NATIONAL HEALTH SCIENCES RESEARCH COMMITTEE

SECRETARY FOR HEALTH
2014 -11- 25
P.O. 30377, CAPITAL
LILONGWE 3

PROMOTING THE ETHICAL CONDUCT OF RESEARCH
Executive Committee: *Dr.C.Mwansambo (Chairman), Prof. E. Molynuex (Vice Chairperson)*
Registered with the USA Office for Human Research Protections (OHRP) as an International IRB
(IRB Number IRB00003905 FWA00005976)

Appendix U: Curtin Human Research Ethics Committee approval letter



Curtin University

Memorandum

To	Dr Garth Kendall, Nursing and Midwifery
From	Professor Peter O'Leary, Chair Human Research Ethics Committee
Subject	Protocol Approval **HR 186/2014**
Date	19 September 2014
Copy	Dr Mohammed Ali Nursing and Midwifery Fatch Kalembo Nursing and Midwifery

Office of Research and Development
Human Research Ethics Committee

TELEPHONE 9266 2784
FACSIMILE 9266 3793
EMAIL hrec@curtin.edu.au

Thank you for providing the additional information for the project titled "*Psychosocial and health system factors in disclosure of HIV status to childrenliving with HIV in Malawi: Needs assessment and formative evaluation of a disclosure resource.*". The information you have provided has satisfactorily addressed the queries raised by the Committee. Your application is now **approved**.

- You have ethics clearance to undertake the research as stated in your proposal.
- The approval number for your project is **HR 186/2014.** *Please quote this number in any future correspondence.*
- Approval of this project is for a period of four years **23-09-2014** to **23-09-2018**.
- Your approval has the following conditions:
  i) Annual progress reports on the project must be submitted to the Ethics Office.
- **It is your responsibility, as the researcher, to meet the conditions outlined above and to retain the necessary records demonstrating that these have been completed.**

Applicants should note the following:

It is the policy of the HREC to conduct random audits on a percentage of approved projects. These audits may be conducted at any time after the project starts. In cases where the HREC considers that there may be a risk of adverse events, or where participants may be especially vulnerable, the HREC may request the chief investigator to provide an outcomes report, including information on follow-up of participants.

The attached **Progress Report** should be completed and returned to the Secretary, HREC, C/- Office of Research & Development annually.

Our website https://research.curtin.edu.au/guides/ethics/non_low_risk_hrec_forms.cfm contains all other relevant forms including:

- Completion Report (to be completed when a project has ceased)
- Amendment Request (to be completed at any time changes/amendments occur)
- Adverse Event Notification Form (If a serious or unexpected adverse event occurs)

Yours sincerely

Professor Peter O'Leary
Chair Human Research Ethics Committee

APPENDIX V: Translated questionnaires, information sheet, consent form and interview guide for primary caregivers

Translated appendix B

FOMU YOLONGOSOLA ZA KAFUKUFUKU KWA MAKOLO KAPENA YEMWE AKUSAMALIRA MWANA

Mutu wa kafukufuku: kufufuza mmene kaganizidwe, chikhalidwe ndi ndondomeko yakaperekedwe kachithandizo chazaumoyo zimagwirizirana ndikufotokozera ana omwe ali ndi kachilombo ka HIV za momwe mthupi mwawo mulili m'dziko la Malawi: Njira yowunikira ndi kufufuza za kufunika kokhala ndi mabuku owunikira ndondomeko yofotokozelera ana kuti ali ndi kachilombo ka HIV.

Anthu woyendetsa (ochita) kafukufuku: Fatch Kalembo, Dr Garth Kendall, Dr Mohammed Ali

Dzina langa ndine Fatch Kalembo wophunzira za udotolo pa sukulu ya ukachenjede ya Curtin ku Australia. Ngati gawo la maphunziro anga, ndikupanga kafukufuku yemwe zolinga zake ndi kuwunika momwe ana amafotokozeredwa kuti ali ndi kachilombo kayambitsa matenda a Edzi, komanso kulemba mabuku omwe adzawunikire makolo momwe angafotokozere ana awo za momwe mthupi mwawo mulili. Mukupemphedwa kuti mutengepo mbali mukafukufukuyu. Mabukuwa akhala olembedwa poganizira msinkhu wa mwana komanso chikhalidwe chanu. Kafukufukuyi athandiza ana omwe ali ndi kachilombo ka HIV kuti azitha kumvetsa bwino za momwe alili komanso kuti azikhala ndi chidwi chosata ndondomeko yakamwedwe ka mankhwala wochepetsa tizilombo ta HIV.

Ngati mmodzi mwa anthu wotenganawo mbali mukafufukuyu, mudzafunsidwa za maganizo and komanso machitidwe anu pankhani yokhudza kufotokozera ana omwe ali ndi kachilombo ka HIV momwe mthupi mwawo mulili. Mufunsidwanso za maganizo anu pa nkhani yakufunika kwakukhala ndi mabuku owunikira makolo kapena omwe amasamalira anawa mmene angawafotokozere anawa zamatenda awo. Mafunso akafukufukuyi atenga mphindi zapakati pa 30 ndi 45 kuti ayankhidwe.

Ndi kofunika kuti musanavomereze kutenga nawo mbali mukafukufukuyi, muyenera kudziwa izi:

- **Dziwani kuti kulowa mukafukufukuyi ndi kosakakamiza:** Kutenga nawo mbali mukafukufukuyi sikukugwirizana munjira iliyonse ndi chithandizo chomwe mumalandira kuchipatala. Mutha kusatenga nawo mbali kapena kutuluka mukafukufukuyi nthawi iliyonse yomwe mwafuna popanda kulandira chilango chilichonse monga kusapatsidwa mankhwala anu kapena a mwana wanu.
- **Muli ndi ufulu woyankha mafunso omwe mukufuna:** Ngati simukufuna kuyakha mafunso ena muli ndi ufulu kutero. Mutha kukambirana ndi woyendetsa kafukufuku za nkhawa kapena mafunso ena aliwonse womwe mungakhale nawo.
- **Zonse zomwe mutatiwuze zikhala zachinsinsi:** okhawo oyendetsa kafukufukuyi ndiwo atakhale ndi chilolezo chowona zomwe mwanena

mukafukufukuyi. Mayankho anu onse asungidwa mwachinsinsi ndipo sazaperekedwa kwa aliyense. Sitizalemba dzina lanu powulutsa zotsatira zakafukufukuyi. Mukafukufukuyi tigwiritsa ntchito nambala m'malo mwa dzina lanu ndicholinga chofuna kukusungirani chinsisi Zonse zokhuza kafukufukuyi zikasungidwa bwino ku sukulu ya ukachanjede ya Curtin.

- Ngati mbali ina iliyonse yakafukufukuyi yingasindikizidwe, tizayesesa kuteteza kuti musazindikiridwe munjira ina iliyonse.

Kafukufukuyi ndiwovomerezeka ndi bungwe lowona za ndondomeko ya kafukufuku la yunivesite ya Curtin (Chiphatso chachilolezo HR 186/2014). Mu gulu la ndondomeko yakafukufukuyi muli akatswiri a zamaphunziro, malamulo, madotolo komanso akuluakulu a mipingo. Ngati mukufuna kufunsa zambiri zokhudza chilolezo cha kafukufukuyi mutha kulemba kalata ku adilesi iyi: Curtin University Human Research Ethics Committee, Office of Research and Development, Curtin University, GPO Box U1987, Perth, 6845 kapena mutha kutchaya lamya pa nambala iyi +6189266 2784 munthanso kulemba imelo ku adilesi iyi hrec@curtin.edu.au

Kafukufukuyi ngovomerezekanso ndi bungwe lowona za ndondomeko yakafukufuku mu unduna wa za umoyo ku Malawi. Ngati muli ndi nkhawa yiliyonse yokhuza kafukufukuyi, chonde yankhulani ndi oyang'anira za ndondomeko ya kafukufuku ku unduna wazaumoyo pa adilesi iyi: Chairman, National Health Sciences Research Committee, Ministry of Health (Research Department, P.O. BOX, 300377, Lilongwe 3, Malawi (kapena yimbani lamya pa nambala iyi: +26 560 1726422).

Ngati muli ndi funso kapena kufuna kudziwa zambiri za kafukufukuyi, khalani omasuka kuyankhulana ndi omwe akuyang'anira kufukufukuyi pogwiritsa ntchito zina ndi nambala ya lamya yili musimu. Oyang'anira kafukufuku: Fatch Kalembo Email: kalembofatch@yahoo.com Nambala ya lamya: +265998260623.

Translated Appendix C

Malo a kafukufuku **Nambala ya wopanga kafukufuku …………**

FOMU YOPEMPHA CHILOLEZO KUCHOKERA KWA MAKOLO KAPENA OMWE AKUSAMALIRA ANA OMWE ALI NDI KACHILOMBO KA HIV KUTI ATENGE NAWO MBALI MUKAFUKUFUKU

Mutu wakafukufuku: Kufufuza mmene kaganizidwe, chikhalidwe ndi ndondomeko yakaperekedwe kachithandizo chazaumoyo zimagwirizirana ndikufotokozera ana omwe ali ndi kachilombo ka HIV za momwe mthupi mwawo mulili m'dziko la Malawi: Njira yowunikira ndi kufufuza za kufunika kokhala ndi mabuku owunikira ndondomeko yofotokozelera ana kuti ali ndi kachilombo ka HIV.

Anthu woyendetsa (ochita) kafukufuku: Fatch Kalembo, Dr Garth Kendall, Dr Mohammed Ali

Ndapatsidwa ndondomeko yolongosola bwinobwino za kafukufuku ndipo ndikumvetsa zolinga zakafukufukuyi.

Ndapatsidwa nthawi yolingalira zotenga nawo mbali mukafukufukuyi

Ndinapatsidwa mwayi ofunsa zambiri zakafukufukuyi ndipo ndakhutitsidwa ndi mayankho ake

Ndipo ndikumvetsa kuti ngati kafukufukuyi angasindikizidwe mumabuku kapena munjira iliyonseyo, sindizazindikiridwa munjira ili yonse.

Ndikumvetsa kuti nditha kusiya kutenga mbali mukafukufukuyi nthawi ina iliyonse popanda kupatsidwa chilango chokhuza ine kapena mwana wanga.

Ndikuziwa kuti ngati ndingakhale ndi madandaulo nditha kuuza oyanganira zakafukufuku mu unduna wa zaumoyo motere: National Health Sciences Research Committee, Ministry of Health (Research Department, P.O. BOX, 30O377, Lilongwe 3, Malawi (Phone: +26 560 1726422).

Mau a wotenga mbali mkafukufuku

Ine………………………………………………………….. (Lembani dzina lonse)

Ndikumvetsa za zolinga za kafukufukuyi ndipo ndikumvetsa kuti ndiri ndi mwayi wofunsa mafunso nthawi inaliyonse.
Ndikuvomera kuyankha mafunso akafukufukuyi
Ndikumvetsa kuti kutenga nawo mbali kwanga mukafukufukuyi ndikochita kufuna mosakakamizidwa ndipo nditha kusiya kutenga mbali mukafukufukuyi nthawi ili yonse yomwe ndafuna popanda chilango chili chonse.

Sayini/chidindo cha chala ……………………………wotenga mbali mukafukufuku
Sayini ……………………………………………wochita yakafukufuku
Tsiku ………………………………………………………

Translated Appendix D

Curtin University

MAFUNSO A KAFUKUFUKU OYENERA KUYANKHIDWA NDI MAKOLO KAPENA YEMWE AKUSAMALIRA MWANA

Mutu wakafukufuku: kafufuzidwe ka mmene kaganizidwe, chikhalidwe ndi ndondomeko yakaperekedwe ka chithandizo chazaumoyo zimagwirizirana ndikufotokozera ana omwe ali ndi kachilombo ka HIV za momwe mthupi mwawo mulili m'dziko la Malawi: Njira yowunikira ndi kufufuza zakufunika kwakukhala ndi mabuku owunikira ndondomeko yofotokozera ana kuti ali ndi kachilombo ka HIV.

Mafunso akafukufukuyi ndiwofuna kudziwa zambiri zokhudza inu, banja lanu, mwana wanu, pakhomo panu, kapezedwe kanu, ntchito yomwe mumagwira, kufotokozera mwana kuti ali ndi kachilombo koyambitsa matenda a Edzi, kufunika kwa kukhala ndi mabuku owunikira momwe makolo angamafotokozere ana awo momwe mthupi mwawo mulili, nkhani yokhuza momwe mwana akukulira, kakhwimidwe ka mwana wanu mu nzeru, nkhawa zanu , chithandizo chomwe mumalandira komanso ziphinjo (or mavuto) zomwe mukukumananazo posamalira mwana yemwe ali ndi kachilombo ka HIV.

Mafunsowa atha kutenga mphindi 30 kufikira 35 kuti ayankhidwe. Chonde yankhani mafunso onse mwatchutchu ndinso mwachilungamo. Muli ololedwa kusiya (kuyankha mafunsowa) kutengapo mbali mukafukufukuyi nthawi ili yonse mopanda kulandira chilango chili chonse. Mayankho onse omwe mutapereke akhala achinsisi. Gwiritsani nchito cholembera poyankha mafunsowa.

Lembani mizereyodutsana mu bokosi yomwe layikidwa pafupi ndi yankho lanu. Mwachitsanzo funso loti: Muli ndi zaka zingati

Zaka 6 ☒

Zaka 7 ☐

Zaka 8 ☐

Zaka 9 ☐

Zaka 10 ☐

Zaka 11 ☐

Zaka 12 ☐

Ngati yankho lanu liri zaka 6, lembani mizere iwiri yodutsana bokosi limene lili pafupi ndi zaka 6 ndi cholembela ngati momwe tapangira pamwambapa.

GAWO A: ZAMBIRI YANU.

A1. Kodi pali ubale wanji pakati pa inu ndi mwana yemwe mukuzamutengera mankhwala?

Mayi ☐
Bambo ☐
Mzakhali ☐
Malume ☐
Gogo ☐
M’bale ☐
Womuyang’anira ☐

Ubale wina (Utchuleni):………………………………………………………………………………

A2. Kodi muli ndi zaka zingati?

Zaka zochepera 15 ☐
Zaka zapakati pa 15- 20 ☐
Zaka zapakati pa 21-25 ☐
Zaka zapakati pa 26-30 ☐
Zaka zapakati pa 31-35 ☐
Zaka zapakati pa 36-40 ☐
Zaka zapakati pa 41-45 ☐
Zaka zapakati pa 46-50 ☐
Zopitirira 50 ☐

A3. Kodi ndinu munthu wamayi kapena bambo?

Bambo ☐
Mayi ☐

A4. Sankhani yankho loyenera lokhuza moyo wanu wa m’ banja

Wokwatira/wokwatiwa ☐
Wosakwatira/wosakwatiwa ☐
Mwamuna/Mkazi anamwalira ☐
Banja linatha ☐

A5. Kodi maphunziro munasiyira pati?

Sindinapite ku sukulu ☐
Pulaimale ☐
Sekondale ☐
Koleji ☐
Sukulu ya ukachenjede ☐

A6. Kodi munthu yemwe munakwatirana naye sukulu anasiyira pati?

Sanapite ku sukulu ☐
Pulaimale ☐
Sekondale ☐
Koleji ☐
Sukulu ya ukachenjede ☐
Funso silikundikhuza ☐

A7. Pa ana omwe mumakhala nawo ndi angati omwe ali wochepera zaka khumi ndi ziwiri (12)?

1-2 ☐
3-5 ☐
6-8 ☐
9-12 ☐

A8. Pa ana omwe mumakhala nawo ndi angati omwe ali wopitirira zaka khumi ndi ziwiri (12)?

0 ☐
1-2 ☐
3-5 ☐
6-8 ☐
9-12 ☐

A9 Ndinu mtundu uti wa anthu?

Chewa ☐
Yao ☐
Tumbuka ☐
Lomwe ☐
Ngoni ☐
Tonga ☐
Sena ☐
Nkhonde ☐

Mtundu womwe sunalembedwe (chonde utchuleni)
………………………………………………………………………………

A10.	Kodi pakhomo panu pali katundu yemwe walembedwa m’musimu (chongani zonse zomwe muli nazo) :		
	Magetsi	Eya ☐	Ayi ☐
	Koloboyi	Eya ☐	Ayi ☐
	Nyali yogwiritsa ntchito parafini	Eya ☐	Ayi ☐
	Wayilesi	Eya ☐	Ayi ☐
	Wayilesi yakanema	Eya ☐	Ayi ☐
	Lamya ya m’manja	Eya ☐	Ayi ☐
	Lamya ya nyumba	Eya ☐	Ayi ☐
	Bedi ndi matiresi	Eya ☐	Ayi ☐
	Mpando wasofa	Eya ☐	Ayi ☐
	Tebulo ndi mipando	Eya ☐	Ayi ☐
	Fuliji	Eya ☐	Ayi ☐
	Njinga yakapalasa	Eya ☐	Ayi ☐
	Njinga yamoto	Eya ☐	Ayi ☐
	Ngolo yokokedwa ndi ng’ombe	Eya ☐	Ayi ☐
	Galimoto	Eya ☐	Ayi ☐

A11.	Kodi madzi omwe mumagwiritsa ntchito pakhomo amachokera kuti? (chongani mayankho onse olondola)	
	Madzi wochokera ku mpopi	Madzi ochokera pakasupe
	Mpopi uli mkati mwanyumba ☐	Kasupe otetezedwa☐
	Mpopi uli panja pa nyumba ☐	Kasupe osatetezedwa ☐
	Mpopi wogwiritsidwa ntchito ndi anthu ambiri a mmudzi ☐	Madzi a mvula ☐
	Mjigo☐	Madzi ongoyenda pansi ☐
	Chitsime chokumba	Madzi a m’botolo ☐
	Chitsime chotetezedwa ☐	
	Chitsime chosatetezedwa ☐	
	Ochokera mmalo ena (tchulani) …..……...…………………………………………………………………….	

A12.	Kodi pakhomo panu anthu amagwiritsa chimbudzi chotani?	
	Chimbudzi chofulasha ndi mmadzi ☐	Chiimbudzi chokolola manyowa ☐
	Chimbudzi chokumba chokhala ndi paipi la mpweya ☐	chimbudzi cha ndowa ☐
	Chimbudzi chokumba chokhala ndi silabu ☐	Palibe chimbudzi ☐
	Chimbudzi chokumba chopanda silabu ☐	

A13.	Kodi pakhomo panu mumagwiritsa mphamvu yanji ya moto pophika?	
	Magetsi ☐	Nkhuni ☐
	Mphweya (Gas) ☐	Udzu ☐
	Parafini ☐	Ndowe ☐
	Malasha ☐	Pakhomo sipamaphikidwa chakudya ☐
	Makala ☐	
	Zina (Tchulani……………………………………………………………………………………	

A14.	Kodi pansi pa nyumba yanu panamangidwa ndi chiyani	
	Dothi/nchenga ☐	Njerwa zogumuka (madukwa) ☐
	ndowe ☐	Matayilosi ☐
	Mitengo ☐	Simenti ☐
	Udzu/nsungwi/kanjedza ☐	
	Dzina (Tchulani)………………………………………………………………………………..	

A15.	Kodi gawo lalikulu la denga la nyumba yanu linamangidwa ndi chiyani?	
	Nyumba ilibe denga ☐	Malata ☐
	Kanjedza ☐	Chipepala cha pulasitiki ☐
	Udzu/nsungwi ☐	Simenti ☐
	Mitengo ☐	Matayilosi ☐
	Katoni ☐	
	Zina (tchulani)……………………………………………………………………………..........	

A16.	**Kodi gawo lalikulu la khoma lakunja kwa nyumba yanu linamangidwa ndi chiyani?**	
	Nyumba yopanda zipupa/khoma ☐	Simenti ☐
	Zidutswa za mitengo ☐	Njerwa zootcha ☐
	Zidutswa za mitengo ndi dothi ☐	Njerwa zosaotcha ☐
	Miyala ndi dothi ☐	Yozira ndi dothi ☐
	pulayiwudu ☐	
	Katoni ☐	
	Zina (Tchulani) ………………………………………………………………………………	

A17.	**Kodi pakhomo panu pali ziweto?**	
	Eya ☐	Ayi ☐ pitani ku funso A19

A18.	**Kodi pakhomo panu pali ziweto zingati, mwa ziweto zalembdwa musimu? (lembani mulingo)**	
	Mbuzi.....................	Nkhuku …………..
	Nkhumba........................	Abakha………………
	Ng’ombe.....................	Nkhunda…………..
	Zina (Tchulani)……………………………………………………………………….....	

A19.	**Kodi pabanja panu muli ndi malo olima?**	
	Eya ☐	Ayi ☐ Pitani ku funso A21

A20.	**Kodi muli ndi malo olima akulu bwanji? (lembani mulingo)**	
	Ekala ………………….	Bwalo lampila……….
	Hekitala………………	Sindikuziwa ☐

A21. Kodi pakhomo panu mumadya kangati pa tsiku mu ma tsiku asanu ndi awiri apitawa?

kamodzi ☐ Katatu kapenena kupitira ☐

Kawiri ☐

A22. Pa miyezi khumi ndi iwiri yapitayi, pakhomo panu panali chakudya chokwanira?

Eya ☐ Ayi ☐

A23. Kodi mu nthawi yanu yambiri mumakhala mukutani? (chonde chongani yankho limodzi, Mungathe kuchonga mayankho angapo ngati muli ndi mayankho ambiri)

Kugwira ntchito (yolandira ndalama kapena bizinesi) ☐ kudwala ☐

Ulimi ☐ Kudwazika matenda ☐

Kufuna ntchito ☐ Kuphunzira ☐

Ntchito za pakhomo/kusamalira ana☐

A24. Kodi amene munakwatirana nawo amakhala akutani mu nthawi yawo yambiri? (chonde chongani yankho limodzi, Mungathe kuchonga mayankho angapo ngati muli ndi mayankho ambiri

Kugwira ntchito (yolandira ndalama kapena bizinesi) ☐ kudwala ☐

Ulimi ☐ Kudwazika matenda ☐

Kufuna ntchito ☐ Kuphunzira ☐

Ntchito za pankhomo/kusamalira ana☐ Funso silikundikhuza ☐

GAWO B: MAFUNSO OKHUZA MWANA WANU KAPENA MWANA YEMWE MUKUMUSAMALIRA. GAWO ILI LIFUNSA MAFUNSO OKHUZA MWANA WANU WANKULU PA ONSE AMENE ALI NDI ZAKA ZAPAKATI PA 6-12 YEMWE ALI NDI KACHILOMBO KA HIV.

B1. Kodi mwana wanu ali ndi zaka zingati?

Zaka 6 ☐ Zaka 10 ☐

Zaka 7 ☐ Zaka 11 ☐

Zaka 8 ☐ Zaka 12 ☐

Zaka 9 ☐

B2. Kodi mwana wanu ndi wamkazi kapena wamuna?

Mkazi ☐ Mamuna ☐

B3. Kodi mwana wanu ali mu gawo liti la mulingo wa matenda a Edzi poyerekaza ndi mulingo womwe unakhazikitsidwa ndi bungwe la zaumoyo pa dziko lonse (WHO)? (pezani mlingo wamatenda kuchokera mu kabukhu ka matenda a mwana)

Mulingo(gawo?) woyamba ☐ Mulingo wachitatu ☐

Mulingo wachiwiri ☐ Mulingo wachinayi ☐

B4. Kodi mwana wanu ali ndi mulingo wanji wa zomwe zalembedwa munsimu? (Please measure)

Kutalika …………………(M) Kulemela……………………..…(Kg)

Kukula kwa pakati pa gawo la nkono lapakati pa bondo lankono ndi khwapa…………......

B5. Kodi mwana wanu akudwala kapena mu miyezi khumi ndi iwiri yadutsayi anadwalapo matenda otsimikizidwa ndi a dotolo ali musimu? (*chongani matenda onse omwe mwana wanu wadwalapo)*

Kutentha thupi	Eya ☐	Ayi ☐
Kutsekula mmimba	Eya ☐	Ayi ☐
Chibayo	Eya ☐	Ayi ☐
Chifuwa cha chachikulu cha TB	Eya ☐	Ayi ☐
Matenda a pakhungu	Eya ☐	Ayi ☐
Kusowa kwazakudya nthupi	Eya ☐	Ayi ☐

Ngati pali zina zitchuleni ………………………………………………………………………………

B6. Kodi mwana wanu pakadali pano akumwa mankhwala wochepetsa kachilombo ka HIV koyambitsa matenda a Edzi?

Eya ☐	Ayi ☐

B7. Ngati ndi yankho lanu lili eya, mwana wanu wakhala akumwa makhwala ochepetsa kachilombo ka HIV kwa nthawi yayitali bwanji?

Kochepera miyezi isanu ndi umodzi ☐	Zaka zinayi mpaka zaka zisanu☐
Miyezi isanu ndi umodzi mpaka chaka ☐	Kupitirira zaka zisanu ☐
Zaka ziwiri mpaka zaka zitatu ☐	

GAWO C. NKHANI YOFOTOKOZERA MWANA KUTI ALI NDI KACHILOMBO KA HIV OYAMBITSA MATENDA A EDZI.

C1. Kodi mwana wanu akuziwa kuti ali ndi kachilombo koyambitsa matenda a Edzi?

Eya ☐	Ayi ☐ (Pitani ku funso C7)

C2. Ndi ndani amene anamuuza mwana wanu kuti ali ndi kachilombo koyambitsa matenda a Edzi? (chongani zonse zomwe zili zolondola)

Kholo/makolo ☐	Azakhali ☐
Agwira ntchito ku chipatala ☐	Agogo ☐
Amalume ☐	Munthu ovomerezeka yemwe akukhala ndi kumusamalira mwana ☐

Ena (atchuleni) ………………………………………………………………………………

C3. Kodi mwana wanu munakambiranbanaye zokhuza matenda a Edzi monga chomwe chimayambitsa matendawa, kafalitsidwe kake komanso mankhwala ake musanamuuze kuti ali ndi kachilombo koyambitsa matenda a Edzi?

Eya ☐	Sindikukumbukira ☐
Ayi ☐	

C4 Kodi mwana wanu anawuzidwa bwanji zoti ali ndi kachilombo koyambitsa matenda a Edzi?

Anawuuzidwa kamodzinkamodzi ☐	Sindikukumbukira ☐
Anawuzidwa pango'nopang'o munthawi yotalikirapo ☐	

C5. Mwana wanu anali ndi zaka zingati nthawi yomwe amawuzidwa kuti ali ndi kachilombo koyambitsa matenda a Edzi?

Kuchepera zaka zisanu ndi chimodzi ☐	Zaka zisanu ndi zinayi ☐
Zaka zisanu ndi chimodzi ☐	Zaka khumi ☐
Zaka zisanu ndi ziwiri ☐	Zaka khumi ndi chimodzi ☐
Zaka zisanu ndi zitatu ☐	Zaka khumi ndi ziwiri ☐

C6. Chongani chifukwa kapena zifukwa mwa zifukwa zalembedwa musimu, zomwe zinakupangitsani kuti mumuwuze mwana wanu kuti ali ndi kachilombo koyambitsa matenda a Edzi. (chongani zifukwa zonse zomwe zili zolondola kwa inu)

Mwana anafika nsiku woti atha kumvetsa za matenda ake	Eya ☐	Ayi ☐
Ndinalangizidwa ndi ogwira ntchito kuchipala kuti ndimuuze mwana za matenda ake	Eya ☐	Ayi ☐
Mwana anandifunsa kuti ndimuuze za matenda omwe akudwala	Eya ☐	Ayi ☐
Mwana amakana kumwa mankhwala ochepetsa tizilombo toyambitsa matenda a Edzi (ARV) chifukwa samadziwa chomwe amamwera mankhwalawa	Eya ☐	Ayi ☐
Matenda a mwana anakula kwambiri	Eya ☐	Ayi ☐
Matenda a kholo anakula kwambiri	Eya ☐	Ayi ☐

Ngati muli ndi zifukwa zina (zitchuleni)………………………………………………………………………………

C7.	**Chonde yankhani mafunso omwe ali m’musiwa okhuza kufotokozera mwana yemwe ali ndi kachilombo koyambitsa matenda a Edzi, za momwe mthupi mwake mulili.**			
	Kodi mwana wanu amadziwa kuti akumwa mankhwala ochepetsa kuchuluka kwa tizilombo toyambitsa matenda a Edzi?	Eya ☐	Ayi☐	Sindikuziwa ☐
	Kodi mwana anayamba wakufusanipo kuti mumuwuze chifukwa chomwe amamwera mankhwala ochepetsa tizilombo toyambitsa matenda a Edzi?	Eya ☐	Ayi ☐	Sindikuziwa ☐
	Kodi mwana amatha kukana kumwa mankhwala ochepetsa tizilombo toyambitsa matenda a Edzi omwe amayenera kumwa?	Eya ☐	Ayi ☐	Sindikuziwa ☐
	Kodi nthawi zina mumatha kukanika kumupatsa mwana wanu mankhwala ochepetsa tizilombo toyambitsa matenda a Edzi kuti amwe chifukwa choti muli pa gulu la anthu?	Eya ☐	Ayi ☐	Sindikuziwa ☐
	Kodi munakhalapo ndi vuto lililonse lokhuza kumupatsa mwana mankhwala ochepetsa tizilombo toyambitsa matenda a Edzi kuti amwe chifukwa choti mwana wanu sakudziwa chomwe akumwera mankhwalawa?	Eya ☐	Ayi ☐	Sindikuziwa ☐
	Kodi mwana wanu anakhalapo kapena ali ndi vuto lilonse lokhuza kumwa mankhwala ochepetsa tizilombo toyambitsa matenda a Edzi tsiku lililonse kapena muyengo yake yoyenerera?	Eya ☐	Ayi ☐	Sindikuziwa ☐
	Kodi ana ena amapewa kucheza ndi mwana wanu chifukwa choti ali ndi kachilombo koyambitsa matenda a Edzi??	Eya ☐	Ayi ☐	Sindikuziwa ☐
	Kodi ana ena amamuzunza kapena kumuitana mwana wanu ndi maina oyipa chifukwa ali ndi kachilombo koyambitsa matenda a Edzi?	Eya ☐	Ayi ☐	Sindikuziwa ☐
	Kodi mwana wanu anakanidwapo ndi anzake kapena achibale chifukwa chakuti ali ndi kachilombo koyambitsa matenda a Edzi?	Eya ☐	Ayi ☐	Sindikuziwa ☐
	Kodi masiku amenewa mwana wanu amakhala wopanda chidwi popanga zinthu?	Eya ☐	Ayi ☐	Sindikuziwa ☐
	Kodi mwana wanu wakhala akuwonetsa kukhumudwa kapena kusasangalalala mumasiku ambuyowa kufika lero?	Eya ☐	Ayi ☐	Sindikuziwa ☐

C8.	**Kodi mukuganiza kuti ndi ndani amene ayenera kumufotokozera mwana kuti ali ndi ka HIVchilombo koyambitsa matenda a Edzi?**		
		Kholo kapena omusamalira mwana ☐ Aphunzitsi ake ☐	Ogwira ntchito ku chipatala ☐ Akulu ampingo/ abusa/ asembe/ sheikh ☐
	Ngati pali ena omwe sanalembedwe pamwambapa atchuleni………………………………………………………………………………		

C9.	**Kodi mukudziwa satanesatane wamomwe mungamufotokozerere mwana wanu kuti ali ndi kachirombo koyambitsa matenda a Edzi.**		
	Ayi ☐	Eya ☐	Sindingathe kuvomereza kapena kukana ☐

C10	**Ndi zifukwa ziti zomwe zalembedwa musimu zomwe zikufotokoza bwino lomwe chomwe chimakulepheretsani kumuudza mwana wanu kuti ali ndi kachirombo koyambitsa matenda a Edzi. (chongani zifukwa zonse zolondola) (Ngati munamufotokozera kale mwana za matenda ake pitani ku funso C11)**		
	Kuopa kuti mwana sangathe kumvetsa za matenda ake chifukwa chosakhwima mu nzeru	Eya ☐	Ayi ☐
	Kuopa kuti mwana angamasalidwe	Eya ☐	Ayi ☐
	Kusoweka kwa chithandizo kuchokera kwa ogwira ntchito m'chipatala	Eya ☐	Ayi ☐
	Kusoweka nzeru za ndondomeko yomwe mungasate pomufotokozerera mwana wanu za matenda ake	Eya ☐	Ayi ☐
	Kuchita manyazi kapena kuziona olakwa kapena okhuzidwa kuti mwana atenga kachirombo koyambitsa matenda a Edzi	Eya ☐	Ayi ☐
	Mwana sakuwonetsa zizindikiro za matenda	Eya ☐	Ayi ☐
	Ngati pali zina zomwe sizinalembedwe kapena kuwerengedwa mutha kuzitchula ………………………………………………………………………………………		

C11. **Tikufuna kulemba mabuku a ana omwe angathandize powunikira makolo za ndondomeko wamomwe angafotokozere mwana yemwe ali ndi kachilombo koyambitsa matenda a Edzi nkhani yokhuza momwe mthupi mwake mulili. Mabukuwa alembedwa malingana ndi kakulidwe ka mwana mu nsinkhu ndi nzeru. Mabukuwa alembedwa mu Chichewa ndipo akhala ndi zithunzi, nthano komanso nyimbo zothandiza kuwuza mwana kuti ali ndi kachilombo koyambitsa matenda a Edzi. Ndiwerenga mizere ya mawu yomwe yili musimu yokhuza mabukuwa, mnzere wuliwonse womwe nditawerenge ndikupemphani kuti mundiwuze ngati i) mukugwirizana nazo kwambiri, ii) kugwirizana nazo chabe, iii) simukugwirizana kapena kovomerezana nazo, iv) simukugwirizananazo v) simukugwirizana nazo olo pang'ono. (*Chonde zungulizani nambala yomwe ikugwirizana ndi yankho lanu pa mzere uli wonse.)***

	Sindikugwirizana nazo olo pang'ono	Sindikugwirizana nazo	Simukugwirizana kapena Kuvomerezana nazo	Ndikugwirizana nazo	Ndikugwirizana nazo kwambiri
Ndiganizo labwino kulemba mabuku oterewo	1	2	3	4	5
Ndizagwiritsa ntchito mabukuwo pamodzi ndi mwana wanga	1	2	3	4	5
Mabuku amenewo azandithandiza powonjezera nzeru za momwe ndingamufotokozerere mwana kuti ali ndi kachilombo koyambitsa matenda a Edzi	1	2	3	4	5
Mabuku amenewa azandithandiiza kukhala ndi mangolomera pankhani yofotokozera mwana kuti ali ndi kachilombo koyambitsa matenda a Edzi.	1	2	3	4	5
Mabuku amenewa athandiza kuchepetsa nkhawa zomwe ndili nazo zokhuza kufotokozera mwana kuti ali ndi kachilombo koyambitsa matenda a Edzi.	1	2	3	4	5

GAWO D. Zimene amalimba nazo ndi zimene amavutika nazo

D1. Pachiganizo chirichonse chimene ndiwerenge ndikufunsani kuti mundiwuze ngati chiganizocho chikunena zonama, zoona pang'ono, kapena zoona zedi. Zitithandiza ngati mungayankhe mafunso onse mmene mungathele ngakhale ziganizo zina zingamveke ngati zachibwana. Muziganizo zotsatilazi mundiuzeko zimene zikulongosola za khalidwe la mwana wanu pa miyezi 6 yapitayi.

	Zabodza	Zoona pang'ono	Zoona zedi
Ndioganizira anthu ena.	○	○	○
Ojijilika, sakhazikika kwa kanthawii	○	○	○
Amadandaula kawirikawiri zakupweteka kwa mutu, m'mimba kapena matenda ena	○	○	○
Amagawana zinthu ndi ana anzake (monga zoseweretsa, masiwiti, mapensulo)	○	○	○
Amapsya mtima kawirikawiri	○	○	○
Amapanga zayekha, amakonda kusewera payekha	○	○	○
Kwakukulu ndi wakhalidwe labwino kawiri kawiri amapanga zomwe akulu akulu amuuza.	○	○	○
Ali ndi madandaulo ambiri kapena kawiri kawiri amaoneka odandaula.	○	○	○
Amathandiza ngati wina wavulala, wakhumudwa kapena sakupeza bwino	○	○	○
Amasuntha thupi mofulukutafulukuta, mosatopa ndi mokwiyitsa anthu.	○	○	○
Ali ndi nzake wina ogwirizana naye kwambiri	○	○	○
Kawiri kawiri amamenyana ndi anzake kapena kuzunguza anzake.	○	○	○
Kawiri kawiri sasangalala kapena amaoneka okhumudwa ndi oliralira	○	○	○
Anzake amamukonda.	○	○	○
Chidwi chake sichikhazikika, sachedwa kusokonezeka	○	○	○
Amaoneka wogwidwa nthumazi kapena amakumatilirani mmalo achilendo, sachedwa kuzikayikira	○	○	○
Ndiwachikondi kwa ana ochepera msinkhu wake.	○	○	○
Kawiri kawiri amakangana ndi akulu.	○	○	○
Amatoledwa kapena kuzunguzidwa ndi ana ena.	○	○	○
Kawirikawiri amathandiza ena mongodzipereka	○	○	○
Amatha kuganiza kaye asanapange chithu	○	○	○
Amaba zinthu pakhomo, kusukulu ndi malo osiyanasiyana	○	○	○
Amacheza bwino ndi akulu kusiyana ndi ana anzake	○	○	○
Ndiwamatha, sachedwa kuopa.	○	○	○
Ndiwachidwi, akayamba kupanga chinthu amafuna mpaka amalize.	○	○	○

D2. Kutengera zonse mukuganiza kuti mwana wanu ali ndi mavuto mu zinthu zotsatilazi: chidwi, khalidwe kapena kutha kukhala ndi anthu ena?		
Ayi (Pitani ku gawo E)	○	Inde, mavuto ochuluka ○
Inde, mavuto ochepa	○	Inde, mavuto kwambiri ○

Ngati mwavomera, chonde yakhani mafunso otsatirawa:

D3. Mavutowa akhalapo nthawi yayitali bwanji?			
Kuchepera mwenzi umodzi	○	Miyezi 6-12	○
Miyezi 1-5	○	Chaka chonse	○

D4. Kodi mavutowa amamukhumudwitsa mwana wanu?	
Sizimukhudza	○
Pang'ono	○
Mochulukirapo	○
Kwambiri	○

D5 Kodi mavutowa amamusokoneza mwana wanu pa moyo wake wa tsiku ndi tsiku m'madela awa?				
	Sizimukhudza	Pang'ono	Mochulukirapo	Kwambiri
Pamoyo wake wapakhomo	○	○	○	○
Maubwenzi	○	○	○	○
Pamaphunziro	○	○	○	○
Chisangalalo/Kucheza	○	○	○	○

D6. Kodi mavutowa ndi chipsinjo kwa inu kapena banja lanu lonse?	
Sizimukhudza	○
Pang'ono	○
Mochulukirapo	○
Kwambiri	○

GAWO E. MOYO WAPA BANJA NDI ZIPHINJO ZAKUDZA CHIFUKWA CHA MATENDA A MWANA

E1. Muchaka chimenechi, mwakumanapo ndi mavuto awa? (Chongani mayankho onse olondola)	Eya	Ayi
Mavuto okhuza mayi oyembekezera kapena wapakati	○	○
Kutha kwa banja kapena kusiyana ndi amuna anu	○	○
Mavuto a m’banja	○	○
Kumwalira kwa m’bale wanu kapena n’zanu kwambiri	○	○
Mavuto okhuzana ndi ana anu	○	○
Kutha kwa ntchito	○	○
Mavuto azachuma	○	○
Kusowa kwa chakudya	○	○
Ngati pali mavuto ena omwe sindinawatchule mutha kundiwuza ……………………………………………..		

E2. Ndiwerenga ziganizo zomwe anthu amakamba zokhuza kukhala ndi mwana wodwala. Chiganizo chilichonse chomwe nditawerenge mundiwuze ngati mukuvomerezana nazo kwambiri, kuvomerezana nazo chabe, kusavomerezana nazo, kusavomerezana nazo kwambiri. (*chonde lembani mzere wuzungulira nambala yolingana ndi yankho lanu ndi cholembela)*

Kuvomerezana nazo kwambiri		**1**			
Kuvomerezana nazo chabe			**2**		
Kusavomerezana nazo				**3**	
Kusavomerezana nazo kwambiri					**4**
		1	**2**	**3**	**4**
a.	aMatendawa abweretsa mavuto azachuma pankhomo.	**1**	**2**	**3**	**4**
b.	Nthawi yogwirira ntchito imaonongeka chifukwa chopita kuchipatala	**1**	**2**	**3**	**4**
c.	Ndachepetsa nthawi yogwirira ntchito kuti ndizimusamalira mwana	**1**	**2**	**3**	**4**
d.	Pakufunika ndalama zoonjezera kuti tilipire ma bilu akuchipatala	**1**	**2**	**3**	**4**
e.	Ndinasiya kugwira ntchito chifukwa cha kudwala kwa mwana wanga	**1**	**2**	**3**	**4**
f.	Chifukwa chakudwala kwa mwana sindimatha kuyenda kupita kutali	**1**	**2**	**3**	**4**
g.	Anthu okhala nafe moyandikana amatipangira zinthu zosiyana ndi momwe amapangira kwa anthu ena chifukwa cha matenda a mwana wathu	**1**	**2**	**3**	**4**
h.	Tili ndi chikhumbokhumbo chochepa choti tipite kwinakwake tikasangalale chifukwa chamatenda a mwana	**1**	**2**	**3**	**4**
i.	Ndizovuta kupeza munthu odalilika kuti amusamalire mwana wanga	**1**	**2**	**3**	**4**
j.	Nthawi zina timalephera kupita kokasangalala nthawi yonyamukira itasala pang'ono chifukwa choti mwana sali bwino	**1**	**2**	**3**	**4**
k.	Tinachepetsa nthawi yocheza ndi abale ndi abwenzi chifukwa cha matenda a mwana	**1**	**2**	**3**	**4**
l.	Matenda amwana atipangitsa anthu tonse a pakhomo pathu kukhala ogwirizana kwambiri.	**1**	**2**	**3**	**4**
m.	Nthawi zina ndimaganiza ngati mwana wathu aziwonedwa ndi anthu mosiyana ndi momwe amaonera ana ena.	**1**	**2**	**3**	**4**
n.	Abale anga ndi omvetsa ndipo amandithandiza kusamala matenda amwanayu.	**1**	**2**	**3**	**4**
o.	Ndikuganiza zosiya kubereka chifukwa chamatenda amwanayu.	**1**	**2**	**3**	**4**
p.	Ine ndi mwamuna/mkazi wanga timakambirana nkhani za matenda a mwana wathu limodzi	**1**	**2**	**3**	**4**
q.	Timayesesa kumusamalira mwanayu ngati kuti alibe vuto lililonse.	**1**	**2**	**3**	**4**
r.	Sindimakhala ndi nthawi yocheza ndi anthu ena apakhomo ndikamaliza kumusamalira mwanayu	**1**	**2**	**3**	**4**
s.	Achibale amalowerera ndiponso amaganiza kuti akuziwa zinthu zoyenera kumuchitira mwanayu.	**1**	**2**	**3**	**4**
t.	Banja lathu limalephera kupanga zinthu chifukwa cha matenda a mwanayu	**1**	**2**	**3**	**4**

u.	Ndiri ndi vuto la kutopa chifukwa chosamalira matenda a mwanayu	**1**	**2**	**3**	**4**
v.	Ndimakhala mmene kwachera tsiku limenelo sinditha kukonza dongosolo la mtsogolo chifukwa cha matenda a mwanayu	**1**	**2**	**3**	**4**
w.	Palibe yemwe amamvetsa chiphinjo chomwe ndasenza	**1**	**2**	**3**	**4**
x.	Maulendo opita kuchipatala ndi mwanayu ndi chiphinjo kwa ine	**1**	**2**	**3**	**4**
y.	Kuphunzira momwe ndingamusamalire mwana wanga kwandipangitsa kuona gawo lina labwino la ine	**1**	**2**	**3**	**4**
z.	Ndimadera nkhawa za zomwe zingazamuchitikire mwana wanga mtsogolo	**1**	**2**	**3**	**4**
aa.	Nthawi zina ndimawona ngati ndimakhala munthawi zosiyana, nthawi yovuta pamene mwana wadwalika komanso nthawi yabwinoko mwana akamapeza bwino	**1**	**2**	**3**	**4**
bb.	Ndizovuta kukhala ndi nthawi yocheza ndi ana ena omwe ndili nawo chifukwa chotanganidwa ndi matenda amwanayu	**1**	**2**	**3**	**4**
cc.	Kukhala ndi mwana wodwalayu kumandipangitsa kukhala ndi nkhawa ndi umoyo wa ana anga ena.	**1**	**2**	**3**	**4**

GAWO E: ZOKHUZA CHITHANDIZO CHAPAKHOMO

E3. Gawo ili ndi lokhuza chithandizo chomwe chimatha kuthandiza anthu pakhomo kapena pa banja lanu. Ziganizo zili mmunsimu zikufunsa kuti musonyeze nthawi yamomwe mumafunira chithandizo chilichonse chomwe chalembedwacho. Chonde lembani mzere wozungulira pa nambala ili yonse yomwe ikulingana ndi yankho lanu. Chonde yankhani mafunso onse.

Kodi ndithawi yochuluka bwanji yomwe mumafunikira mitundu ya chithandizo ili musimuyi	**Ayi ndi kale lomwe**	**Kamodzi mwaka thawi**	**Nthawi zina**	**Nthawi zochulukirapo**	**Nthawi zambiri**
Munthu wina yemwe mungamakambirane naye zazomwe zimakudetsani nkhawa.	1	2	3	4	5
Munthu yemwe angamapereke chithandizo cha ndalama zogulira chakudya, zovala ndi zina zotero.	1	2	3	4	5
Munthu yemwe angamasamalire mwana wanu munthawi zambiri.	1	2	3	4	5
Munthu yemwe mungakambirane naye za mavuto akasamalidwe ka mwana wanu.	1	2	3	4	5
Munthu yemwe angamathandize kupeza chisamaliro chomwe mwana akufunikira.	1	2	3	4	5
Munthu yemwe angathe kukulimbikitsani mtima mukakhala kuti simukumva bwino	1	2	3	4	5
Munthu yemwe angamakonze zinthu zomwe zikufunikira kapena zawonongeka pa pankhomo	1	2	3	4	5
Munthu wokhala ndi vuto ngati langali yemwe ndingakambirane naye zamavuto anga	1	2	3	4	5
Munthu amene angathe kumachita zinthu ndi mwana wanu	1	2	3	4	5
Munthu yemwe mungamamudalire	1	2	3	4	5
Munthu yemwe angakuthandizeni kuyendetsa zinthu zomwe inu mumayenera kuchita koma mukukanika	1	2	3	4	5
Munthu yemwe angamakubwerekeni ndalama	1	2	3	4	5
Munthu yemwe angamulandire mwana wanu mosaganizira vuto lomwe ali nalo	1	2	3	4	5
Munthu yemwe mutha kumacheza ndi kuseka naye	1	2	3	4	5
Munthu yemwe angamakuthandizeni ndi ntchito za pakhomo	1	2	3	4	5
Munthu yemwe angamakulimbitseni mtima munthawi yomwe muli ndi mabvuto	1	2	3	4	5
Munthu yemwe angathe kumathandiza mwana wanu munthawi ya mavuto akugwa mwazizi.	1	2	3	4	5
Munthu yemwe mungamalankhulane naye munthawi yomwe mukufuna kulangizidwa	1	2	3	4	5
Munthu yemwe angamakupatseni inu ndi mwana wanu ndalama zoti muziyendera kuchipatala	1	2	3	4	5
Munthu yemwe angamakuuwzeni za chithandizo chokhuza mwana kapena banja lanu	1	2	3	4	5

Apa nde pamathero pa mafunso.

Zikomo kwambiri potenga nawo mbali mu kafukufukuyu.

Translated Appendix H

GULU LOKAMBIRANA

FOMU YOLONGOSOLA ZA KAFUKUFUKU KWA MAKOLO KAPENA YEMWE AKUSAMALIRA MWANA

Mutu wakafukufuku: kufufuza mmene kaganizidwe, chikhalidwe ndi ndondomeko yakaperekedwe kachithandizo chazaumoyo zimagwirizirana ndi kufotokozera ana omwe ali ndikachilombo ka HIV za momwe nthupi mwawo mulili m'dziko la Malawi: Njira yowunikira ndi kufufuza zakufunika kwakukhala ndi mabuku owunikira ndondomeko yofotokozera ana kuti ali ndikachilombo koyambitsa matenda a Edzi.

Anthu woyendetsa kafukufuku: Fatch Kalembo, Dr Garth Kendall, Dr Mohammed Ali

Dzina langa ndine Fatch Kalembo wophunzira za udotolo pa sukulu ya ukachenjede ya Curtin ku Australia. Ngati gawo la maphunziro anga, ndikupanga kafukufuku yemwe zolinga zake ndi kuwunika momwe ana amafotokozeredwa kuti ali ndi kachilombo kayambitsa matenda a Edzi, komanso kulemba mabuku omwe adzawunikire makolo momwe angafotokozere ana awo za momwe mthupi mwawo mulili. Mukupemphedwa kuti mutengepo mbali mukafukufukuyu. Mabukuwa akhala olembedwa poganizira msinkhu wa mwana komanso chikhalidwe chanu. Kafukufukuyi athandiza ana omwe ali ndi kachilombo ka HIV kuti azitha kumvetsa bwino za momwe alili komanso kuti azikhala ndi chidwi chosata ndondomeko yakamwedwe ka mankhwala wochepetsa tizilombo ta HIV.

Ngati wotenga mbali mukafufukuyu, mupemphedwa kukambirana ndi gulu la anzanu za maganizo and komanso machitidwe anu pankhani yokhunza kufotokozera ana omwe ali ndi kachilombo koyambitsa matenda a Edzi momwe mthupi mwawo mulili. Mufunsidwanso za maganizo anu pakhani yakufunika kwakukhala ndi mabuku owunikira makolo kapena omwe amasamalira anawa mmene angawafotokozere anawa zamatenda awo. Zokambiranazi zitenga mphinda 45.

Ndi kofunika kuti musanavomereze kutenga nawo mbali mukafukufukuyi, muyenera kudziwa izi:

- **Dziwani kuti kulowa mukafukufukuyi ndi kosakakamiza:** Kutenga nawo mbali mukafukufukuyi sikukugwirizana munjira iliyonse ndi chithandizo chomwe mumalandira kuchipatala. Mutha kusatenga nawo mbali kapena kutuluka mukafukufukuyi nthawi iliyonse yomwe mwafuna popanda kulandira chilango chilichonse monga kusapatsidwa mankhwala anu kapena a mwana wanu.
- **Muli ndi ufulu woyankha mafunso omwe mukufuna:** Ngati simukufuna kuyakha mafunso ena muli ndi ufulu kutero. Mutha kukambirana ndi woyendetsa kafukufuku za nkhawa kapena mafunso ena aliwonse womwe mungakhale nawo.
- **Zonse zomwe mutatiwuze zikhala zachinsinsi:** okhawo oyendetsa kafukufukuyi ndiwo atakhale ndi chilolezo chowona zomwe mwanena mukafukufukuyi. Mayankho anu onse asungidwa mwachinsinsi ndipo sazaperekedwa kwa aliyense. Sitizalemba dzina lanu powulutsa zotsatira zakafukufukuyi. Mukafukufukuyi tigwiritsa ntchito nambala m'malo mwa dzina

  lanu ndicholinga chofuna kukusungirani chinsisi Zonse zokhuza kafukufukuyi zikasungidwa bwino ku sukulu ya ukachanjede ya Curtin.

- Ngati mbali ina iliyonse yakafukufukuyi yingasindikizidwe, tizayesesa kuteteza kuti musazindikiridwe munjira ina iliyonse.

Kafukufukuyi ndiwovomerezeka ndi bungwe lowona za ndondomeko ya kafukufuku la yunivesite ya Curtin (Chiphatso chachilolezo HR 186/2014). Mu gulu la ndondomeko yakafukufukuyi muli akatswiri a zamaphunziro, malamulo, madotolo komanso akuluakulu a mipingo. Ngati mukufuna kufunsa zambiri zokhudza chilolezo cha kafukufukuyi mutha kulemba kalata ku adilesi iyi: Curtin University Human Research Ethics Committee, Office of Research and Development, Curtin University, GPO Box U1987, Perth, 6845 kapena mutha kutchaya lamya pa nambala iyi +6189266 2784 munthanso kulemba imelo ku adilesi iyi hrec@curtin.edu.au

Kafukufukuyi ngovomerezekanso ndi bungwe lowona za ndondomeko yakafukufuku mu unduna wa za umoyo ku Malawi. Ngati muli ndi nkhawa yiliyonse yokhuza kafukufukuyi, chonde yankhulani ndi oyang’anira za ndondomeko ya kafukufuku ku unduna wazaumoyo pa adilesi iyi: Chairman, National Health Sciences Research Committee, Ministry of Health (Research Department, P.O. BOX, 300377, Lilongwe 3, Malawi (kapena yimbani lamya pa nambala iyi: +26 560 1726422).

Ngati muli ndifunso kapena kufuna kudziwa zambiri za kafukufukuyi, khalani omasuka kuyankhulana ndi omwe akuyanganira kufukufukuyi pogwiritsa ntchito zina ndi nambala ya lamya yili musimu. Oyang’anira kafukufuku: Fatch Kalembo Email: kalembofatch@yahoo.com Nambala ya lamya: +265998260623.

Translated Appendix I

GULU LOKAMBIRANA

Malo a kafukufuku ……………………………………

KALATA YOPHEMPHA CHIVOMEREZO KUCHOKERA KWA MAKOLO KAPENA OMWE AKUSAMALIRA ANA OMWE ALI NDI KACHILOMBO KOYAMBITSA MATENDA A EDZI KUTI ATENGE NAWO MBALI MUKAFUKUFUKU

Mutu wakafukufuku: kafufuzidwe ka mmene kaganizidwe, chikhalidwe ndi ndondomeko yakaperekedwe ka chithandizo chazaumoyo zimagwirizirana ndikufotokozera ana omwe ali ndi kachilombo koyambitsa matenda a Edzi za momwe mthupi mwawo mulili m'dziko la Malawi: Njira yowunikira ndi kufufuza zakufunika kwakukhala ndi mabuku owunikira ndondomeko yofotokozera ana kuti ali ndi kachilombo koyambitsa matenda a Edzi.

Anthu ochita kafukufuku: Fatch Kalembo, Dr Garth Kendall, Dr Mohammed Ali

Ndapatsidwa ndondomeko yolembedwa bwino yokhuza kafukufuku ndipo ndikumvetsa zolinga zakafukufukuyi.
Ndapatsidwa nthawi yolingalira zotenga nawo mbali mukafukufukuyi

Ndinapatsidwa mwayi ofunsa zakafukufukuyi ndipo ndakhutisidwa ndi mayankho ake

Ndipo ndikumvetsa kuti ngati kafukufukuyi angasindikizidwe mumabuku kapena munjira

ina iliyonseyo, sindizazindikiridwa munjira ili yonse.

Ndikumvetsa kuti nditha kusiya kutenga nawo mbali mukafukufukuyi nthawi ina iliyonse popanda kupatsidwa chilango chokhuza ine kapena mwana wanga.

Ndikuziwa kuti ngati ndingakhale ndi madandaulo nditha kuuza oyanganira zakafukufuku mu unduna wa zaumoyo motere: National Health Sciences Research Committee, Ministry of Health (Research Department, P.O. BOX, 30O377, Lilongwe 3, Malawi (Phone: +26 560 1726422).

Mawu ochokera kwa otenga nawo mbali mu kafukufuku

Ine……………………………………………………………….. (Lembani Dzina lonse)

Ndikumvetsa za zolinga za kafukufukuyi ndipo ndikumvetsa kuti ndiri ndi mwayi wofunsa mafunso nthawi inaliyonse.

Ndikuvomera kuyankha mafunso akafukufukuyi

Ndikumvetsa kuti kutenga kwanga mbali mukafukufukuyi ndikochita kufuna mosakakamizidwa ndipo nditha kusiya kutenga mbali mukafukufukuyi nthawi ili yonse popanda chilango chili chonse.

Sayini/chidindo cha chala ……………………………. wotenga mbali mukafukufuku

Sayini …………………………………………… woyendetsa kafukufuku

Tsiku ……………………………………………………

Translated Appendix J

NDONDOMEKO YOTSOGOLERA ZOKAMBIRANA ZA GULU LA MAKOLO NDI OSAMALIRA ANA OMWE ALI NDIKACHILOMBO KOYAMBITSA MATENDA A EDZI

Chiyambi

Dzina langa ndine Fatch Kalembo ndikupanga kafukufuku woona zammene mwana angafotokozeredwe kuti ali ndi kachilombo koyambitsa matenda a Edzi komanso kufufuza ngati kuli kofunika kukhala ndi mabukhu omwe azawunikira makolo momwe angawafotozere ana awo kuti ali ndi kachilombo koyambitsa matenda a Edzi. Cholinga cha zokambilanazi ndikudziwa maganizo anu pankhani yokhuza kuwuza ana momwe mthupi mwawo mulili komanso zakufunika kwa kukhala ndi mabukhu omwe aziwunikira momwe anawa angawuziridwe za matenda awo. Kukambirana kwathu lero kutenga mphindi 45.

Tisanayambe, ndikupemphani kuti musayine chikalata chosonyeza kuvomereza kwanu kulowa mukafukufukuyu. Ndikoyenera kuti muyenera kudziwa zambiri zokhuza kafukufukuyu, zolinga zake komanso ufulu wanu woyankhidwa mafunso wonse womwe mungakhale nawo okhuza kafukufukuyu komanso ufulu wanu wukusungirani chinsisi pankhani zonse zomwe titakambirane.

Ndiwerenga pepala lomwe ndakupatsani lokhuza zakafukufukuyu. *Werengani.* Muli ndifunso, chonde khalani omasuka kufunsa funso lililonse lokhuza kafukufukuyi. Chonde yankhani mafunso onse.

Ndifuna kukutsimikizirani kuti mayankho onse omwe mutapereke akhala achinsisi. Palibe dzina lomwe lizalembedwe posindikiza zosatira zakafukufukuyu. Palibe yankho lokhonza kapena lolakwa. Mungoyenera kuyankha mowona mayankho onse. Ngati simukufuna kusayina kalata yovomereza kulowa kwanu mukafukufukuyu muli ndi ufulu kusatenga nawo mbali muzokambiranazi. Ngati wina aliyense atakhale omangika ndi funso lililonse kapena ndi chinachilichonse chomwe titakambirane, atha osayankhapo, kapena kulankhulapo.

Mafunso wotsogolera zokambirana pakati pa makolo kapena osamalira ana womwe ali ndi kachilombo koyambitsa matenda a Edzi.

1. Kodi mukuganiza bwanji pa nkhani yofotokozera mwana yemwe ali ndi kachirombo koyambitsa matenda a Edzi, mmene mthupi mwake mulili?
   1.1 Kufunikira kwake?
2. M'banja mwanu ndi ndani yemwe amapanga kapena angapange ganizo loti mwana afotokozeredwe kuti ali ndi kachilombo koyambitsa matenda a Edzi?
   2.1 Chiwunikiro: bambo? Mayi? Bombo ndi mayi? Achibale ena?
3. Kodi mwana ayenera kufotokozeredwa bwanji kuti ali ndi kachirombo koyambitsa matenda a Edzi?
   3.1 Chiwunikiro: Ndani ayenera kufotokozera mwanayo za matenda ake?
   3.2 Mwanayu ayenera kufotokozeredwa kuti (malo ati/or otani) (malo) kuti ali ndi kachirombo koyambitsa matendawa?
   3.3 Mwanayi ayenera kufotokozeredwa pang'onopang'ono za matenda ake kapena mwanthawi yimodzi?
4. Kodi ndithandizo lotani lomwe mungafunikire kuti mumufotokozere mwana wanu kuti ali ndi kachirombo koyambitsa matenda a Edzi?
   4.1. Chiwunikiro: Maphunziro? Chithandizo kuchokera kwa ogwira ntchito mchipatala? Chithandizo kuchokera ku banja kwanu? Buku loti likutsogolereni pomufotokozera mwana za matendawa?
5. Kodi ndi zifukwa ziti zomwe zimalepheretsa makolo kapena osamalira ana kufotokozera ana awo kuti ali ndi kachirombo koyambitsa matenda a Edzi?
   5.1. Chiwunikiro: Ndalama? kusalana? Kusakhana? Kusowa kwathandizo? Kuchepekeredwa nzeru? Zaka za mwana? Chikhalidwe cha makolo?
6. Kodi makolo ndi osamalira ana angalimbikitsidwe bwanji kuti azitha kufotokozera ana awo womwe ali ndikachirombo koyambitsa matenda a Edzi za matenda awo?
   6.1. Chowunikira: Maphunziro? Kupatsidwa chithandizo?
7. Tili ndi ganizo lofuna kulemba mabuku a ana omwe angathandize powunikira makolo kuti azitha kuwafotokozera ana omwe ali ndi kachilombo koyambitsa matenda a Edzi nkhani yokhuza momwe mthupi mwawo mulili. Mabukuwa alembedwa poganizilira kukula kwa mwana mu msinkhu ndi nzeru. Mabukuwa alembedwa muchichewa ndipo akhala ndi zithunzi, nthano komanso nyimbo zothandiza kuwuza mwana kuti ali ndi kachilombo koyambitsa matenda a Edzi. Maganizo anu ndi otani pa nkhani imeneyi?
   7.1. Chiwunikiro: Kufunikira kwa mabukuwa? Kalandiridwe kapena kavomerezedwe ka mabukuwa? Kagwiritsidwe ntchito ka mabukuwa?
8. Kodi mabuku anawa mungakonde mutakhala zinthu zotani?
9. Pali china chomwe mungafune kuti muwonjezere pa zomwe takambiranazi?

Apa ndi pamapeto pa zokambirana zathu.

Zikomo kwambiri chifukwa chotenga nawo mbali pazokambiranazi. Tiliwothokoza chifukwa chogawana nafe maganizo anu.

Translated Appendix Q

GAWO LOPHATIKIZA: MAFUNSO

PEPALA LOFOTOZA NDONDOMEKO YAKAFUKUFUKU KWA ATSOGOLERI A MMADERA

Mutu wakafukufuku: kufufuza mmene kaganizidwe, chikhalidwe ndi ndondomeko yakaperekedwe kachithandizo chazaumoyo zimagwirizirana ndi kufotokozera ana omwe ali ndikachilombo koyambitsa matenda a Edzi za momwe nthupi mwawo mulili m'dziko la Malawi: Njira yowunikira ndi kufufuza zakufunika kwakukhala ndi mabuku owunikira ndondomeko yofotokozera ana kuti ali ndikachilombo koyambitsa matenda a Edzi.

Anthu ochita kafukufuku: Fatch Kalembo, Dr Garth Kendall, Dr Mohammed Ali

Dzina langa ndine Fatch Kalembo wophunzira za udotolo pa sukulu ya ukachenjede ya Curtin ku Australia. Ngati gawo la maphunziro anga, ndikupanga kafukufuku yemwe zolinga zake ndi kuwunika momwe ana amafotokozeredwa kuti ali ndi kachilombo kayambitsa matenda a Edzi, komanso kulemba mabuku omwe adzawunikire makolo momwe angafotokozere ana awo za momwe mthupi mwawo mulili. Mukupemphedwa kuti mutengepo mbali mukafukufukuyu. Mabukuwa akhala olembedwa poganizira msinkhu wa mwana komanso chikhalidwe chanu. Kafukufukuyi athandiza ana omwe ali ndi kachilombo ka HIV kuti azitha kumvetsa bwino za momwe alili komanso kuti azikhala ndi chidwi chosata ndondomeko yakamwedwe ka mankhwala wochepetsa tizilombo ta HIV.

Ngati wotenga mbali mukafufukuyu, mufunsidwa mafunso okhuza nzeru zanu, maganizo and komanso machitidwe anu pankhani yokhunza kufotokozera ana omwe ali ndi kachilombo koyambitsa matenda a Edzi momwe nthupi mwawo mulili. Mufunsidwanso za maganizo anu pakhani yofunikira ndi kukhala ndi mabuku owunikira makolo kapena omwe amasamalira ana omwe ali ndi kachilombo koyambitsa matenda a Edzi kuti azitha kuwafotokozera za momwe nthupi mwawo mulili. Mafunso akafukufukuyi atenga mphindi 45.

Ndi kofunika kuti musanavomereze kutenga nawo mbali mukafukufukuyi, muyenera kudziwa izi:

- **Dziwani kuti kulowa mukafukufukuyi ndi kosakakamiza:** Kutenga nawo mbali mukafukufukuyi sikukugwirizana munjira iliyonse ndi chithandizo chomwe mumalandira kuchipatala. Mutha kusatenga nawo mbali kapena kutuluka mukafukufukuyi nthawi iliyonse yomwe mwafuna popanda kulandira chilango chilichonse.
- **Muli ndi ufulu woyankha mafunso omwe mukufuna:** Ngati simukufuna kuyakha mafunso ena muli ndi ufulu kutero. Mutha kukambirana ndi woyendetsa kafukufuku za nkhawa kapena mafunso ena aliwonse womwe mungakhale nawo.
- **Zonse zomwe mutatiwuze zikhala zachinsinsi:** okhawo oyendetsa kafukufukuyi ndiwo atakhale ndi chilolezo chowona zomwe mwanena mukafukufukuyi. Mayankho anu onse asungidwa mwachinsinsi ndipo sazaperekedwa kwa aliyense. Sitizalemba dzina lanu powulutsa zotsatira zakafukufukuyi. Mukafukufukuyi tigwiritsa ntchito nambala m'malo mwa dzina

lanu ndicholinga chofuna kukusungirani chinsisi Zonse zokhuza kafukufukuyi zikasungidwa bwino ku sukulu ya ukachanjede ya Curtin.

- Ngati mbali ina iliyonse yakafukufukuyi yingasindikizidwe, tizayesesa kuteteza kuti musazindikiridwe munjira ina iliyonse.

Kafukufukuyi ndiwovomerezedwa ndi gulu lowona za ndondomeko ya kafukufuku ya sukulu ya ukachenjede ya Curtin (Chiphatso chachilolezo HRxxx/2014). Mu gulu la ndondomeko lakafukufukuyi muli akatswiri a zamaphunziro, malamulo, madotolo komanso akuluakulu a mipingo. Ngati mukufuna kufusa za mbiri zachilolezo chakafukufukuyi mutha kulemba kalata ku adilesi iyi: Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University, GPO Box U1987, Perth, 6845 kapena mutha kutchaya lamya pa nambala iyi +6189266 2784 munthanso kulemba imelo ku adilesi iyi hrec@curtin.edu.au

Kafukufukuyi ngovomerezekanso ndi bungwe lowona za ndondomeko yakafukufuku mu unduna wa za umoyo ku Malawi. Ngati muli ndi nkhawa yiliyonse yokhuza kafukufukuyi, chonde yankhulani ndi oyang'anira za ndondomeko ya kafukufuku ku unduna wazaumoyo pa adilesi iyi: Chairman, National Health Sciences Research Committee, Ministry of Health (Research Department, P.O. BOX, 300377, Lilongwe 3, Malawi (kapena yimbani lamya pa nambala iyi: +26 560 1726422).

Ngati muli ndi funso kapena kufuna kudziwa zambiri za kafukufukuyi, khalani omasuka kuyankhulana ndi omwe akuyang'anira kufukufukuyi pogwiritsa ntchito zina ndi nambala ya lamya yili musimu. Oyang'anira kafukufuku: Fatch Kalembo Email: kalembofatch@yahoo.com Nambala ya lamya: +265998260623.

Translated Appendix R

MAFUNSO

Malo a kafukufuku ……………………………………

KALATA YOPEMPHA CHIVOMEREZO KUCHOKERA KWATSOGOLERI A MABUNGWE NDI MMDZI (atsogoleri ammadera)

Mutu wakafukufuku: kufufuza ka mmene kaganizidwe, chikhalidwe ndi ndondomeko yakaperekedwe kachithandizo chazaumoyo zimagwirizirana ndikufotokozera ana omwe ali ndikacholombo koyambitsa matenda a Edzi za momwe nthupi mwawo mulili m'dziko la Malawi: Njira yowunikira ndi kufufuza zakufunika kwakukhala ndi mabuku owunikira ndondomeko yofotokozera ana kuti ali ndikachilombo koyambitsa matenda a Edzi.

Anthu woyendetsa kafukufuku: Fatch Kalembo, Dr Garth Kendall, Dr Mohammed Ali

Ndapatsidwa ndondomeko yolembedwa bwino yokhuza kafukufuku ndipo ndikumvetsa zolinga zakafukufukuyi.

Ndapatsidwa nthawi yolingalira zotenga nawo mbali mukafukufukuyi

Ndinapatsidwa mwayi ofunsa zakafukufukuyi ndipo ndakhutisidwa ndi mayankho ake

Ndipo ndikumvetsa kuti ngati kafukufukuyi angasindikizidwe mumabuku kapena munjira iliyonseyo, sindizazindikiridwa munjira ili yonse.

Ndikumvetsa kuti nditha kusiya kutenga mbali mukafukufukuyi nthawi ina iliyonse popanda kupatsidwa chilango chokhuza ine kapena mwana wanga.

Ndikuziwa kuti ngati ndingakhale ndi madandaulo nditha kuuza oyanganira zakafukufuku mu unduna wa zaumoyo motere: National Health Sciences Research Committee, Ministry of Health (Research Department, P.O. BOX, 30O377, Lilongwe 3, Malawi (Phone: +26 560 1726422).

Mawu ochokera kwa otenga nawo mbali mu kafukufuku

Ine………………………………………………………………….. (Lembani Dzina lonse)

Ndikumvetsa za zolinga za kafukufukuyi ndipo ndikumvetsa kuti ndiri ndi mwayi wofunsa mafunso nthawi inaliyonse.

Ndikuvomera kuyankha mafunso akafukufukuyi

Ndikumvetsa kuti kutenga kwanga mbali mukafukufukuyi ndikochita kufuna mosakakamizidwa ndiponditha kusiya kutenga mbali mukafukufukuyi nthawi ili yonse popanda chilango chili chonse.

Sayini/chidindo cha chala ……………………………wotenga mbali mukafukufuku
Sayini ……………………………………………woyendetsa kafukufuku
Tsiku ………………………

Translated Appendix S

NDONDOMEKO YOYENDETSERA MFUSO WA ATSOGOLERI A MABUNGWE NDI MMUDZI:

Chiyambi

Dzina langa ndine Fatch Kalembo ndikupanga kafukufuku woona zammene mwana angafotokozeredwe kuti ali ndi kachilombo kayambitsa matenda a Edzi komanso kufufuza ngati kuli kofunika kukhala ndi mabukhu omwe azawunikira makolo momwe angawafotozere ana awo kuti ali ndi kachilombo koyambitsa matenda a Edzi. Cholinga cha zokambilanazi ndikudziwa maganizo anu pankhani yokhuza kuwuza ana momwe nthupi mwawo mulili komanso zakufunika kwa kukhala ndi mabukhu omwe aziwunikira momwe anawa angawuziridwe za matenda awo. Kukambirana kwathu lero kutenga mphindi 45.

Tisanayambe, ndikupephani kuti musayine chikalata chosonyeza kuvomereza kwanu kulowa mukafukufukuyu. Ndikoyenera kuti muyenera kudziwa zambiri zokhuza kafukufukuyu, zolinga zake komanso ufulu wanu woyankhidwa mafunso aliwonse womwe mungakhale nawo okhuza kafukufukuyu komanso ufulu wanu wokusungirani chinsisi pankhani zones zomwe titakambirane.

Ndiwerenga pepala lomwe ndakupatsani lokhuza zakafukufukuyu. *Werengani.* Muli ndifunso, chonde khalani omasuka kufunsa funso lililonse lokhuza zakafukufukuyi. Chonde yakhani mafunso onse.

Ndifuna kukusimikizirani kuti mayankho onse omwe mutapereke akhala achinsisi. Palibe dzina lomwe lizalembedwe posindikiza zosatira zakafukufukuyu. Palibe yankho lonkhoza kapena lolakwa. Mungoyenera kuyankha mowona mayankho onse. Ngati simukufuna kusayina kalata yovomereza kulowa kwanu mukafukufukuyu muli ndi ufulu kusatenga nawo mbali muzokambiranazi. Ngati wina aliyense atakhale omangika ndi funso lililonse kapena ndi chinachilichonse chomwe titakambirane, atha osayakhapo, kapena kulankhulapo.

Mfuso wa Atsogoleri a mabungwe ndi m'midzi

1. Malingana ndimomwe mwakhalira mukugwira ntchito yanu, ndimavuto ati omwe ana omwe ali ndi kachilombo koyambitsa matenda a Edzi akukumana nawo mmadera momwe akukhala?
    1.1. Chiwunikiro: kusalidwa ndi kusankhidwa
2. Mukuganiza bwanji pa nkhani yofotokozera ana omwe ali ndi kachirombo koyambitsa matenda a Edzi momwe mthupi mwawo mulili?
    2.1. Chiwunikiro: Boma la Malawi likulimbikitsa kuti ana a zaka zapakati pa 6 ndi 12 womwe ali ndi kachilombo koyambitsa matenda a Edzi aziwuzidwa momwe nthupi mwawo muliri? Inu maganizo anu ndi wotani pankhani imeneyi? Nanga pali ubwino uliwonse? Ngati ulipo fotokozani?
3. Kodi maganizo anu ngotani pa nkhani yoti atsogoleri a m'madera azitenga nawo mbali pankhani yofotokozera ana womwe ali ndi kachilombo koyambitsa matenda a Edzi momwe mthupi mwawo mulili?
    3.1. Chiwunikiro: Ubwino?
4. Kodi atsogoleri a mudzi ndi mmabugwe angathandize bwanji kupitsa patsogolo nkhalidwe wofotokozera ana womwe ali ndi kachirombo koyambitsa matenda a Edzi za matenda awo?
    4.1. Chiwunikiro: misonkhano ya anthu? Kuthana ndi nkhalidwe wakusalana ndi kusankhana?
5. Tili ndiganizo lofuna kulemba mabuku a wana womwe angathandize powunikira makolo kuti azitha kuwafotokozera ana womwe ali ndi kachirombo koyambitsa matenda a Edzi nkhani yokhuza momwe mnthupi mwawo mulili. Mabukuwa alembedwa malingana ndi kakulidwe ka mwana mu nsinkhu ndi nzeru. Mabukuwa alembedwa muchichewa ndipo akhala ndi zithunzi, nthano komanso nyimbo zothandiza kufotokozera mwana kuti ali ndi kachilombo koyambitsa matenda a Edzi. Maganizo anu ndi otani pa nkhani imeneyi?
    5.1. Chiwunikiro: Kufunikira kwa mabukuwa? Kalandiridwe kapena kavomerezedwe ka mabukuwa? Kagwiritsidwe ntchito ka mabukuwa?
6. Kodi mabuku anawa mungakonde mutakhala zinthu zotani?
7. Pali china chomwe mungafune kuti muwonjezere pa zomwe takambiranazi?

Apa ndi pamapeto pa zokambirana zathu.

Zikomo kwambiri chifukwa chotenga nawo mbali pazokambiranazi. Tiliwothokoza chifukwa chogawana nafe maganizo anu.