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**Caregivers' Readiness to Disclose HIV Status:
Experiences and Challenges of Child Disclosure in South Africa**

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A mini-dissertation submitted in partial fulfilment of the requirements for the degree of Master of Public Health (Social and Behavioural Sciences), School of Public Health and Family Medicine, University of Cape Town.

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ABSTRACT

Disclosure of HIV plays an important role in the disease management and care of HIV positive children. However, primary caregivers, who are typically responsible for disclosure, delay or avoid the process due to various challenges, which discourage them from disclosing. Aside from the lack of support available to caregivers in the process of disclosing to their children, caregiver 'readiness' influences the process of HIV disclosure, and the delay in disclosing can have a significant effect on children's anti-retroviral treatment adherence and retention in care. This thesis considers these issues in three parts as follows: (1) a protocol for a study (Part A) of primary caregivers in Khayelitsha, an impoverished peri-urban township in Cape Town, intended to explore the experiences and challenges that caregivers face with having to disclose HIV status to a child; (2) a review of the literature (Part B) on the conceptualisation of child disclosure and the importance of the practice, as well as the barriers to and facilitators of this process, and how these factors influence caregivers' decision to disclose; and (3) a qualitative study (Part C) exploring and analysing the experiences and perspectives of HIV disclosure among primary caregivers in Khayelitsha, specifically describing the factors that influence their readiness to disclose HIV status to children. By conducting qualitative research on the perceptions of primary caregivers in a hitherto under-researched region of South Africa, it is intended that this thesis will both broaden the evidence base of available data on caregivers' perceptions on disclosure and will contribute to ongoing endeavours to develop a set of national guidelines on child disclosure.

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ACRONYMS AND ABBREVIATIONS

AIDS	Acquired immune deficiency syndrome
ART	Antiretroviral therapy
ARV	Antiretroviral
CDP	Caregiver-led Disclosure Programme
DR-TB	Drug-resistant tuberculosis
FAMSA	Families South Africa
FD	Full disclosure
FGD	Focus group discussion
GAPA	Grandmothers Against Poverty & AIDS
HIV	Human immunodeficiency virus infection
HREC	Health Sciences Faculty Human Research and Ethics Committee
HSRC	Human Sciences Research Council
HTS	HIV testing services
MSF	Médecins Sans Frontières
MTCT	Mother-to-child-transmission
NCD	Non-communicable disease
ND	Non-disclosure
NGO	Non-governmental organisation
PD	Partial disclosure
PMTCT	Prevention of mother-to-child transmission
SI	Semi-structured interview
StatsSA	Statistics South Africa
TB	Tuberculosis
Team PATA	Paediatric Aids Treatment for Africa
UCT	University of Cape Town
UNAIDS	The Joint United Nations Programme on HIV and AIDS
WHO	The World Health Organisation
WMA	The World Medical Association

PART A: RESEARCH PROTOCOL

INTRODUCTION

Over the past decade, disclosure of HIV/AIDS, and particularly disclosure to children and adolescents, has received substantial attention in the literature globally. Disclosure may be particularly challenging for caregivers and healthcare providers in resource limited settings, as disclosing HIV status involves discussing a potentially life threatening, transmissible and highly stigmatised disease in a process that may create distress for a child.^{1,2} However, despite these difficulties, the process of disclosure and the associated barriers and facilitators that impact the experience for primary caregivers of HIV positive children have not been well researched in South Africa.¹ This is particularly important as primary caregivers are often uncertain about how and when to talk about HIV to their children, and their lack of knowledge and skills results in the process of disclosure being delayed or ignored.³

According to UNAIDS, in 2014 there were approximately 37 million people across the world living with HIV, of whom 16 million had access to antiretroviral therapy (ART). The highest proportion of HIV positive people live in sub-Saharan Africa, amounting to 66% of the global aggregate of HIV infections. In this region, South Africa has the highest HIV infection rate and disease-related deaths worldwide.⁴ The latest available statistics show that there are 360 000 children in South Africa living with HIV with a prevalence of roughly 6% among adolescent girls aged 15 to 19 years and roughly 1% of among adolescent boys of the same age.⁵ Although many of these children acquired HIV perinatally through mother-to-child-transmission (MTCT), South Africa has the largest ART programme in the world and with the increasing availability of drugs, the rate of MTCT has dropped significantly, contributing to an overall reduction in AIDS infections and mortality among HIV-infected children.⁶ As more HIV-infected children gain access to treatment, fewer are dying and more are surviving into adolescence and adulthood, creating a new concern about how to inform these children about their HIV status.⁶

Disclosure of HIV is argued to have a significant effect on the clinical care of HIV-infected children, including their retention in care and adherence to ART, and is seen to influence their decision making related to their healthcare.⁷ It has been shown in the literature that children benefit from openly discussing their illness and this often leads to improved self-esteem.⁸ Evidence suggests that children who are disclosed experience less psychological problems (particularly lower levels of anxiety), have greater adherence to their anti-retrovirals (ARVs), thus slowing the progression of their disease, and have a better understanding of their health and the need for ART.^{9, 10} Furthermore, upon disclosure, children are reported to take more responsibility for their treatment as they become less dependent on

parental or guardian supervision, and have improved health outcomes and quality of life due to greater access to psychosocial support structures.^{10, 11}

In many family units, caregivers of HIV-positive children (including biological or foster parents, or members of the extended family) usually control the flow of information to their children, resulting in a situation where children have very little power over how, when, and where they are informed of their HIV status.⁷ However, the disclosure process itself poses a variety of challenges to caregivers as they face making decisions about how and when to disclose to a child his or her HIV status.⁷ In addition, there are often uncertainties about whether responsibility for the disclosure process lies with the primary caregiver or a healthcare provider.¹ Research suggests that stigma, discrimination and shame,¹² fear of negative emotional consequences and social isolation,¹³ parental guilt regarding MTCT,^{14, 15} together with cultural and social norms all present challenges to the disclosure of HIV diagnosis.¹⁶ Caregivers are also often reluctant to disclose HIV status to their child, because they believe he or she is too young to understand the nature of the disease. As seen in the literature, some caregivers view children below the age of five as too young for disclosure, and only children over twelve as old enough to understand the concepts of health and the implications of HIV.^{17, 18} Furthermore, caregivers delay disclosure as they are often worried about upsetting the child and fear that the child may suffer psychological harm as a result of disclosure. As a consequence, caregivers would often prefer to ‘protect’ their child from what they perceive to be a ‘harmful truth’, which they believe, could lead to negative outcomes.¹⁹

However, as intimated, non-disclosure can have long lasting effects on the psychological development of a child, as avoidance of the issue can insulate him or her from potential sources of support, thus leading to psychosocial problems, anxiety, emotional distress and depression.¹⁰ Furthermore, this is also a critical public health issue as non-disclosure may lead to non-adherence of ARV medication regimens, which, in turn, could serve to advance drug resistant strains of HIV.⁹ In addition, as these children grow up unaware of the dangers of the disease they may engage in precarious sexual activities as adolescents, and thereby contribute to further transmission of the virus, including the transmission of drug-resistant strains of the disease to the uninfected population.² Furthermore, in South African households primary caregivers are often hesitant to disclose because of the social and cultural environment surrounding the family unit.⁷ Such social and cultural norms often govern discussions relating to sexuality and thus discourage caregivers from disclosing HIV to their children.²⁰ These norms create a barrier to caregiver-child communication as discussions of sex and HIV disclosure cannot take place without violating cultural conventions.²⁰ This is further compounded by the lack of knowledge on sexual and reproductive health issues on the part of the caregivers themselves.⁶

Despite the overall importance of the process, disclosure in South Africa remains consistently low with countless HIV-positive children unaware of their diagnostic status. This is exacerbated by the fact that

some children become orphans due to their parents' death from HIV/AIDS, and their primary caregiver is often not their biological parent and hence may not be aware of the child's status.¹¹ Coupled with social stigma and discrimination, disclosure remains difficult because of generally low education and literacy levels in a community, and limited access to relevant health information.¹¹ As a consequence, open communication between caregivers and children about HIV is generally poor, and this is known to hinder the process of disclosure.²⁰ This can have significant implications for children's health, adherence, treatment and long-term disease management as well as their emotional well-being.¹¹

STATEMENT OF THE PROBLEM

It is evident that relatively little is known about the experiences of child disclosure for primary caregivers across South Africa and the complex issues they face in how and when to disclose HIV status to a child.⁸ As a consequence, there is a need to further explore and understand the experiences and perspectives of primary caregivers of HIV disclosure, looking specifically at the barriers and facilitators to disclosure and how they respond and manage these factors. This will provide important insights into how interventions should be designed to assist caregivers in the initiation and progression of disclosure.

RATIONALE AND AIMS OF THE STUDY

This study intends to explore the experiences and challenges of primary caregivers in Khayelitsha, Cape Town, in order to gain information about how they communicate and interact with their children about their HIV and health status, and how this affects the process of child disclosure. The study aims to analyse the narratives and perspectives of primary caregivers to generate a broader understanding of how they make decisions regarding child disclosure and how existing patterns of information-sharing and practices of communication shape this process. The study further aims to broaden the case base by collecting information from caregivers of HIV positive children as well as from other key informants, including healthcare providers and staff from local non-governmental organisations (NGOs) involved in child disclosure in an area as yet un-researched. In understanding the role that primary caregivers play in the process, this research will identify what factors assist or hinder them in disclosing to their children. As there is currently a lack of guidelines and recommendations for child disclosure in South Africa, this research could help to inform the development of interventions that will be of assistance to primary caregivers in acquiring the necessary knowledge and skills to communicate effectively and manage the process of HIV disclosure with their children.

RESEARCH QUESTIONS

Main research question

What are the experiences and challenges of primary caregivers in the process of disclosure of HIV status to infected children in Khayelitsha?

Subsidiary research questions

- Who is involved in child disclosure and what role do they play in the decision to disclose?
- What are the barriers and facilitators to child disclosure?
- How are these barriers addressed, actively managed and overcome by primary caregivers in the process of disclosure?
- What do primary caregivers feel they need to know in order to initiate the process of disclosure with their children? What are primary caregivers' needs during the process of disclosure?
- How does information and support from others shape the process of child disclosure for primary caregivers?
- How does disclosure with a child affect a primary caregiver's own HIV disclosure?
- What are the existing practices of communication and information sharing between primary caregivers and HIV-infected children regarding health and health risks, and how do these patterns shape child disclosure?
- What is the effect of disclosure on the caregiver-child relationship and how does the process influence broader family and social networks?
- How do healthcare providers and NGO staff understand and engage in the process of disclosure?

METHODOLOGY

Study design

An explorative qualitative design with an in-depth thematic analysis approach has been selected as a suitable method to examine the experiences of caregivers in the process of child disclosure. With this study design, it will be possible to gain a deeper understanding of the perspectives of the participants, and this will allow the researcher to discover and identify the meanings caregivers assign to the process of disclosure.²¹

In response to the challenges surrounding child disclosure in South Africa, Médecins Sans Frontières (MSF) developed a disclosure programme to empower caregivers to initiate and sustain the disclosure

process with their children in their own homes with the support of healthcare providers. The Caregiver-led Disclosure Programme (CDP) was first piloted at Ubuntu Clinic in Khayelitsha in 2011, and the programme aimed to ensure that children and families could be targeted, and that the process of disclosure could be integrated within homes and communities. Prior to the implementation of the CDP, MSF and the University of Cape Town (UCT) partnered to conduct a qualitative research study to strengthen the intervention model, and to inform further development of the programme and adaptation of its materials. The proposed study, therefore, constitutes a component of the research conducted by UCT and MSF.

Study population and setting

The main field sites for this study will be Kuyasa Clinic and Ubuntu Clinic in Khayelitsha, as well as broader healthcare services and NGOs in the area involved in disclosure practices. Khayelitsha, a peri-urban township located on the outskirts of Cape Town, with a population of approximately 1 000 000 people, has one of the highest infections rates of HIV, tuberculosis (TB) and drug-resistant tuberculosis (DR-TB) in the country and indeed the world.²² This township has a high proportion of informal housing and a lack of access to such basic services as piped water, sanitation, refuse, electricity and health care amenities.²³

The primary research population, which will be sourced from the larger study, will comprised of three key informant groups including (1) caregivers from the Ubuntu Clinic Family Club, (2) healthcare providers at Kuyasa Clinic, and (3) NGO staff working at local organisations in Khayelitsha who are involved in disclosure practices. These groups have been chosen to support a process of triangulation whereby the perspectives of different informants can be assessed in order to identify common factors that hinder or facilitate disclosure practices in Khayelitsha. In addition, this will also allow for comparison between the groups to determine the different roles they play in the process of disclosure.

Caregivers from the Ubuntu Family Club

The Ubuntu Clinic is a public primary care HIV/TB facility serving one of the biggest groups of ART patients in Khayelitsha.²² The Ubuntu Clinic Family Club is one of the many adherence clubs established around Khayelitsha to improve clinic efficiency, sustain retention in care and improve long-term ARV adherence.²⁴ The Ubuntu Clinic Family Club, which is specifically for caregivers and their children who are stable on their medication, is run by healthcare workers from the clinic and they meet every two months. On club days, caregivers receive ARV medication for themselves and/or their children, both are screened for HIV-related opportunistic infections (children are weighed and blood is taken when necessary), and patients receive an educational talk.²⁴ In addition, the club provides a

supportive network for the caregivers of HIV positive children, which enables them to discuss their experiences with other caregivers and healthcare providers. All of the children currently in the Family Club have been disclosed to, and the caregivers attending may be their biological, adoptive or foster parents, or members of their extended family.²⁴ The participation of the caregivers in this study will provide insights into the successes and challenges of disclosure practices at the clinic, as well as the experiences of caregivers in the disclosure of HIV to their children.

Healthcare providers at Kuyasa Clinic

Kuyasa Clinic, which is a public primary healthcare facility supported by MSF, provides HIV/AIDS and TB-related treatment services to patients in the surrounding township areas. These include awareness training and prevention services, and psycho-social and socio-economic support.²⁵ The clinic provides treatment-related services such as ARV treatment initiation, family planning, HIV testing services (HTS), and maternal and obstetrics healthcare including antenatal care and prevention of MTCT.²⁵ This study will include healthcare providers from the clinic who are involved in disclosure practices, such as facility managers, physicians and nurses and lay counsellors who may already have participated in the larger study. Their participation will reveal the complexities of the disclosure process in terms of who is involved or responsible for disclosing, and the legal and ethical implications relating to the rights of the child. Their responses will also shed light on their experiences with the caregivers of HIV positive children.

Staff working for NGOs and other organisations

Several NGOs, who are involved in disclosure practices and previously identified in the larger study, including Anova Health, FAMSA, GAPA, Generation Ubuntu, Mercy AIDS, South-to-South, Team PATA, Ubuntu Africa and Yabonga, will be approached to participate in this study. The focus here will be to explore the cultural and community based challenges that these organisations face in the disclosure services they provide. This will touch on such issues as caregivers' resistance to disclosure and attitudes towards the process; cultural issues, discrimination and stigmatisation; relationships and communication between caregivers and children; and the effectiveness of provider support services.

Sampling and recruitment

The selection of participants for the study will be based on purposive sampling techniques, as potential respondents will be chosen based on their experience and/or knowledge of child disclosure. The participants will be recruited through the larger study. Inclusion criteria for the key informant groups will be as follows:

- **Caregivers** will be eligible to participate if they are the primary or secondary carer of a child (the sex of the caregiver is irrelevant) who is HIV positive, who is between the ages of 4 and 18, and who may or may not have been disclosed to at the time when the study commences. In addition, the caregiver may or may not have had experience with child disclosure. Caregivers will be selected predominantly from adherence and support groups at the Ubuntu Clinic Family Club. The researcher will also aim to include caregivers who attend NGOs and other organisations, which offer disclosure programs in Khayelitsha.
- **Healthcare providers** will be selected to participate if they are involved in disclosure practices within Kuyasa Clinic or have experience with disclosure in other settings. If necessary, the researcher will also aim to include healthcare providers who work at NGOs and other organisations, which offer disclosure programs in Khayelitsha.
- **Staff working for NGOs and other organisations** will be eligible to participate if they have knowledge and/or experience of disclosure of HIV and are willing to comment on child disclosure practices.

Participants will be excluded from the study if, as caregivers, their children are not HIV positive, or if, as healthcare providers or other experts, they do not have knowledge or experience of child disclosure. Similarly, as the study involves interviews and groups discussions (to be discussed below), some participants from the group discussions will be invited to participate in one-on-one interviews, based on their particular experiences of child disclosure. The benefits of this recruitment strategy is that it allows for a more focused selection of participants and the development of rapport with participants will be easier (as they are familiar with the research conducted in the larger study).

Data collection

The data for this study will be collected through focus group discussions (FGDs) and semi-structured interviews (SIs), and eligible participants will be invited to participate in both.

Focus group discussions

Two focus group discussions of caregivers, 8-15 participants in each, will be conducted at Ubuntu Clinic to investigate their experiences of child disclosure. In addition, a FGD will be conducted with healthcare providers at Kuyasa Clinic (including facility managers, physicians, nurses and lay counsellors) to explore their perspectives and experiences of helping caregivers to disclose HIV status to children. These discussions will be important as they allow for group interaction and insightful information as

participants are able to share their views, perceptions and attitudes about disclosure.²⁶ As a result of the sensitive nature of HIV and disclosure, the assistance of a HIV counsellor at Ubuntu Clinic will be sought to identify eligible caregivers for the FGDs, who are comfortable and willing to discuss these topics. Participants who agree to participate will be given an information sheet and consent form, and the purpose of the study will be explained to them. Following this, informed consent, including for the use of audio equipment, will be attained from caregivers and healthcare providers prior to the FGD commencing. The FGDs will be between 45 minutes to an hour in duration. The questions will be asked in English and will then be translated into isiXhosa (the dominant language in Khayelitsha) by a translator fluent in the language. Participants will be invited to respond to the questions in English or in isiXhosa.

A FGD interview guide, with open-ended questions and themes (see Appendix 1 and 2), will be used to facilitate the group discussions. These guides were adapted from the larger study and literature on child disclosure. FGDs with the caregivers will be conducted on a day when the Ubuntu Family Club meets at the clinic, and the group discussion with the healthcare providers will be conducted on a day when a minimum of 5 healthcare providers are available to participate. Both discussion groups will be conducted in a private room, and will be recorded using an audio device and with written notes. At the end of the discussion, FGD participants will be thanked for their time and cooperation, and they will be provided with refreshments as a token of appreciation for their participation.

Semi-structured interviews

Semi-structured, in-depth interviews will be conducted by the researcher with approximately 8 to 10 caregivers individually. These participants will be purposively selected from those who have previously participated in the FGDs at the clinic, and from support groups at various NGOs. In addition, healthcare providers and experts or staff from local organisations will also be approached and invited to participate in an interview. These interviews will aim to explore further the views of the participants' and their experiences of disclosure practices. As privacy and individual attention is ensured in a one-on-one interview, this will allow the participants to discuss openly their personal experiences. This form of data collection was chosen as it enables rapport to be developed between the researcher and the participants, and allows for the development of a richer understanding of the participants' knowledge and experiences.²⁷ As HIV and disclosure of status is a sensitive topic, issues that were not originally addressed in the FGDs, due to the dynamic of the group interaction, will then be investigated in more detail in the one-on-one interviews. Topics such as how participants feel about disclosure, experiences of their own disclosure (if they themselves are HIV), challenges regarding disclosure to a child, the level of support and information available, as well as the effect of disclosure on the child, will, amongst other issues, be discussed.

All potential participants will be contacted individually to arrange a day and time when the interview will be conducted. Attempts will be made to arrange interviews with caregivers on the days when they attend the Ubuntu Family Club, so that their participation does not incur any additional travel expenses. Participants who agree to participate will be given an information sheet and consent form, and the purpose of the study and interview will be explained to them. Thereafter written informed consent will be sought. The interviews will be 45 minutes to 90 minutes in duration, and the questions will be conducted in English or Xhosa depending on the preference of the participant.

Semi-structured and open-ended questions in an interview guide (see Appendix 3 and 4), derived and adapted from the original study and child disclosure literature, will be used to facilitate the interviews. All interviews will be conducted in a private room, and will be audio recorded and written notes will be taken. All participants will be thanked for their time and cooperation, and they will be provided refreshments for having participated.

Data safety and management

In order to protect participants' privacy, all hardcopy data from the study, including written notes and audio recordings, will be stored and securely locked in a cupboard. The electronic data, including the transcripts and translated material, will be stored on two hard drives (one laptop and one external hard drive) both protected by a password, and will also be backed up on Dropbox and Google Drive. In order to ensure confidentiality, only the primary researcher will have access to the hardcopy and electronic data, however the write up of the report will be overseen by the researcher's supervisor. All data will be disposed of following the submission of the report and any possible publication of the research.

Data analysis

The data from this study will be analysed using in-depth thematic analysis, which is a commonly used approach applied to qualitative data. This involves analysing the data to identify various patterns and relationships which emerge from the participants' responses.²⁶ Thematic analysis as a methodology is sensitive to the terms used by participants, and uses a method of sorting and coding to create and integrate categories of themes and sub-themes.²⁷ In this way, this method facilitates the investigation of the participants' lived experiences as a means to gaining a deeper understanding of the factors that facilitate or inhibit child disclosure.^{26, 27} For the purposes of this study, an inductive approach will be used whereby the researcher will identify themes in the full data set, without using a specific hypothesis.

Following the data collection, all audio recordings will be transcribed verbatim, after which the data will be organised and interpreted using the qualitative data package Nvivo 10. Whilst interpreting the

data, the researcher will look for patterns and regularities as well as contrasts and paradoxes, in order to identify central themes and categories on issues such as child disclosure and disclosure to others, facilitators and barriers to the disclosure process, and ART adherence and retention in care. By using the Nvivo software, it will be possible to label and code the data, and as relationships between the codes emerge through an on-going process of analytic induction, the researcher will be able to build a greater understanding of the information generated for further in-depth analysis.²⁸

Methodological considerations

Language barriers

In the group discussions and individual interviews, questions will be conducted in English and then translated into isiXhosa by a translator. Notwithstanding the potential language barrier, in facilitating the discussions with the assistance of a translator it is the intention of the researcher to be directly involved in the data collection process. The researcher will familiarise the translator with the questions of the FGDs and interviews ahead of time, and will clarify the meaning of questions for translation purposes. As evident from the larger study, some patients attending Ubuntu Clinic, along with healthcare providers at Kuyasa, do speak and understand English, and it is hoped that miscommunication between the participants and the researcher in the discussion groups will be kept to a minimum.

Reflexivity

Authors of qualitative research methods suggest that reflexivity is one of the most distinctive features of qualitative research, as it involves acknowledging the primary role of the researcher in constructing new knowledge.²¹ The key is for the researcher to recognise that all findings are constructs or personal narratives of reality of both the researcher and the study participants. This construction is often shaped by the effects of race, gender, age and class.²¹ In addition, the researcher's own assumptions and ideological and theoretical positions are influential in shaping the research process. Reflexivity can be personal in nature and relate to the characteristics of the researcher, or can be functional in the way in which the characteristics of both the researcher and the study participants direct and shape the research.²¹

In order to reflect on her position within the study, the researcher plans to keep a diary throughout the course of the study to record her thoughts, feelings, and understandings of how the FGDs and interviews have proceeded. This will allow her to consider her own subjectivity and influence over the participants, the research design, data collection, and data analysis. It will also allow her to reflect on power dynamics that develop in the interview and focus group discussions, and to reflect on how the

differences and similarities between herself (a white, middle-class English-speaking female in her late 20s) and her study participants (predominantly black African, Xhosa speaking women of different ages) will influence her research. She intends to establish suitable rapport with each study participant and will aim to do so by conducting the interviews and focus group discussions in a secure and comfortable and environment. By asking questions in a friendly and interactive way, she aims to create a relaxed and informal atmosphere in which participants feel at ease to speak openly.

Rigour

Qualitative research demands an active process of questioning and checking during the exploration of data. It also requires the researcher to engage in the practice of conceptualising and operationalising to create interpretative judgements, while being reflexive at the same time.²⁹ To ensure that a study is rigorous, a researcher needs to identify foreseeable challenges and problems at the start and throughout the study. There are various strategies, which can be used to strengthen the rigour of a study and the following steps will be taken to ensure validity and reliability throughout the investigation:

Triangulation

The combination of information generated in the interviews and FGDs will allow for the triangulation of data from different sources to gain a broader understanding of the topic of interest.

Member checking

During the data analysis, the researcher will request the assistance of another credible researcher to analyse and code the data separately, so as to make the data more dependable. By involving an independent researcher in assessing the findings, the subjective bias of the main researcher will be offset. In addition, the researcher will aim to involve the participants in a process of mutual feedback, in that where possible, she will share the findings of the study with them and will ask for their comments. This will allow the participants to correct any misunderstandings in content of the data, thus avoiding potential problems in the analysis. In addition, through ongoing feedback, important codes and themes can be identified which will assist the researcher's overall understanding of the data.

Confirmability

The researcher will at all times recognise her own central role in defining the primary issues, in interpreting the data as well as in guiding the overall research process. In so doing, the researcher will be conscious of her own subjectivity, which will allow her to better understand and limit her effects on the research process, from the collection of data to analysis.

Audit trails

The researcher will keep a record of all data and analyses excluding the identifiable details of the participants, which will allow other researchers to track the process that led to the final conclusions and interpretations of the study.

Ethical considerations

For the duration of the proposed study, the researcher will adhere to the ethical principles of the Declaration of Helsinki, established by the World Medical Association (WMA) for medical research involving human participants.³⁰ The proposed research, which will be governed by principles respecting health and human rights, will ensure that the well-being and interests of all participants (including their integrity, dignity, privacy and confidentiality of personal details and information shared) will take precedence over the primary purpose and aims of this research.

Ethical approval

Ethical approval for this proposed research will be sought from UCT Health Sciences Faculty Human Research and Ethics Committee (HREC), and from the School of Public Health and Family Medicine, UCT. As this research is a sub-study of a larger project already approved, permission has already been granted by Western Cape Provincial Department of Health, Kuyasa Clinic and the Ubuntu Clinic in Khayelitsha.

Informed consent, anonymity and confidentiality

Eligible participants will be identified through the larger project and thereafter will be invited to participate in the study. They will be given an information sheet with a consent form (see Appendix 5, 6 and 7), which will outline the purpose of the study together with the contact details of the researcher. For those participants in the FGDs, details will also be provided regarding follow-up interviews and that the fact that they may be invited to participate in a one-on-one discussion at a later stage. All participants will be informed that their participation is voluntary and that they may withdraw from the study at any time, without giving any reasons for doing so. They will also be informed that withdrawal from the study will not influence any future affiliations with the health clinic they attend or work at, or with UCT.

Prior to the interviews and group discussions, participants will be required to sign the consent form, acknowledging that they understand the information provide and that they consent to participating. Anonymity and confidentiality will be assured to each participant before each interview, and all

participants will be given the choice of whether or not to use their own name or a pseudonym. Furthermore, participants will be informed that the information they share with the researcher and translator (in the focus groups) will be kept strictly confidential, and only those involved in the research, namely the researcher, her supervisor and co-supervisor, and the person who transcribes, will have access to that information.

In particular, prior to the FGDs, the researcher will explain the importance of confidentiality within the group. Participants will be asked to respect the privacy of others by not repeating what is said in the discussion and by not revealing to anyone else the names and HIV status of others in the group or that of their children. However, it will also be cautioned that the researcher cannot guarantee that those who take part in the FGDs will keep shared information confidential.

Potential benefits

Although the participants may not receive any direct benefits for participating in the proposed study, it is the researcher's hope that the information generated will be beneficial to the caregivers, healthcare providers and other NGO staff who participated. Their involvement will allow for deeper insight into their disclosure experiences or practices, as well as their attitudes and behaviours towards child disclosure. In order to gain knowledge about the factors that facilitate and hinder child disclosure, it is useful to understand what information and support systems caregivers and healthcare providers draw upon to navigate this process. It is the hope of the researcher that the findings of this research can be of assistance in the development of child disclosure programmes and guidelines.

Potential harm

The research to be conducted with the caregivers will present minimal risk since these participants are already members of the Ubuntu Family Club and are part of a network of caregivers who meet regularly to discuss living with HIV, HIV adherence and disclosure, and provide support to one another. The activities of the proposed study are also similar to those in the larger project, and consequently there is no expected harm to any participants. Likewise, the research to be conducted with healthcare providers and staff at local NGOs will pose little or no risk since the interviews and FGDs will be about their daily work and experiences with disclosure, and questions will not be personal in nature.

Nevertheless, due to the sensitive nature of disclosure experiences, the group discussions and interview processes may elicit an emotional response from the caregivers, as they re-tell and re-experience their child's disclosure. Utmost care will be taken to ensure that the sharing of their experiences of HIV disclosure does not lead to the distress of those participating in the study. The research questions will also be devised in an open-ended and non-obtrusive style to avoid such distress. Following each group

discussion and interview, if needed, the researcher will also provide a list of counselling services in Khayelitsha, which the participants can use should they need further emotional support.

STUDY BUDGET

The following is an indicative budget for the proposed study, based on an approximation of the anticipated costs. Where necessary, the researcher will apply to the Department for funding to assist with the expenses of translation and transcription.

Table 1. Budget for Proposed Study

Item	Cost per unit	Number of Units	Total
Field Worker	–	–	Author's own time
Translation services	R60/hour	25 hours	R1,500
Transcription services	R60/hour	25 hours	R1,500
Mileage	R3/km	20 visits to study sites (approx. 60km/visit)	R3,600
Photocopying/Printing of consent forms	R0.50/page	50 pages	R25
Refreshments for participants	–	–	R500
Total			R7,125

STUDY PERIOD AND TIME FRAME

The following is the proposed time frame for the study (see the GANNT Chart of the study timeline below):

- **Study approval:** The study protocol was finalised and submitted towards the end September 2015 for ethics approval from HREC at UCT. The study will commence as soon as ethical approval is secured.
- **Recruitment (FGDs):** Following study approval, during October and November, recruitment for the focus group discussions with the Ubuntu Family Club caregivers and Kuyasa healthcare providers will be initiated and organised.
- **Data collection (FGDs):** Focus group discussions with caregivers and healthcare providers will be conducted from mid-October to the end of November.
- **Recruitment (SIs):** From the beginning of November to mid-December, the FGDs will generate a list of potential key informants to be contacted, and dates for semi-structured interviews will be arranged.

- **Data collection (SIs):** The first round of preliminary interviews will be conducted from mid-November to the end of December, with caregivers, healthcare providers and other staff from local NGOs. Second rounds will be conducted end of December to mid-January if necessary.
- **Transcription & data analysis:** Transcription will occur as data is collected, and thereafter the findings will be analysed.
- **Write up and dissemination:** Compilation of the report will begin in December and will be finalised into February.

Task Descriptions	2015-2016											
	Sept-Oct 2015				Nov-Dec 2015				Jan-Feb 2016			
	1	2	3	4	1	2	3	4	1	2	3	4
STUDY APPROVAL												
DATA COLLECTION												
Recruitment (FGD) - Meeting with Ubuntu Clinic & Kuyasa												
Data Collection (FGD) - Caregivers & healthcare providers												
Recruitment (SI) - Key informants at healthcare facilities & local NGOs												
Data Collection (SI) - 1st round caregivers, healthcare workers & NGO staff												
Data Collection (SI) - 2nd round caregivers, healthcare workers & NGO staff												
DATA ANALYSIS												
WRITE UP AND DISSEMINATION												

WRITE UP AND DISSEMINATION OF FINDINGS

The findings of the proposed study will be submitted in fulfilment of the requirements for the Masters of Public Health (Social and Behavioural Sciences) Degree at UCT, and to a peer-reviewed journal for publication. The results will be presented in the form of a report and disseminated to interested stakeholders involved in the study including caregivers, healthcare providers and NGO staff.

IMPLICATIONS FOR POLICY AND PRACTICE

The intention is that the findings of the proposed research will provide new insights into how caregivers experience disclosure and, by broadening the case base, it will lead to a better understanding of the factors, which enhance or hinder the process of disclosure. From the literature, it is evident that there is a need for standardised, but culturally sensitive HIV child disclosure guidelines that can be used by healthcare providers to assist primary caregivers, as many of them lack the skills and knowledge to initiate the disclosure process themselves.⁶ It is intended that the findings of the proposed study will assist in the development of child disclosure guidelines. In doing so, the focus can also be directed to the patterns of communication that exist between caregivers and their children in different cultural settings, and how these can be improved upon to facilitate disclosure.¹⁹

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PART B: STRUCTURED LITERATURE REVIEW

INTRODUCTION

Disclosure of HIV status to children is a developing practice that continues to be a challenge for caregivers and healthcare providers alike.¹ In South Africa, child disclosure presents an obstacle to the management of treatment and care as well as to the support of children living with HIV.² As anti-retroviral therapy (ART) is increasingly available, children are surviving to adolescence and adulthood, and this has brought to the fore new issues regarding their treatment adherence and self-care.^{3,4} More importantly is the matter of HIV disclosure, and of how and when to inform HIV-infected children about their status.⁵ Disclosure of HIV status has been shown to have a significant effect on ART adherence and retention in care, on access to support services (and thus improved levels of self-esteem and fewer signs of depression), as well as on improved long-term health outcomes and better emotional well-being for children.^{3,5,6}

Notwithstanding these benefits, however, HIV disclosure rates continue to be low in South Africa, as caregivers continue to delay the process until later childhood or adolescence.^{7,8} Evidence from resource-limited settings suggests that caregivers are often uncertain about how to talk to their children about HIV, which results in caregivers maintaining a veil of secrecy around their children's illness to avoid or delay disclosure.⁷ As a result, children are left feeling anxious, confused or resentful towards their caregivers for concealing their status, and more importantly, are denied the right to make their own healthcare decisions.² Understanding the experiences of primary caregivers and the complex issues they face on how and when to disclose HIV status to their children is an important area of investigation, as their lack of knowledge and skills has an influence over their decision to disclose. The following review will explore the various factors, which facilitate or inhibit the process of disclosure.

OBJECTIVES OF THE LITERATURE REVIEW

The objective of this review is to examine the existing literature on the perspectives of HIV child disclosure among primary caregivers of HIV positive children (including their knowledge and attitudes regarding HIV disclosure), looking specifically at the barriers to and facilitators of this process and how these influence their decision to disclose. The review is also intended to assess the extent to which current research on the topic provides sufficient empirical evidence on which to base the development of a standardised set of guidelines for disclosure to HIV infected children.

LITERATURE SEARCH STRATEGY

A review of the literature on primary caregivers' disclosure of HIV status to children was conducted and this included studies conducted in sub-Saharan Africa, with a particular focus on South Africa. In view of the limited amount of literature available in this region, the review also incorporated research conducted elsewhere in the world. The process commenced with a search for relevant peer and non-peer reviewed articles in the PubMed Central and SAGE Online databases, and in the Google Scholar search engine. Websites such as the Joint United Nations Programme on HIV AIDS (UNAIDS), the World Health Organisation (WHO), the South African Human Sciences Research Council (HSRC), and Statistics South Africa (Stats SA) were also searched for information and statistics on global and South African HIV epidemiology.

Key words used in the search criteria included "HIV", "child disclosure", "paediatric disclosure", "child disclosure AND caregiver readiness", and "HIV child disclosure AND South Africa". Reference lists of relevant articles were also hand-searched to identify additional articles for review. Abstracts were read and then all relevant articles were organised and summarised into an annotated bibliography, which included a citation and a brief descriptive paragraph on the relevance and quality of the sources retrieved. Studies were excluded if the research was conducted before the year 2000 and if the article was in any other language other than English.

SUMMARY OF THE LITERATURE

HIV/AIDS epidemic

There are approximately 37 million people living with HIV worldwide, 16 million of whom have access to ART.⁹ Sub-Saharan Africa is stated to be the region worst affected by the HIV/AIDS pandemic, with two-thirds of the world's sufferers living in this region.^{3, 9} South Africa, in particular, has the highest prevalence of HIV/AIDS in the world, with an estimated 16.8% of the total adult population living with HIV, and with some 360 000 children between the ages of 0 and 14 years believed to be infected.⁹⁻¹¹ Nevertheless, South Africa has made noteworthy progress in combating the disease and is currently rolling out the biggest ART programme in the world, and with the increasing availability of drugs, mother-to-child transmission (MTCT) rates and HIV-related childhood mortalities have dropped significantly in the last decade.^{12, 13} As a result of more HIV positive children gaining access to essential ART, fewer numbers are dying and more are surviving into adolescence and adulthood, creating a new concern of how and when to inform these children of their HIV status.¹⁴

What is child disclosure?

Disclosure of status is an essential process in the clinical care and psychological development of HIV-positive children. In recent years, the significance of HIV disclosure has been drawn from literature on diagnostic disclosure in oncology, and this has been applied to research on child HIV/AIDS.^{8, 15, 16} In this field of investigation, disclosure is defined as a person gaining knowledge of his or her HIV status, and this can occur as single, discrete event or as a gradual process.⁸ Disclosure also involves communicating HIV status in different ways with different people (partners, families or children) at various points in time. For instance, parental disclosure is defined as parents telling their HIV status to their infected or uninfected children. Child disclosure, on the other hand, refers to disclosure to a child of his or her status HIV status by the primary caregiver or parent, or to a child's disclosure of their own status to other people.⁶

Who should disclose?

Caregivers of HIV-positive children (including biological or foster parents, or members of the extended family) usually control the flow of information to their children, resulting in a situation where children have very little power over how, when, and where they are informed of their HIV status.⁵ In and of itself, therefore, the disclosure process poses various challenges to caregivers as they face decision making regarding the child's welfare. Furthermore, healthcare providers are confronted with their own obstacles in terms of disclosure, as their roles and responsibilities in the process are not well understood, and it is often unclear whether they should initiate or facilitate the disclosure process themselves, or just provide support to caregivers to disclose.^{17, 18} This is largely the result of inadequate standardised materials, tools and guidelines available to healthcare providers to support caregivers through the process of disclosure.^{19, 20} In addition, as a result of legal and ethical obligations relating to children's right to information and participation in healthcare decisions, healthcare providers are faced with the task of encouraging caregivers to initiate disclosure with their children, even though they often meet resistance.^{18, 21} Coupled with caregivers' reluctance to disclose, or their lack of knowledge and skills to facilitate the process, the gaps between the policy and practice of disclosure result in confusion and uncertainty on the part of healthcare providers.^{17, 18}

Timing and phases of disclosure

At present, there are few culturally-sensitive and context-specific disclosure guidelines regarding the timing and most effective strategies for child disclosure interventions in resource-limited settings.^{22, 23} The WHO recommends that disclosure be conducted as a process rather than a single event, and this should consider the cognitive and emotional maturity of children, allowing them and their caregivers

time to adjust to the illness and the life challenges it poses.²⁴ WHO guidelines recommend that a child should be told his or her HIV status by school going age, that is between the ages of 6 to 12 years, with younger children being told their status gradually, to accommodate their cognitive skills and emotional maturity, in preparation for full disclosure.²⁴ In addition, it is suggested that disclosure is best initiated by the primary or secondary caregiver of the child, and this decision is guided by the intent to improve and promote the child's well-being and minimise any risk associated with the process.²⁴

The process of child disclosure, as indicated above, can range from non-disclosure (ND), to partial disclosure (PD), to full disclosure (FD). The timing of these phases of disclosure, as suggested, should typically correspond to the age and maturity of the child, although research regarding the appropriate age at which children should progress from ND to PD to FD is still under debate.⁵ *Non-disclosure* involves caregivers providing no information to the child regarding their illness.²⁵ In such instances, any questions from the child concerning their health status are generally ignored or deflected with misleading information, such as by referencing their condition to unrelated medical conditions, like asthma or pneumonia, that are more socially acceptable.^{21, 25, 26} Children are also sometimes told that their anti-retroviral (ARV) medications are common daily vitamins that they need to take to stay healthy.^{5,14}

Following non-disclosure, *partial disclosure* refers to the process whereby caregivers provide children with a limited amount of information regarding their illness without specifically naming the virus. This occurs, for example, when caregivers tell children that they have “germs in their blood”^{5, 27, 28} and that the medication they are taking is to keep the “germs” and their symptoms at bay.²⁵ This approach helps to inform children why they have to attend the clinic and have blood taken regularly, and why sometimes they feel ill. *Full disclosure* refers to the process whereby a child is told the name of his or her illness (i.e. HIV) and is given specific information about the disease, such as how it affects the body and how it is transmitted, together with information regarding ARVs which must be taken daily.^{8, 29} This step may involve the caregiver explaining to the child how he or she acquired the disease, and this process may also include disclosure of the caregiver's own HIV status.⁸ Full disclosure can be successful if it is a gradual and progressive process conducted by the primary caregiver with the support and guidance of healthcare professionals, and where children are given age appropriate information as they develop the level of maturity necessary to understand their diagnosis and health status.^{30, 31}

The process continues to *post full disclosure* as caregivers reinforce on-going dialogue with their child, so that he or she can be encouraged to ask questions regarding their health status and to discuss relationships and safe sexual practices.^{30, 32} Following full disclosure, caregivers' can encourage gradual independence and responsibility in their child to take their ARVs and to understand the importance of adherence.^{33, 34} Essentially, the process of disclosure (from ND to post FD) should evolve as the child

progresses through their psychosocial and emotional developmental stages. Disclosure practiced in this manner, it is argued, improves children's understanding of their HIV status and of the importance of taking ARVs, such that they can survive into adulthood adhering to medication and taking adequate control of their health needs.³⁰

Approaches and models to disclosure

In addition to the WHO disclosure guidelines, Médecins Sans Frontières (MSF) published 'Recommendations Regarding Disclosure of HIV Status to Children under ARV' in 2005, which focuses on the objectives and means of disclosure of paediatric HIV.³⁵ The general objective of the guideline is to help the child to remain healthy and develop into a young adult despite their diagnosis, and, where possible, to live in a structured caring environment. Other aims include helping children to manage their emotions in the face of their disclosure and to build their self-esteem, facilitating communication between caregivers and their children, and assisting children to understand their health status, their illness and the necessary treatment.³⁵ However, neither the WHO nor MSF have a broad evidence base, and their respective guidelines are not context-specific or culturally-sensitive to low and middle income countries in that they do not adequately consider such contextual variances as the age, maturity and psychological development of a child.⁶

Thus healthcare providers, across a variety of resource-limited settings, continue to search for approaches to manage the challenges, which they face in assisting caregivers to begin, and continue, the process of HIV disclosure with their children.² There are a number of approaches that are currently in use to help healthcare staff navigate the challenges and complexities of disclosure. A five step approach has been proposed by Gerson and colleagues³⁶ to guide healthcare providers in assisting caregivers with child disclosure. This model advocates a staged process commencing with (1) gathering information and building a trusting relationship within the family; (2) making an assessment of the attitudes and knowledge of the caregiver and child; (3) determining the right time for disclosure; (4) involving the family unit in the process and preparing them for the disclosure event; and (5) monitoring post-disclosure coping and providing on-going support.^{2, 36}

Blasini et al.³⁷, likewise, designed and implemented a disclosure model in a HIV hospital in Puerto Rico with the aim of improving medication adherence and healthy psychological adjustment.² This model also consisted of five components aimed at guiding the disclosure procedure for healthcare workers, families and HIV-infected youth, which entailed (1) developmentally appropriate disclosure training for healthcare professionals; (2) preparing parents for disclosure through peer support groups and educational training for healthcare workers; (3) individual, interactive assessment sessions for families throughout the disclosure process; (4) disclosure sessions with parents and children; and (5) post-

disclosure follow up including teaching and support groups for families to improve their psychosocial adjustment and emotional well-being.³⁷ The results of the study revealed that 70% of the youth had feelings of normalcy and had improved adherence to therapy after disclosure.³⁷ In addition, the majority of caregivers and youth considered disclosure to be a positive event for themselves and their families, and healthcare providers reported fewer feelings of fear and anxiety regarding disclosure following implementation of the model. These outcomes confirmed the primary hypotheses of the study, namely that implementation of a structured clinical disclosure model can result in positive post-disclosure psychological adjustment and ART adherence.³⁷ This model was adapted and applied to other settings around the world including Haiti and the Dominican Republic.³⁸

Although a continuous and process-oriented approach to disclosure is encouraged in the literature, as evident in the models discussed above, there are always a variety of social, familial and cultural factors at play, which influence caregivers' readiness to disclose.³⁴ In South Africa in particular, children sometimes have limited communication with their caregivers, and disclosure thus occurs as a discrete and delayed event rather than as a gradual process.^{5, 34}

Factors supporting disclosure: Why is it important?

Multiple studies have identified the beneficial impacts of disclosure, both in low-middle and high income countries. Evidence has shown that children greatly benefit from openly discussing their illness with their caregivers, which in turn boosts self-esteem and reduces mental health problems, including depression, anxiety and stress.^{28, 34, 39} Children are also shown to have greater adherence to ART and an improved understanding of the importance of adhering to treatment and maintaining their health.³⁴ Arrive and colleagues⁴⁰ assessed the effect of HIV status on retention in care from initiation of ART among HIV-infected children, and showed that retention in care was higher for those adolescents disclosed, compared to those not. This confirms previous studies that have demonstrated that disclosure is positively associated with ART adherence.^{21, 22, 29, 31, 33, 41-43} Medication adherence, according to Beima-Sofie et al.¹, is an important component of children's acceptance of their HIV status, as well as a significant "symbol of ownership" over their illness. As a result, they are empowered and confident to assume responsibility for their own treatment and are less dependent on their caregivers for overseeing their ARV consumption. In addition, adherence is associated with slowing of the progression of the virus as well as with reducing HIV-related opportunistic infections.^{28, 41} This equates to improved health outcomes for HIV-infected children, and better quality of life as they potentially have more access to sources of support.^{18, 33} Thus, communicating the importance of adherence during the disclosure process is vital to the maintenance and provision of care for a child, and to improving their psychosocial adjustment and well-being.¹ Caregivers are therefore motivated to disclose to keep their

children physically and mentally healthy by adhering to their medication.² Conversely, studies have shown that caregivers are more likely to disclose either once their children have initiated ART or if they had been on their medication for a long duration of time.^{26, 29, 44}

Further motivating factors towards disclosure are caregivers' concerns about their children's transmission of HIV to others through risky sexual behaviour, and the need to protect others, as well as their own children.^{8, 39} Additional factors influencing caregivers' decision to disclose include a child's increasing age;⁴² persistent questioning from the child regarding his or her illness;^{6, 25} fears of accidental disclosure to the child by someone else;^{2, 45} fears of the child's health state worsening and the appearance of symptoms of HIV/AIDS;^{45, 46} or HIV-related illness or death of a parent or family member.⁵ Moreover, from a human rights perspective, a number of researchers argue that caregivers believe that a child has a right to know their status, and this is a motivating factor for disclosure.^{3, 5, 47, 48} As stipulated in the South African Children's Act No. 38 of 2005,⁴⁹ children have the right to participate in their own healthcare including health related decisions, and have the right to access information regarding his or her health status. As such, the realisation and appreciation of this right is very important to disclosure discussions.²

Another strong theme raised in the literature is the importance of social support for caregivers from healthcare providers and HIV counsellors during the process of disclosure.¹ Family structure is also identified as having a powerful effect on disclosure, in that a stable home environment can influence whether disclosure is initiated and whether it is done in an appropriate manner.^{1, 20, 29, 42} In addition, school attendance and level of education (of caregivers and children) has been identified as a further factor associated with disclosure.^{6, 14, 26, 29, 50} A study conducted in the Democratic of Congo found that school enrolment of children and a higher educational status of caregivers (beyond 5th grade) increased the likelihood of disclosure.²⁶ Throughout the literature reviewed, disclosure is strongly advocated as it has a positive effect on the long-term physical and mental health outcomes of children, and on their health-seeking behaviours and decision making processes.⁷ Likewise, disclosure is also believed to improve communication between caregivers and children and thus can foster the development of a trusting relationship.²⁶

Factors inhibiting disclosure: Why does this matter?

There are, however, a number of factors that inhibit caregivers' disclosure of HIV status to their children. A plethora of studies have illustrated the long-lasting effects of non-disclosure on the clinical and psychological wellbeing of children, including their isolation from potential sources of support and healthcare services.³³ Stigma and ostracism, along with the fear of the negative reactions of family and community members, as indicated, discourage caregivers from disclosing.^{21, 33, 34, 42, 51} Caregivers fear

that if they do disclose to the child, their child may unwittingly disclose to other people, resulting in possible discrimination and social isolation.¹⁴ In an attempt to avoid or delay disclosure, evidence suggests that caregivers use various forms of deception or the selective communication of information to their children, to deflect questions which they might ask about HIV.^{14, 21, 26, 48} For example, caregivers may tell their children that they have tuberculosis (TB), as this is less stigmatised than HIV. This use of deception is also related to cultural and social taboos, which prohibit discussion of sex and HIV and which present serious challenges to the disclosure of HIV status.⁵²

Biological caregivers, in particular, are often overwhelmed by guilt for having infected their children with HIV.^{21, 48, 53, 54} Parents fear having to explain how they acquired HIV and transmitted it to their child, and worry about the possible blame, anger, and rejection that could result from this disclosure.^{14, 48, 51} This is also associated with the shame about their own HIV infection, and it is stated in the literature that caregivers are sometimes less likely to disclose if they have not come to terms with their own HIV status.³ Likewise, caregivers who had a traumatic or negative experience disclosing their own status to their families and partners may also avoid disclosure of their child's status.^{3, 7} According to Domek⁵¹, the anticipated fear of negative reactions and stigmatisation prevents many caregivers from disclosing HIV status to their children.

Caregivers are also reluctant to disclose to their HIV-positive child, because they believe the child is too young to be told that they have HIV. In the literature, age is cited as one of the strongest determining factors of disclosure, as caregivers are often concerned that their children are not cognitively or emotionally ready to understand or comprehend the implications of their illness.^{5, 6, 19-21, 25-28, 34, 42} The preferred age of HIV disclosure cited by caregivers is generally any time from late childhood up until mid-adolescent years.^{48, 51} Furthermore, caregivers avoid talking to their children about HIV as they are concerned about upsetting them and fear that a child may experience adverse psychological consequences as a result.^{25, 26} In these circumstances, caregivers choose to protect their children from knowing what they believe to be the 'harmful' truth of their status, for fear of the associated negative outcomes of disclosure.²⁵ In addition, studies have shown that some caregivers avoid disclosing because their children have not asked any questions about their medication or health status, and they see this as an indication that they are not ready for disclosure.⁵¹ Over and above the impact on a child, caregivers themselves also experience psychological distress as a consequence of non-disclosure due to prolonged silence about HIV and the avoidance of open communication.³⁰

Although some caregivers desire to disclose, it is reported that many of them struggle to communicate with their children and do not know when, where and how to disclose to their child.^{3, 7, 51} More likely than not, they also lack support from others to initiate this process on their own.⁵¹ This is problematic as their decision not to disclose has implications for their children's adherence to ARVs, and this

becomes a critical public health issue as non-disclosure could lead to the advancement of drug-resistant strains of HIV.⁸ In addition, as Wiener et al.⁸ point out, children grow up, unaware of their diagnosis and engage in unsafe sexual activities which contributes to the spread of the disease into the uninfected population.⁸ These barriers to disclosure mentioned above are further compounded by inadequate HIV services and healthcare systems including insufficient psychosocial support and disclosure counselling for caregivers and their children.³³

IDENTIFICATION OF GAPS IN THE LITERATURE

Caregivers and child disclosure in South Africa

It is evident in the literature, from both low-middle and high income countries, that caregivers are the ones largely responsible for disclosure of HIV status to their positive children, with the assistance of healthcare workers when available, and that there are a range of barriers and triggers which motivate them either towards or away from the disclosure process. The factors that facilitate or hinder disclosure also differ from context to context and between individuals.⁵⁵ In South Africa, it is typical that the primary caregiver or guardian makes the decisions regarding the care and treatment of the HIV-positive child, and disclosure of the child's status is the prerogative of that caregiver. Despite the overall importance of the process, studies have shown that South African caregivers are often reluctant to disclose, as a result of the social and cultural expectations that govern the norms of the family unit, to the point that discussions around sexuality and HIV/AIDS are strongly inhibited.^{5, 22} This creates a barrier to caregiver-child communications as discussions of HIV disclosure cannot take place without violating cultural norms, leaving many HIV-positive children unaware of their diagnostic status.

Non-disclosure is further constrained by stigma and discrimination, which impacts negatively on the quality of life of those living with HIV. As Skhosana and colleagues⁵⁵ have pointed out, stigma and disclosure are inversely related, in that in contexts where there is a greater likelihood of stigma, there is a lower chance of people's disclosing HIV. In this way, non-disclosure is used as a means to protect oneself and one's family from prejudice but which, on the flipside, insulates a person from accessing sources of social support.⁵⁵ Furthermore, the high prevalence of gender-based violence in South Africa and the fear of abuse from partners also restrains disclosure, and condemns many women into silence and isolation, fostering feelings of shame and self-blame.^{55, 56} As a consequence of women's fear of disclosing their own status, disclosure to their children is also deferred or avoided. In addition to social stigma and ostracism, disclosure remains challenging for caregivers because of their lack of knowledge about HIV and reproductive health, and that they do not know how to talk to their children about HIV.¹⁴ As a consequence, open communication between caregivers and children is hindered and this has

significant implications for the adherence and care of infected-children, in addition to affecting their emotional and psychological welfare.¹⁸

The concept of disclosure and the fundamental elements of the process are multifaceted and complex. Evidence has shown the positive effects of child disclosure as it improves adherence, enables children to better understand their illness and make sense of their disease-related experiences, and yet disclosure rates remain low.⁵⁷ As Moodley et al.²⁰ point out, despite the fact that issue of HIV disclosure amongst adults has received considerable attention in the literature, there are few guidelines for *child* disclosure and most are still in the process of development. Empirical research on child disclosure that has been conducted in sub-Saharan African countries include Namibia, Botswana, Mozambique, Zambia, the Democratic Republic of Congo, Uganda, Kenya and Ethiopia. However, to date, there have been few studies conducted in South Africa looking at caregiver readiness for disclosure and their perceptions of the risks and benefits entailed.⁵⁸ In addition, the majority of the studies, which have been conducted, have been quantitative in nature or randomised controlled trials and there have been very few qualitative data studies on child disclosure. Some those that have been conducted in South Africa in the last 15 years include Kouyoumdjian, Meyers and Mtshizana¹⁶ (Soweto, 2001), Skhosana⁵⁵ (Soweto, 2006), Madiba⁵⁹ (Gauteng, 2012), Madiba and Mokwena⁷ (Gauteng, 2012), Watermeyer¹⁸ (Gauteng, 2013), Heeren et al.⁶⁰ (Eastern Cape, 2012), Cluver et al.⁴¹ (Eastern Cape, 2015), Myer et al.¹⁹ (Cape Town, 2006), Vujovic² (Gauteng, Limpopo and Western Cape, 2010), and Coetzee, Kagee and Bland⁶¹ (KwaZulu-Natal, 2015). As has been widely discussed in the literature, there is considerable merit in combining quantitative and qualitative methods in the assessment of such a socially and culturally charged field of study as HIV disclosure and this is an area which has hitherto been under-researched in the country. There is also a strong need to broaden the base of empirical evidence across South Africa in order to incorporate regional and cultural variances when developing a standardised set of disclosure guidelines, which can be rolled out to health care facilities across the country.

This study aims to contribute to the empirical case base by presenting the findings of qualitative research on the perceptions of primary caregivers and healthcare providers, conducted in an area previously un-researched in this way. In that regard, despite an extensive search of the literature, it would appear that there have been no prior qualitative studies conducted on caregiver readiness for disclosure in the context of Khayelitsha. The most recent study conducted in the Western Cape was undertaken by Vujovic² in 2010. In light of this, the following study will unpack questions regarding child disclosure in a resource-limited, ethnically Xhosa community situated in a peri-urban area in Cape Town. In so doing, it is intended that the study will provide further insights into the process of child disclosure that cannot always be derived from quantitative data. Of particular importance, insights from Khayelitsha will serve to affirm or dispute the current findings on the factors promoting or hindering child disclosure conducted in other provinces around the country. This will include assessment of the extent to which

there can be sufficient generalisation of contextual factors to warrant the development of uniform disclosure guidelines across South Africa's diverse socio-cultural society. The effectiveness of these guidelines will, in considerable measure, be influenced by the extent to which they accommodate contextual variances throughout the country.

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PART C: JOURNAL MANUSCRIPT

Title of manuscript: Caregivers' Readiness to Disclose: Experiences and Challenges of Child Disclosure in South Africa

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³ This article has been prepared for submission to the journal AIDS Patient Care and STDs. Author instructions have been attached (see Appendix 9). Variations from journal requirements: For the purpose of the dissertation submission, tables are inserted in the text of the manuscript rather than appended at the end of the manuscript.

⁴ Acknowledgments have also been listed in a separate section at the beginning of the dissertation document, and not ahead of the Reference section in the Manuscript.

ABSTRACT

Disclosure of HIV status to children is a challenging process for caregivers, as it involves discussing a highly stigmatised disease, which may cause psychological stress to a child. Despite the benefits of disclosing, rates of HIV disclosure remain low as caregivers face various obstacles preventing them from disclosing, and this can have long-lasting effects on the treatment adherence of HIV-positive children. This qualitative study explored the perspectives and experiences of caregivers, in order to understand their readiness to disclose HIV status to their children, and address the factors that assist and hinder the process. Caregivers of HIV positive children (aged 5-15 years) participated in two focus group discussions (11 in each), and in-depth interviews were conducted with eight additional caregivers. Two healthcare workers and 10 NGO staff were also interviewed. Three key themes emerged from the data: caregivers' avoidance or delay of disclosure, factors related to caregivers' motivations to disclose, and caregiver's perception of child readiness for disclosure. The findings support the view that caregiver readiness is a key element of child disclosure. The research identified how caregivers can be educated about the benefits of disclosure, and be guided to take responsibility for the process. As there is a lack of context-specific and culturally-sensitive recommendations for child disclosure in South Africa, this research can be used to broaden the case base to inform the development of standardised guidelines that will assist caregivers to effectively communicate and manage the process of HIV disclosure with their children.

Key words: Child disclosure; HIV; Caregiver readiness; qualitative study; South Africa

INTRODUCTION

Disclosure of HIV status to a child is seen as an essential step in the model of care and disease management for HIV positive children.¹ Child disclosure, however, is challenging for caregivers and healthcare providers alike, as disclosing HIV status involves discussing a highly stigmatised, and potentially life-threatening infectious disease in a process that may create distress for a child.² South Africa has one of the highest HIV infection rates and disease-related deaths globally, and it is estimated that some 360 000 children in the country are living with HIV.^{3,4} South Africa also has the largest anti-retroviral therapy (ART) programme in the world and with the increasing availability of drugs, mother-to-child transmission (MTCT) rates have dropped by 50% since 2009.⁵ This has contributed to a considerable reduction in new infections and mortalities of HIV-infected children.⁶ As more HIV positive children have access to ART, fewer are dying and more survive into adolescence and adulthood, creating a new challenge as to how and when to inform these children of their HIV status.^{7,8} In addition, there is often general uncertainty as to whether the responsibility for disclosure lies with the primary caregiver of the child or a healthcare provider.⁹ Little is known about the experiences of child disclosure for primary caregivers in South Africa, and the complex issues they face about how and when to disclose HIV status to a child. This is critical as their lack of knowledge and skills on how to proceed has an influence over their readiness to disclose and this may often result in the process being delayed or avoided.¹⁰

Disclosure involves communicating HIV status in different ways with different people (partners, families or children) at various points in time. For instance, parental disclosure is defined as parents telling their HIV status to their infected or uninfected children. Child disclosure, on the other hand, refers to a child gaining knowledge of his or her HIV status (typically from a primary caregiver or parent), and this can occur as single, discrete event or as a gradual process.¹¹ Child disclosure progresses in different phases from *non-disclosure*, where the child is not informed about their disease, to *partial disclosure* where the child is informed about their illness but where the disease is not named as HIV, and, finally to *full disclosure* where a child is told that the name of their disease is HIV and its implications are described to them.¹² At present, there are few guidelines to determine the appropriate timing of these phases of child disclosure or effective strategies for caregivers to initiate this process. The World Health Organisation (WHO), however, recommends that child disclosure be conducted as an on-going process, taking into account the child's cognitive ability and emotional maturity, and allowing the child and their caregivers sufficient time to adjust to the life challenges that the new diagnosis presents.¹³ These guidelines advocate that a child should be told his or her status by school going age (between the ages 6 to 12 years), and that disclosure is best directed by the child's primary caregiver.¹³

It is evident from the literature that non-disclosure of HIV status can have a long-lasting effect on the psychological and social development of a child as well as on the clinical course of the disease.^{12, 14} It can isolate a child from potential sources of support, resulting in negative psychosocial reactions including depression, anxiety, anger and behavioural issues including suicide, and drug and alcohol abuse.^{15, 16} Furthermore, it has a significant public health implication in that it may lead to children defaulting on their ART, resulting in the advancement of drug resistant strains of HIV.¹⁷ In addition, without the knowledge of their status, children may grow into adolescence engaging in unsafe sexual behaviour and thus further contributing to the onward transmission of the disease.¹¹

Research has shown that children who are disclosed benefit from discussing their illness, and this has an influence on their decision making regarding their own healthcare.¹⁴ Evidence suggests that children who are disclosed experience fewer psychological problems and have increased self-esteem.¹⁸ They also have improved long-term health outcomes, including retention in HIV care and adherence to ART,¹⁹ which is associated with reduced opportunistic infection symptoms.^{8, 20} Upon disclosure, children are more likely to take responsibility for their treatment as they have a better understanding of their illness and the necessity for medication.^{15, 17} Additionally, disclosing HIV to children has been shown to assist them in coping with the emotional consequences and social prejudices associated with the disease²¹ and, later in adolescence, to encourage safer sexual practices to prevent secondary transmission.^{18, 22} Overall, research has shown that disclosed children have improved health outcomes due to greater access to social support structures and ART at healthcare facilities.^{16, 18}

Despite the significance and benefit of the discussing HIV with infected children, disclosure in South Africa remains consistently low, with countless HIV-positive children unaware of their diagnostic status.¹⁰ This is partly due to the lack of formal disclosure guidelines to support the process, but is also due to the factors that hinder caregiver readiness to disclose.¹⁴ Evidence from resource limited settings suggests that stigma and social isolation^{23, 24} and the guilt and shame for the transmission of the virus²⁵ present challenges to caregivers' readiness to disclose HIV status.²⁶ Caregivers are often reluctant to disclose to their child, claiming that he or she is too young to understand the nature and the ramifications of the disease, and they see non-disclosure as a form of protection from the perceived emotional stress, which will result from their diagnosis.^{12, 27} One of the biggest concerns cited in the literature is that caregivers are fearful that their child may disclose their status to other people, which could result in the child and/or caregiver being ostracised and discriminated against.⁷ This is exacerbated by the fact that caregivers often experience a double burden of anxiety, as they have not yet come to terms with their *own* HIV status, thus making it especially difficult to disclose to their child.¹⁸ This creates an additional fear of having to explain how they acquired HIV and transmitted it to their child, combined with worry about the possible blame, anger, and rejection that could result from disclosure.^{24, 28} In many cases, caregivers also do not have adequate emotional and social support to aid them in the process of

disclosure.²⁹ Inadequate health systems and HIV services also compounds the above mentioned challenges.¹⁵

In South African households, it is common that the primary caregiver holds the power to make decisions about the best interests of an HIV-positive child, and they are often reluctant or resistant to disclose because social and cultural norms inhibit discussion of HIV and sexuality.¹⁶ These customs create a barrier to caregiver-child communication, as discussions of HIV disclosure cannot take place without violating cultural conventions.¹⁸ This is further aggravated by low levels of literacy amongst caregivers, who often have limited access to information on sexual and reproductive health information in their communities.^{7, 16} In addition, many children in South Africa become orphans, following the death of their parents due to HIV/AIDS, and their primary caregiver is very often not their biological parent and is unaware of their child's HIV status.¹⁶ This, as Watermeyer¹⁶ asserts, can have significant implications for children's health, treatment adherence, and long-term disease management as well as for their emotional well-being. As disclosure is largely determined by the primary caregiver, it can be argued that their perceived readiness to disclose is the primary factor influencing this process, and it is this level of readiness, which ultimately motivates them towards or away from disclosure.

In light of the low disclosure rates in South Africa discussed above, this study sought to explore and understand the experiences and perspectives of HIV disclosure among primary caregivers, looking specifically at the barriers to and facilitators of this process, how they respond to, and manage these factors in readying themselves for disclosure. These barriers and facilitators, as well as how they are understood and navigated, all contribute to what is described in this article as "caregiver readiness" to disclose. This study expanded on the current body of literature by collecting qualitative information from caregivers of HIV positive children as well as from other key informants involved in child disclosure.

METHODOLOGY

Study setting and participants

The study was conducted at a primary health care clinic in Site B District in Khayelitsha, a peri-urban township located 30km from the centre of Cape Town. Khayelitsha, with a population of roughly one million, has among the highest infection rates of HIV, tuberculosis (TB) and drug-resistant tuberculosis (DR-TB) in the country.³⁰ The clinic provides HIV/AIDS and TB-related services to patients in the surrounding area, including ARV treatment initiation, family planning, and HIV testing services (HTS). The clinic also facilitates adherence clubs run by HIV counsellors for caregivers and children who are stable on their medication.³⁰

Three key informant groups were purposively sampled for the study: (1) caregivers of HIV positive children, (2) healthcare providers, and (3) staff working at local non-governmental organisations (NGOs) which are involved in child disclosure practices. A caregiver is defined as the person caring for an HIV positive child on a daily basis, living in the same household, and responsible for the taking the child to the clinic for regular visits. Caregivers were eligible to participate in the study if they were the primary carer of a child who is HIV positive, between the ages of 4 and 18, and who may or may not have been disclosed to at the time when the study commenced. Caregivers were enrolled in the study through the adherence clubs at the HIV clinic, and from support groups at local HIV/AIDS organisations. Healthcare providers and local NGO staff were eligible to participate if they had knowledge and/or experience of disclosure of HIV and were willing to comment on child disclosure practices. The researcher approached selected participants with a brief summary of the purpose of the research, and invited them to participate in the study.

Data collection

Two groups of caregivers, 11 in each, participated in focus group discussions of 45 minutes to an hour. With the support and guidance of an HIV counsellor at the clinic, the focus groups were conducted during the time when participants met for their monthly adherence club meeting. The discussions were conducted in English by the primary researcher facilitating the group and then translated for the participants by an isiXhosa speaker, the dominant local language in Khayelitsha. Participants were invited to respond to the questions in English or isiXhosa. To ensure privacy, each discussion group was conducted in a private room, away from other clinic patients and children. Five caregivers from the group discussions were invited to participate in a 60 minute individual interview thereafter, however three of these caregivers declined to participate. Another eight caregivers were recruited for individual interviews through a local HIV/AIDS organisation. In addition, two healthcare providers from the clinic, and 10 staff members from various NGOs were also interviewed. An interview guide with semi-structured and open-ended questions, developed following a review of the literature, was used to facilitate the focus group discussions and interviews (See Appendices 1-4). Written informed consent was obtained from all the participants prior to the focus group discussions and individual interviews (See Appendices 5-7). With the permission of participants, all discussions and interviews were audio recorded and written notes or memos were taken.

Data analysis

All focus group discussions and interview recordings were independently translated to English and transcribed verbatim. The transcribed data was organised and coded using the qualitative data analysis

computer software program NVivo 10. Thematic analysis was used inductively to code the data and this proceeded in three phases.³¹ In the first phase, one third of the data was analysed and a preliminary codebook was created, which was based on topics that were frequently cited or which had relevance to caregiver readiness for disclosure.³² Key codes were generated and amendments to the codebook were made iteratively as the researcher analysed the rest of the data, until a point of saturation was reached.³³ ³⁴ In the second phase, with the final codebook, the researcher constructed overarching categories to group similar codes, and to identify emerging patterns and relationships as well as contrasts and paradoxes between the codes. In the third phase, the researcher analysed and modified the central themes and sub-themes to summarise the key findings across the data, which reflected the participants' experiences of child disclosure.^{32, 34}

Ethical considerations

The qualitative data described here, collected from November 2014 to December 2014, was a component of the Caregiver-Led Disclosure Program (CDP) study piloted by the University of Cape Town (UCT) and Médecins Sans Frontières (MSF) in Khayelitsha. This sub-study was conducted in partial fulfilment of the requirements for the degree of Masters of Public Health (Social and Behavioural Sciences) from the School of Public Health and Family Medicine, UCT. It was approved by the UCT Health Sciences Faculty Human Research and Ethics Committee (HREC), and by the School of Public Health and Family Medicine (see Appendix 8).

RESULTS

Description of participants

A summary of the main characteristics of the caregivers is presented (see Table 1). In total, the views of 30 caregivers of HIV positive children were canvassed in the study. Twenty-two caregivers participated in two focus group discussions (11 in each group) and 10 participated in semi-structured interviews (two of whom who recruited from the focus group discussions). Healthcare providers interviewed included one clinic nurse and one HIV counsellor, while the 10 staff members interviewed worked at six different NGOs. Caregivers interviewed were predominantly female (97%), ranging in age from 20 to 50 years, and the majority were the biological mothers of the children (87%). Half of the caregivers disclosed their status as positive, 3 as negative while the rest chose not to disclose.

The demographic information on the children collected from the caregivers is also presented in Table 1. The children ranged in age from 5 to 15 years, more than half were female (63%), and the majority

were on ART at the time of the interview. According to the caregivers interviewed, more than half of the children (56%) were fully disclosed between the ages of 8 and 10 years, with 4 children being disclosed under the age of 7, and 6 children being disclosed between 11 and 15 years. At the time of the interview, only 2 out of the 30 caregivers had not fully disclosed to their child, although they had partially disclosed to their children and intended to fully disclose within the following months. The majority of caregivers (86%) reported that they had taken their children through a process from partial disclosure to full disclosure over a period of several months or years, whilst 4 caregivers (14%) had disclosed as a single, once-off event.

Table 1. Characteristics of caregivers and children (n=30)

Characteristic	Frequency	Percent
Caregiver's age		
20-30	10	33%
31-40	14	47%
41-50	1	3%
Unknown	5	17%
Caregiver's sex		
Female	29	97%
Male	1	3%
Caregiver's relationship to the child		
Mother	26	87%
Father	1	3%
Aunt	3	10%
Caregiver's HIV status		
Positive	15	50%
Negative	3	10%
Unknown	12	40%
Child's ages		
5-7	11	37%
8-10	14	47%
11-15	5	16%
Child's sex		
Female	19	63%
Male	11	37%
Child's age at disclosure (years)		
5-7	4	13%
8-10	17	57%
11-15	6	20%
Unknown	3	10%
Child on ART		
Yes	29	97%
No	1	3%

Key themes

Three key themes emerged from the data, including (1) the caregiver's avoidance or delay of disclosure, (2) the caregivers' motivations for disclosure, and (3) the caregiver's perception of child readiness for disclosure (see Table 2). As the majority of caregivers had fully disclosed at the time of the interview

their responses about their own disclosure experience were retrospective. However, this did enable them to express their views on the barriers and facilitators to disclosure that other caregivers who have not yet disclosed may face. The sections that follow discuss the three themes identified in greater detail.

Table 2. Summary of main themes and sub-themes

Caregivers' avoidance or delay of disclosure
Child's age and maturity
Lack of knowledge on how or when to disclose
Feelings of guilt and fear of being blamed
Fear of negative reaction from family and partners
Fear of stigma and discrimination from the broader community
Culture and social norms
Caregivers' motivations for disclosure
Acceptance of their own HIV status
Disclosure is the caregivers' responsibility
Relationship with the child & telling the truth
Benefits of disclosure
Self-care and adherence
Protection of others
Knowledge and awareness of HIV
Support from others for disclosure
Caregivers' perception of child readiness for disclosure
Child's age and cognitive ability
Child's behaviour
Child's right to know

Caregivers' avoidance or delay of disclosure

Caregivers face various barriers and challenges, which inhibit disclosure of their HIV status to their children (see Table 2). In the focus group discussions and one-on-one interviews, caregivers were asked about the strategies and techniques they used to delay or avoid disclosure. Several caregivers reported that prior to disclosure they had consciously used various methods of deception in an attempt to deflect questions raised by children regarding their HIV medication. Caregivers explained that they told their children that they were suffering from conditions other than HIV, such as tuberculosis (TB), asthma, or eczema, in order to avoid having to tell the child the truth about their status. Other caregivers reported bribing their children with money and toys, which helped to distract them and thereby to avoid disclosure.

A child's age was a strong predictor of whether or not a caregiver would disclose. Caregivers stated that they believed that some children are too young for disclosure, because they are too "childish and they don't know about secrets, that's why it is difficult to tell them" (Caregiver 1 of 13 year old boy). The fear of the child prematurely disclosing his or her status to members of the community, and the

possible discrimination that could follow, discouraged caregivers from disclosing. Many believed that a child is ready for disclosure between the ages of 12 to 15, although some disclosed to their own children at an earlier age. The decision to disclose at the onset of puberty is motivated by the caregivers' perception that an adolescent child is better able to understand the full implications of the disease and to adhere to their medication. When asked about why they delayed disclosure to an older age, caregivers' responses indicated that many of them did not know how or when to initiate the process. Their biggest concerns were the anticipated, yet difficult, questions raised by their children about HIV transmission, and how they would be able to respond to them. In that regard, NGO staff and healthcare providers expressed the view that caregivers very often do not have adequate HIV-related education and therefore lack the confidence to disclose to their children:

"One of the parents said to me 'How can I tell my child what HIV is, I don't even know what it is'. She said 'I know people are talking about it and it is a bad thing, but to be honest I don't know what it is'. So if people don't even know what it is, how will they disclose what they don't understand?" (NGO staff member 3)

Caregivers also reported being worried about how their child would react to the disclosure, and feared possible negative psychological consequences. As one caregiver explained:

"Children will have a low self-esteem all of a sudden; maybe they will withdraw from their parents or from their peers. If the child will know, maybe she will drink or commit suicide or she will just get angry at the parent." (Caregiver 5 of 11 year old girl).

Biological mothers, in particular, also had to deal with strong feelings of guilt and shame for "bringing this on the child," and feared the blame that their child would place on them. Another concern that caregiver's expressed was their struggle to communicate and form a positive relationship with their children, which was cited as a further reason for avoiding disclosure. This was particularly pertinent for non-biological or foster caregivers, some of whom stated that they had little open dialogue with the children in their care and this presented a further barrier to disclosure.

Several of the caregivers stated that they had initially been reluctant to disclose due to fear of the anticipated negative reactions of their immediate family. In that regard, privacy is often an issue when discussing HIV with a child, especially when other family members in the home do not know the status of the mother and/or child. This unwillingness to disclose on the part of the caregiver is often compounded by the negative experience of their own disclosure, and the fear that disclosure of a child's status to their partners, could lead to negative consequences for their child and themselves:

"Caregivers fear disclosing their own status. You see 'my partner may leave me, what is going to happen?' There has been violence, because unfortunately the man will see that you brought this disease into the house, so there are some issues like being kicked out. Especially with the man who is working, and if I disclose to him, he might stop financially supporting me." (Caregiver 4 of 9 year old boy)

Stigma and discrimination was also cited as a major barrier to disclosing HIV to children, since HIV is often associated with promiscuity and deviant sexual behaviour. Healthcare workers stated that caregivers "don't trust that their child will keep this a secret at home, he or she may be disclosing this to his or her friends" (Clinic nurse), and then the child could be teased and ostracised consequently. Caregivers further asserted that they were unwilling to disclose to their children because of the prevailing cultural and social norms in their communities. It was reported that in 'African' cultures, talking to children about sex is a social taboo and it is considered highly inappropriate to talk about HIV in the home:

"HIV disclosure basically puts a big finger on the breakdown of family communication. The aspect that is hard to deal with is the fact that people don't want to talk to their children about sex and HIV at all, so there are all sorts of cultural dynamics going on. People will say 'that's not in our culture'" (Caregiver 6 of 13 year old girl).

From this it can be seen that caregivers' decisions to avoid or delay disclosure is strongly influenced by a variety of factors which challenge them within their home and community environments, and which ultimately motivate them to keep their children in the dark regarding their HIV status.

Caregivers' motivations for disclosure

Caregivers were asked their opinion on what encouraged or prepared them to disclose HIV status to their children (see Table 2). To begin with, caregivers reported that when they finally accepted their own HIV status, they had felt empowered to disclose to their children. Once they had come to terms with their own status, caregivers reported, they felt better prepared to tackle the difficult questions, which their child might raise. According to one NGO staff member, caregivers are able to overcome their uncertainties of disclosing when:

"Their parenting shifts to be about creating a future for the child, in which their role is to support the child, rather than feeling that that they have no influence over what happens. When this guilt shifts, and basically once they start dealing with their own fear, their own guilt, their own understanding of their HIV, then they begin to see that they are not defined by HIV" (NGO staff member 2).

The theme of caregivers' acceptance of status was also highlighted in the responses of some caregivers who drew comparisons between HIV and other non-communicable diseases (NCDs), such as diabetes and hypertension. One caregiver stated:

"Diabetes, high blood, those are killer diseases, those are the things they should concentrate on. HIV is not a special disease, it's just a virus in your blood, you don't feel anything. If you are on medication, you will live a long life. But if you have diabetes, you can take medication and anything can still happen." (Caregiver 7 of 10 year old boy).

Most caregivers agreed that the responsibility of disclosure should lie with the primary caregiver or mother of the child, even though some felt that there was a need for a healthcare provider to assist in the process. Caregivers who had initially lied to their children about their health status stated that rebuilding trust and a strong relationship with their children had motivated them to take responsibility for disclosure. They also maintained that the anxiety of keeping the child's status a secret was overwhelming, and this became a motivating factor for telling the truth. Furthermore, caregivers stated that one of their biggest fears was that their children might find out their status from someone else, and of the confusion, anger and sadness, which would follow. In reality, as children get older they do start asking more questions, and become more aware of their treatment and caregivers feared that they would eventually figure out the truth. Thus, developing and maintaining an open dialogue between caregivers and their children was cited as an important factor, which encouraged them to disclose.

The perceived benefits of disclosure of HIV, according to caregivers, healthcare providers and NGO staff alike, contributed towards initiation of the process of disclosure. Caregivers maintained that one of the significant advantages of disclosure is that informed children are more likely to adhere to their medication than children who do not know their status. Many caregivers stated that amongst other reasons, the fear of their children defaulting on their medication prompted them considerably to disclose. One healthcare provider commented:

"If you want your child to be adherent in future then we need to tell them why they must take treatment and what the treatment is for. Then the child going forward will be an independent adult or a teenager that has the information and who is going to be independent in taking the treatment" (HIV counsellor).

Caregivers further commented that the added fear of their children becoming sexually active without protection and infecting other young children triggered them to disclose. As illustrated by one caregiver, many young children in Khayelitsha are unaware of their status, and "from age fifteen, sixteen, even from twelve these days, they are active early." She explained that "it's very important that they know so that when they get partners, they know that the medication is for life, and secondly they are supposed to condomise so that they don't infect their partners" (Caregiver 1 of 13 year old boy).

Comments from caregivers indicated that having knowledge and understanding of HIV gave them the ability and confidence to disclose. Several caregivers reported receiving information from support groups at local NGOs and community awareness programs, and this equipped them with the skills to discuss HIV with their children and to answer challenging questions. The majority of caregivers stated that seeking information from NGOs is very helpful, in that these organisations can prepare caregivers for disclosure. Caregivers were also asked to comment on what advice they would give to other caregivers who are struggling to disclose to their children, and many of their responses centred on the importance of first accepting their own HIV status (for those HIV-positive mothers) and then seeking help from others to navigate this process with children. This leads on to the significant role that family, friends, healthcare providers and local NGOs played in the caregivers' decision to disclose. Psycho-social support provided to caregivers was cited as a motivating factor that readied them to disclose:

"What was the most valuable was the help of the doctors and counsellors. When the child asked questions, as a parent you could answer and deal with them because of the assistance that we would get from the clinic. So that is why it was so nice to work with the clinic rather than to stand on our own on the issue with the child." (Caregiver 2 of 12 year old boy)

It may be seen, from the factors described above, that understanding and accepting HIV status with practical information and guidance from various sources of support was of considerable importance in readying caregivers to initiate the process of disclosure.

Caregivers' perception of child readiness for disclosure

Caregivers were also asked about their perspectives on what made their children ready for disclosure (see Table 2). In that regard, a child's age and level of maturity was cited as a primary determinant of his or her readiness for disclosure. One healthcare provider maintained that "we as black people tend to want to wait because we say that the child is not old enough to know their HIV status" (Clinic nurse). She added that caregivers perceive a child to be ready when they are able handle the news of their HIV status, although what this entailed was not specified. Opinions on the appropriate age for disclosure differed amongst the caregivers however. Some stated that the mid-teenage years were the best age because a child has the emotional aptitude to understand his or her illness, and will not disclose to other people and bring shame to the family. Whilst other caregivers argued that children should be disclosed before going to school (between the age of 6 and 7) as their level of awareness of HIV is developed by that age and early disclosure will ensure better adherence to medication.

Caregivers further perceived their children to be ready for disclosure when they begin asking many questions about their medication and begin refusing to take their treatment. According to one NGO staff member, "at some point the medication prompts them to ask questions" and she maintained that children

are often more aware about the topic of HIV than caregivers believe, because of the knowledge of the disease gained at school and through the media. Lastly, caregivers concurred that children have the right to know that they have HIV, and once they are ready to cope with the consequences of their status, this right should be respected. They commented that it is important for children to know their status so that they can take control of their treatment and protect themselves from future infection:

"I think it's the right time for her to know whilst she is young, so that when she reaches that stage, because there is that stage of peer pressure outside there. When she starts dating. I don't want it to seem to be a new thing. She should also be able to defend herself in things that involve the youth and keep others around her safe"(Caregiver 11 of 9 year old girl)

Although not as prominent a theme as the other two, this information did provide insights into caregivers' understanding of readiness, and that their readiness is largely contingent on the readiness of their children. In other words, it is evident that the process of determining whether or not to disclose was conditioned by their desire to weigh up their own perceptions of their children's readiness against their own readiness to disclose. Once they perceived their children to be ready for disclosure, this bolstered their own readiness and motivated them to disclose.

DISCUSSION

This paper has described the barriers and facilitators that influence caregiver readiness to disclose HIV status to their children. In this study of 30 primary caregivers in the peri-urban township of Khayelitsha, it was found that their avoidance or delay in disclosing was associated with a number of factors including: (1) a child's age and perceived cognitive ability to understand his or her diagnosis; (2) caregivers' lack of knowledge on how or when to disclose; (3) caregivers' feelings of guilt and fear of being blamed for their child's status; (4) the fear of negative reactions from their families and partners; (5) the stigma and discrimination they experience from others; as well as (6) the cultural and social norms, which prohibit discussions around sex and HIV. On the other hand, the data also revealed a variety of factors, which motivated caregivers to disclose. These included acceptance of their own HIV status; the belief that disclosure is a caregiver's responsibility; the importance of building a relationship and trust with their child; the perceived benefits of disclosure (which included treatment adherence as well as the protection of others); their knowledge and awareness of HIV; and the support from others for disclosure. Caregivers also cited the factors, which they believed made their children ready for disclosure and, in that regard, the findings of this investigation confirm that of child disclosure research conducted elsewhere in the world in several significant ways. In the first instance it has found that caregivers' *own* readiness to disclose is closely associated with their perception of their children's readiness for disclosure,^{10, 35, 36} and, in the second instance, and consonant with other studies, that age is a significant predictor of how and when children are informed about their status.^{2, 8, 14, 19, 25, 37-39} Further

factors associated with a child's perceived readiness were his or her emotional ability to cope with the diagnosis; the child's behaviour (in terms of asking questions about HIV and/or refusing medication); and the belief that it is a child's right to know their HIV status.

In analysing the factors that influenced disclosure, it is evident that a child's age, stigma, and a lack of HIV knowledge were the primary influences inhibiting caregiver readiness for disclosure. According to the Children's Act No. 38 of 2005,⁴⁰ a child has a right to have access to information regarding his or her health status, and to participate in healthcare decisions concerning his or her own health. Despite this right, several caregivers delayed disclosure, citing that their children were too young and immature to comprehend the circumstances of their diagnosis. However, as argued by Domek,²⁹ children are often aware of their illness long before they are disclosed, and that avoiding disclosure, until an age deemed appropriate by a caregiver, is often more harmful to the child. This is of concern because, as recommended by the WHO,^{7, 13} it is in children's best interest to be disclosed at a school going age. In addition, as stated by caregivers, children as young as twelve are becoming sexually active, often unaware of their status, and thus were furthering the transmission of the disease. In that regard, it can be argued that disclosure of HIV status to children is one step towards preventing that transmission.

Fear of stigmatisation is also seen to discourage caregivers from accessing healthcare services and support, resulting in the delay or avoidance of HIV disclosure. Stigma and HIV disclosure, and the relationship between the two, have been widely researched in resource limited settings.^{18, 22-25, 35, 36, 41-43} It has been shown that stigma and disclosure are inversely related to one another, in that caregivers are less likely to disclose HIV status to their children in an environment where there is a greater likelihood of stigmatisation.^{37, 44} As described by Amzel and colleagues¹⁵, prejudice and social exclusion from others are highly problematic as they foster poorer health outcomes in HIV-infected adults and children, including negative effects on mental health and reduced health-seeking behaviours. Moreover, caregivers reported being hesitant to disclose to their children, as they feared the negative reactions of the people living in their own household. In other words, the fear of discrimination following disclosure is a doubled-edged sword that exists both within and outside the caregivers' homes. For some caregivers, this fear stemmed directly from their personal experience of prejudice following disclosure of their own status to their husbands or boyfriends, who blamed them for bringing the disease into the home. This resonates with the fact that there is a high prevalence of violence against women in Khayelitsha, and gender-based violence has been cited as a significant driver of the increasing levels of HIV infection in South Africa.⁴⁵ In addition, healthcare workers in the study maintained that as women are very often financially dependent on their partners, they fear being abused and 'kicked out' of the house. This, therefore, compels them to keep their children's HIV status a secret, which has serious implications for future ARV adherence and retention in care for their HIV positive children.

The failure to disclose may also be related to prevailing cultural and social norms that govern discussion of sexuality and HIV, which, as reported by the caregivers, discouraged them further from disclosing to their children.^{18, 29} This may explain their use of deception and bribery to deflect their children's questions away from the socially prohibited subject of HIV, strategies that are cited in other studies.^{2, 7, 18, 24, 46} In light of this, it is evident that future research will need to investigate further the role that stigma and culture plays in the process of HIV disclosure of status to children in South Africa and of how its influence might be diminished.

A lack of knowledge on how to communicate HIV status to their children emerged as another factor inhibiting disclosure. Caregivers reported that their anxiety around disclosure originated from their lack of skills on how to initiate the process and their fear of opening a Pandora's Box on the topic of HIV transmission and sexual history. Furthermore, many of them commented that they struggled to communicate and therefore form a positive bond with their children in general. This is consistent with other studies, which have shown that poor caregiver-child relationships and weak communication affect disclosure of HIV status.^{18, 25, 47, 48} Likewise, healthcare workers in the study asserted that caregivers' avoidance of disclosure is often associated with their own lack of knowledge on the benefits of child disclosure.^{7, 16} It can be argued that this is indicative of a larger systemic problem, where despite extensive educational and awareness campaigns, people continue to be ill-informed about the benefits of child disclosure for the purposes of ART adherence and prevention of the spread of HIV. Moreover, economic factors may also create barriers to accessing such HIV information in that caregivers not living in close proximity to HIV clinics are unable to afford transport or take time off from work to obtain information about disclosure practices.^{47, 49, 50} Although this is beyond the scope of this paper, the inability of caregivers to attend HIV facilities is a systemic problem of the healthcare system, and needs to be addressed as it prevents the access of HIV information regarding child disclosure.

Apart from the barriers discussed above, there were three key factors, which strengthened caregiver readiness for disclosure, namely the acknowledgment of their own status, the role of information, and social support from others once they had taken the decision to disclose. Acceptance of their own status essentially empowered caregivers and gave them the confidence to disclose in a positive manner as well as to tackle the questions that might arise. This supports research by Dematteo et al.⁵¹ who found that disclosure of diagnosis is determined by caregivers' trust in their own readiness to disclose and competency to initiate the process, and that this is largely associated with acceptance of their status. Expanding on this, several caregivers reported that they had come to terms with their diagnosis by drawing comparisons between HIV and other NCDs, and by recognising that HIV is no more life-threatening than any other disease if managed correctly. In effect, this comparison of diseases normalised the illness for them, and helped them to push back against social stigma and the dominant discourse, which presents HIV/AIDS as a disease associated with illness and death. Furthermore,

caregivers stated that accepting their status better prepared them for the responsibility of disclosure and establishing a trusting relationship with their child. This is similar to the findings of Brown et al.²⁴ in Nigeria, Arun et al.¹⁹ in India, and Vaz et al.²⁵ in the Democratic Republic of Congo, where caregivers believed that they were the persons best suited to disclose to their children.

Several caregivers stressed the importance of being informed about sex, reproductive health, and HIV, and of the need to understand the benefits of disclosing to their children. It was stated that the advice which they received gave them confidence in how to begin the process of disclosure and, in particular, in how to respond to the anticipated awkward questions raised by their children. This information also helped them to overcome the issues of their children refusing to take their medication. As Jemmott et al.⁷ maintain, adolescence is characterised as a time when children increase their independence from their parents, and they are known to assert themselves, to the extent of refusing to take their ARVs. In this way, disclosure has implications for the development of children, as they will grow into independent teenagers and adults, and having been provided all the information about their health status can become responsible for their own self-care and treatment. Abebe and Teferra¹⁷ report that disclosure essentially helps children to gain a better understanding about the need to adhere to ART, and this helps to prevent drug resistant strains of the virus.¹¹

In addition, caregivers argued that disclosure was not only beneficial for their children, but also for their future sexual partners. In that regard, they feared their children, unaware of their status, would become sexually active and infect other people. This finding was similar to research conducted in Puerto Rico, which showed that a third of the caregivers interviewed had chosen to disclose out of fear that their children would have unprotected sex.⁵² However, this reason for disclosure presupposes that the caregivers have some prior knowledge of HIV/AIDS and of the way in which it is transmitted, since those who are largely uninformed about the disease would be less likely to be concerned about this possibility. This then points to the need for HIV information and awareness campaigns to make explicit the fact that even young children are capable of both contracting and transmitting the disease in a school playground.

The importance of the psychosocial support and guidance that they received from family, healthcare workers, and staff at local NGOs, also had a meaningful impact on their readiness to disclose. The clinics and NGOs, in particular, provided caregivers with important social support in the form of comprehensive information about HIV and ART, and helped them to manage and overcome their fears of disclosure. As previously mentioned, this is especially important when caregivers face the challenge of children refusing to take their medication. Whilst the value of the assistance received in the disclosure process from various health care providers in Khayelitsha confirms the findings of research conducted

elsewhere, further research is required to deepen understanding of the factors, which lead to a more supportive environment in their homes, since this appears to vary significantly from case to case.

LIMITATIONS

In addition to the insights gained from this investigation, the limitations of the study should be considered. Firstly, the small sample size of the study is not representative of all caregivers of HIV children in Khayelitsha and the results may not be generalizable to other geographic areas. Secondly, the data collected through the focus groups and individual interviews is subject to potential recall bias. As most caregivers had disclosed at the time of the group discussion or interview, they were asked to comment on the factors, which had previously readied them for disclosure. It is possible that the caregivers may not have recalled all the potential motivators, which readied them for disclosure as they may not have been aware or may not have felt comfortable to share all of them. Thirdly, it is possible that there could have also been social desirability bias in the responses of the caregivers in the focus group discussions, in that the HIV counsellor who facilitated the discussions with the primary researcher was known to the participants. However, the researcher tried to mitigate this effect by emphasising to the participants that their honest responses would contribute to the broader area of research, which could be used to develop interventions and guidelines that would assist caregivers like themselves in the disclosure process.

A final limitation is that because the caregivers were recruited through adherence clubs and support groups at NGOs (including MSF, a high functioning and successful organisation), many of them (and their children) had received considerable support from healthcare workers and counsellors. This was evident in that many caregivers cited the support they received at the clinic and NGOs, and emphasised this as the principal factor that had readied them for disclosure. As a result, this would have greatly influenced their perceived readiness for disclosure, and would further limit the generalizability of this study. Further research is needed to explore the perspectives of caregivers who are not receiving psychosocial support and guidance from these kinds of sources. In addition, it would have also been valuable to interview a group of caregivers who had not yet disclosed to their children or who had partially disclosed, in order to get their perspectives on readiness for disclosure. Despite these limitations, however, a strength of the study was the depth of the interviews and focus groups conducted with caregivers, healthcare workers and NGO staff in the community of Khayelitsha. The data from this study offered insights into the perspective of caregivers' conceptualisation of disclosure and the factors affecting their readiness for disclosure. Understanding child disclosure through the perspectives of various stakeholders represents an important step in determining the type of information and support needed to assist caregivers in the disclosure process.

CONCLUSION

In this study, it was found that caregivers are faced with a variety of challenges and barriers in disclosing HIV status to their children, which essentially determines their readiness to initiate the process. Some of these challenges relate to insufficient knowledge about the appropriate age of a child to disclose, and of how and when to disclose, whilst others stem from broader societal factors relating to the stigmatisation, ostracisation, and even victimisation of those known to be HIV positive. Many of these findings support the data of other studies conducted in South Africa and elsewhere in sub-Saharan Africa, suggesting that there are similarities in the types of challenges experienced by caregivers in child disclosure both within this country and across the continent. As a result, this research adds to the growing evidence base on caregiver readiness for disclosure and how they might be better supported in this process in resource-limited settings like Khayelitsha. These insights point to the need for the continuation, and expansion, of HIV information and awareness programs in primary healthcare institutions and especially in paediatric clinics, as well as for continued support of NGOs, which run HIV support groups. Further research should investigate the factors, which give rise to stigmatisation within the home, and on how this might be addressed in local communities.

The research has also underscored the significant role that paediatric healthcare providers and NGO staff play in the disclosure process, and that this form of professional support needs to be enhanced both to increase the number of caregivers who are prepared to disclose and when and how they do so. As Watermeyer¹⁶ asserts, healthcare workers are at the ‘coalface’ of disclosure, and as they grapple with issues of disclosing to HIV-infected children on a regular basis, they are strategically positioned to support caregivers and children through the disclosure process. From this, it would appear that there is a need for greater attention to be paid to child disclosure as part of clinical consultations in healthcare institutions, in order to inform caregivers about the benefits of disclosure for the health and welfare of their children.

Finally, as there are few context and culturally specific recommendations available to steer child disclosure in South Africa, these results can also be used in the development of standardised guidelines that are responsive to the challenges faced by caregivers, which have been shown in this study to influence their readiness for disclosure. These can, therefore, be used by paediatric healthcare providers to assist those caregivers avoiding child disclosure. In order to strengthen the content and orientation of these guidelines, future research, based on both qualitative and quantitative methods, should aim to assess the perspectives of children themselves and their experiences of disclosure as a means to identifying the factors that make them ready for this process. Understanding disclosure through the eyes of children could contribute to the further development of optimal disclosure practices and to improved quality of care for this vulnerable population.

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PART D: APPENDICES

APPENDIX 1: Focus Group Discussion Question Guide for Caregivers

The goal of this question guide is to allow caregivers to narrate their experience as much as possible. The questions below can be used to facilitate the conversation and to probe and encourage further reflection but do not need to be asked in a systematic fashion.

Section A: Attitudes regarding disclosure

1. In general, how do you feel about child disclosure?
2. When do you consider a child ready to be disclosed to about their HIV status?
3. Do you think it is important for a child to know about their status? Why
4. At what age do you think an HIV positive child should know her/ his HIV status?
5. Who do you think is the best person to tell a child that s/he is HIV positive? Why?
6. What do you think caregivers need to know (information) in order to initiate the process of disclosure with their children?
7. What support do caregivers need to be able to disclose to their children?
8. What difficulties did you experience when disclosing to your child?
9. What questions did your child ask you about their HIV status?
10. What were the main worries or concerns that *your child* raised when going through the child disclosure process?
11. What were your main worries or concerns as *you* went through the child disclosure process?
12. In what way has the disclosure process had an effect on your relationship with your child?

APPENDIX 2: Focus Group Discussion Question Guide for Healthcare Providers

The goal of this question guide is to allow caregivers to narrate their experience as much as possible. The questions below can be used to facilitate the conversation and to probe and encourage further reflection but do not need to be asked in a systematic fashion.

Section A: Structure of your organisation/clinic

1. What are your roles and responsibilities:
 - a. in the clinic
 - b. in disclosure practices

Section B: Attitudes regarding disclosure

1. In general, how do you feel about child disclosure?
2. What is your view on the disclosure programmes that you have experienced at clinics/hospitals/HIV organisations?
 - a. Please describe the programme that you have had experiences with
3. What are your positive and negative experiences with child disclosure?
4. Do you feel there is anything lacking with the process of disclosure?
5. When do you consider a child ready to be disclosed to about their HIV status?
6. At what age do you think an HIV positive child should know her/ his HIV status? Please explain your reasons.
7. Who do you think is the best person to tell a child that s/he is HIV positive?

Section C: Working with caregivers

1. What are your experiences in working with caregivers in disclosure programmes?
2. What were the attitudes of caregivers surrounding child disclosure in Khayelitsha?
3. What does the communication between caregivers and children look like?
4. What are the implications of disclosure on the relationship between the caregivers and the healthcare providers in your organization?
5. What are some of the things that might assist or restrict the success of child disclosure in Khayelitsha? (i.e. lack of facility resources or skills, heavy work load, high needs of community)
6. What are the needs of healthcare providers to implement disclosure programmes effectively?

APPENDIX 3: Interview Question Guide for Caregivers

The goal of this question guide is to allow caregivers to narrate their experience as much as possible. The questions below can be used to facilitate the conversation and to probe and encourage further reflection but do not need to be asked in a systematic fashion.

Section A: General information on care of child

1. Please tell me about yourself and your child.
2. How many children do you have?
3. How old is/are your child/children?
4. Who helps the child take his/her ARVs at home?
5. Who lives in the house with you and your child?
6. Do the people you live with know your child's status?
7. Do people in your family know your child's status?
8. Do people outside your family/household know your child's status?

Section B: Experienced with disclosure

Note: These questions are for those caregivers who have disclosed to their child:

1. Could you tell me if your child knows about his/her status?
 - a. How did your child learn about his/her status?
 - b. Who told your child about his/her status?
 - c. How old was your child when he/she was told?
2. Could you please explain the main reasons for telling your child about his/her HIV status?
3. What were the strategies you used to facilitate disclosure?
4. What made it easy for you to tell your child about his/her HIV status?
5. What were some of the challenges you experienced when disclosing HIV status to your child?
6. Were there other family members/friends/healthcare providers involved when you disclosed to your child?
 - a. If so, how did disclosing to your child affect the other members of your family?
7. What were some of the things you needed to know in order to disclose HIV status to your child?
8. How did disclosing HIV status to your child affect your relationship with him/her?
9. How did they react when you told them their status?
10. Do you talk to your child about their HIV and health status?
11. Do you think it is a child's right to know their status? Why?
12. When do you consider a child ready to be disclosed to about their HIV status?

Note: These questions are for those caregivers who have not disclosed to their child:

1. If your child does not know his/her HIV status,
 - a. Please explain the reasons for not disclosing to your child.
 - b. Have you ever considered telling your child that s/he is HIV positive?
 - c. Has s/he child ever asked you why s/he must take pills every day? And why they need to go to the clinic?
 - d. Has your child ever asked you any questions about HIV?
 - e. When would you say is the right time to tell your child? Please explain.

APPENDIX 4: Interview Question Guide for Healthcare Providers & Staff at NGOs

The goal of this question guide is to allow caregivers to narrate their experience as much as possible. The questions below can be used to facilitate the conversation and to probe and encourage further reflection but do not need to be asked in a systematic fashion.

Section A: Structure of your organisation/clinic

1. What are your roles and responsibilities:
 - a. in the clinic
 - b. in disclosure practices

Section B: Attitudes regarding disclosure

1. In general, how do you feel about child disclosure?
2. What is your view on the disclosure programmes/practices that you have experienced at clinics/hospitals/HIV organisations?
3. What are your positive and negative experiences with child disclosure?
4. What works well in the process of disclosure?
5. Do you feel there is anything lacking with the process of disclosure?
6. When do you consider a child ready to be disclosed to about their HIV status?
7. At what age do you think an HIV positive child should know her/ his HIV status?
8. Who do you think is the best person to tell a child that s/he is HIV positive?
9. Do you think it is important for a child to know about their status? Why?
10. Do you think it is a child's right to know their status? Why?

Section C: Working with primary caregivers

1. What are your experiences in working with caregivers in disclosure programmes?
 - a. What are the attitudes of caregivers surrounding child disclosure in Khayelitsha?
 - b. What does the communication between caregivers and children look like?
2. What are the implications of disclosure on the relationship between the caregivers and the healthcare providers/staff members in your organization?
3. What do you think caregivers need to know (information) in order to initiate the process of disclosure with their children?
4. What support from others do caregivers need to be able to disclose to their children?
5. Could you please explain the main reasons that caregivers give for telling/not telling their child about his/her HIV status?
6. What makes it easier for caregivers to tell their child about his/her HIV status?
7. What were some of the strategies used by caregivers to facilitate disclosure?
8. What were some of the challenges caregivers experience when disclosing HIV status to their child?
 - a. How do they deal with/overcome these challenges?
9. How does disclosing to a child affect the relationship between the caregiver and the child?
10. How do children typically react when they are told about their status?
11. In your opinion, do you think caregivers talk to their child about their HIV and health status?
12. What are some of the things that might assist or restrict the success of child disclosure in Khayelitsha? (i.e. lack of facility resources or skills, heavy work load, high needs of the community)
13. What are the needs of healthcare providers/NGO staff to implement disclosure programmes effectively?

APPENDIX 5: Consent Form and Information Sheet for Caregivers

The following consent form is for caregivers in Khayelitsha, who are invited to participate in the following research study.

Principle investigator:	Kim Tapscott
Co-investigators:	Prof Chris Colvin, Alison Swartz & Ruth Mathys
Name of organization(s):	University of Cape Town (UCT) & Médecins Sans Frontières (MSF)
Name of project:	Caregivers' Readiness to Disclose: Experiences and Challenges of Child Disclosure in South Africa
Study site:	Khayelitsha

This Consent form has two parts:

Part 1: Information Sheet (to share information about the study with you)

Part 2: Consent Form (for signatures if you choose to participate)

You will be given a copy of the full Consent Form.

PART 1: INFORMATION SHEET

Introduction

In South Africa, many HIV positive children do not know their HIV status. "Disclosure" of HIV status is when a person is told or tells someone else that they are HIV positive. Child disclosure is when a child is told his or her HIV status by their caregiver or someone else. The World Health Organisation suggests child disclosure should happen over a few years. But child disclosure of HIV is difficult for caregivers because of stigma and discrimination. Caregivers also do not know how or when to talk to their children about HIV.

Purpose of the research

The purpose of this study is to find out what you think about child disclosure and what your experience of disclosure is. We would like to talk to you to understand how you make decisions about disclosure and how you talk to your child about HIV. We would also like to find out what difficulties you have had in trying to disclose HIV to your child and what made this process easier for you.

Voluntary participation

Participating in this study is voluntary. If you do not want to talk to us, you do not have to. If you want to leave the study, you are welcome to leave at any time without giving any reasons. Your choice will not affect your treatment and care that you and your family get at _____. You may change your mind later and stop talking, even if you agreed earlier. If you decide to leave the study, this will not affect your relationship with _____, University of Cape Town, or any other organisation.

Procedures

You are invited to participate in a **focus group discussion/one-on-one interview** (circle), which will be run by the main researcher at _____ (place) from _____ - _____ (time) on _____ (day & date). If you choose to accept, we will tell you about your role in the study. You may also be contacted in the future to participate in further interviews or focus group discussions after the first phase of the study. We would also like to share our results with you, so you may be contacted in the future and asked for your feedback and comments. You will be free to participate or not in these follow-up meetings and there will be a separate consent process for those future meetings.

The focus group discussion/interview will begin with a brief explanation about the study. During the focus group discussion/interview, we will not ask you to share personal beliefs, practices or stories and you do not have to share any information that you are not comfortable sharing. At the end of the focus group discussion/interview you will be invited to ask the researcher any questions that you have about the discussion on child disclosure.

The focus group discussion/interview will be tape-recorded, but you will not be identified on the tape. The tape will be kept stored in a safe cabinet at the University of Cape Town. The information recorded is private, and no one else will have access to the tapes. The tapes will be destroyed after _____ number of days/weeks.

For the focus group discussions: The focus group discussion will be guided by us in English and a translator will be present to translate the discussion into isiXhosa. You may respond to our questions in isiXhosa or English. The focus group discussion will take about 45 minutes to an hour. The focus group will have a maximum of 15 caregivers of HIV positive children and who may have experienced child disclosure.

For the individual interviews: The interview will be guided by us in English and a translator will be present to translate the interview into isiXhosa. You may respond to our questions in isiXhosa or English. The interview will take about 45 minutes to an hour.

Your participation will be important, as we believe it is valuable to learn about disclosure from caregivers of HIV positive children.

Risks

There will be no social or physical risks to you if you decide to participate in the study. We will ask you to share some personal information, and you may feel uncomfortable talking about some of the topics. You do not have to answer any questions or take part in the focus group discussion/interview if you are uncomfortable. You do not have to give us any reason for not responding to any question, or for refusing to take part in the focus group discussion/interview.

Benefits

If you decide to participate in the focus group discussion/interview, this will help us to collect information on disclosure and the experiences of caregivers. This will help in the development of guidelines to help other caregivers like yourself to be able to disclose HIV status to their children and help them stay on their ARV treatment.

Reimbursements

You will not be provided any incentive to take part in the research study. However, refreshments will be provided during the focus group discussion/interview.

Confidentiality & sharing of results

The information that you share during the focus group discussion/interview group will be kept private. The information will not be discussed with anyone. All information collected will be kept safe in locked filing cabinets, and on password-protected computers. When the results of the study become available, your name in the focus group discussion/interview will not be mentioned in the report. However, The Research Ethics Committees may inspect the research records if required.

For the focus group discussions: If you agree to take part in the focus group discussion, you are asked to keep any information that is shared in the group private and not to share this with anyone outside of the group. We want you to know, however, that we cannot stop or prevent caregivers in the focus group from sharing information that should be private. We will respect confidentiality of the caregivers by not revealing the names and HIV status of those who take part in focus group discussion or that of their children, and we will not repeat what was said in the group.

Right to refuse or withdraw

You do not have to take part in this research study if you do not wish to do so, and choosing to participate will not affect you in any way. You may stop participating in the focus group discussion/interview at any time that you wish. We will give you an opportunity at the end of the focus group discussion/interview to review your comments. You can ask to change or remove parts of the information, if you do not agree with our notes or if we did not understand you correctly.

Who to contact

If you have any questions or concerns at any point during the study, you may contact either the UCT Research Ethics Committee (021 406 6492), Kim Tapscott (083 645 6424) or Prof Chris Colvin (021 406 6706).

This proposal has been reviewed and approved by University of Cape Town Human Research Ethics Committee, who are responsible for making sure that participants in the study are safe from harm.

You can ask us any more questions about study, if you wish to. Do you have any questions?

PART 2: CONSENT FORM

I _____ have been invited to participate in research study, which is about experiences with child disclosure. I have read the information sheet, or it has been read to me. I have had the chance to ask questions about the study, and any questions that I have asked, have been answered. I consent voluntarily to be a participant in this study.

Print name of participant/caregiver: _____

Signature of participant: _____

Date: _____

Day/month/year

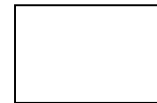
If illiterate:

I have witnessed the accurate reading of the consent form to the potential participant/caregiver, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness: _____

Thumb print of participant

Signature of witness: _____



Date: _____

Day/month/year

Statement by the researcher/person taking consent:

I _____, have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands that the information provided in these documents. I confirm that the participant/caregiver was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this consent form has been provided to the participant/caregiver.

Print name of researcher/person taking the consent: _____

Signature of researcher/person taking the consent: _____

Date: _____

Day/month/year

An informed assent form will ____ OR will not ____ be completed.

APPENDIX 6: Consent Form and Information Sheet for Healthcare Providers

The following consent form is for healthcare providers in Khayelitsha, who are invited to participate in the following research study.

Principle investigator:	Kim Tapscott
Co-investigators:	Prof Chris Colvin, Alison Swartz & Ruth Mathys
Name of organization(s):	University of Cape Town (UCT) & Médecins Sans Frontières (MSF)
Name of project:	Caregivers' Readiness to Disclose: Experiences and Challenges of Child Disclosure in South Africa
Study site:	Khayelitsha

This consent form has two parts:

Part 1: Information Sheet (to share information about the study with you)

Part 2: Consent Form (for signatures if you choose to participate)

You will be given a copy of the full Consent Form.

PART 1: INFORMATION SHEET

Introduction

In South Africa, disclosure of HIV status is low with many HIV-positive children unaware of their diagnostic status. The World Health Organisation (WHO) suggests that child disclosure is a process, which should happen over a few years. But, disclosure of HIV for caregivers is difficult, because of stigma and discrimination, and caregivers often don't know how or when to talk to their children about HIV. There are also no guidelines available to help healthcare providers to assist caregivers in learning about disclosure and how to talk to their children about HIV.

Purpose of the research

The purpose of study is to find out what you, as healthcare providers, think about the process of child disclosure and what your experience of disclosure is. The researcher would like to talk to healthcare providers to understand how they make decisions regarding disclosure and how they talk to caregivers about disclosing HIV to their children. The researcher would also like to find out about the difficulties caregivers face when trying to disclose to their children, and the factors that make this process easier. The researcher feels that your experience as a healthcare provider can contribute to the understanding and knowledge of child disclosure practices.

Voluntary participation

Your participation in this study is voluntary. If you wish to leave the study, you may do so at any time, without giving any reasons for doing so. The choice that you make will not affect your employment at _____. You may change your mind later and stop participating even if you agreed earlier. If you decide to leave the study, this will not affect your relationship with _____, University of Cape Town, or any other organisation.

Procedures

You are invited to participate in a **focus group discussion/one-on-one interview** (circle), which will be run by the main researcher at _____ (place) from _____ - _____ (time) on _____ (day & date). If you choose to accept, we will tell you about your role in the study. You may also be contacted in the future to participate in further interviews or focus group discussions after the first phase of the study. We would also like to share our results with you, so you may be contacted in the future and asked for your feedback and comments. You will be free to participate or not in these follow-up meetings and there will be a separate consent process for those future meetings.

The focus group discussion/interview will begin with a brief explanation about the study. During the focus group discussion/interview, we will not ask you to share personal beliefs, practices or stories and you do not have to share any information that you are not comfortable sharing. At the end of the focus group discussion/interview you will be invited to ask the researcher any questions that you have about the discussion on child disclosure.

The focus group discussion/interview will be tape-recorded, but you will not be identified on the tape. The tape will be kept stored in a safe cabinet at the University of Cape Town. The information recorded is private, and no one else will have access to the tapes. The tapes will be destroyed after _____ number of days/weeks.

For the focus group discussions: The focus group discussion will be guided by us in English and a translator will be present to translate the discussion into isiXhosa. You may respond to our questions in isiXhosa or English. The focus group discussion will take about 45 minutes to an hour. The focus group will have a maximum of 15 healthcare providers, who have experienced child disclosure.

For the individual interviews: The interview will be guided by us in English and a translator will be present to translate the interview into isiXhosa. You may respond to our questions in isiXhosa or English. The interview will take about 45 minutes to an hour.

Your participation will be important, as we believe it is valuable to learn about disclosure from healthcare providers.

Risks

There will be no social or physical risks to you if you decide to participate in the study. We will ask you to share some personal information, and you may feel uncomfortable talking about some of the topics. You do not have to answer any questions or take part in the focus group discussion/interview if you are uncomfortable. You do not have to give us any reason for not responding to any question, or for refusing to take part in the focus group discussion/interview.

Benefits

If you decide to participate in the focus group discussion/interview, this will help the researcher to collect information on disclosure and the experiences of healthcare providers. This will help in the development of guidelines to help other healthcare providers to be able to assist caregivers in the disclosure of HIV status to their children and help them stay on their ARV treatment.

Reimbursements

You will not be provided any incentive to take part in the research study. However, refreshments will be provided during the focus group discussion/interview.

Confidentiality & sharing of results

The information that you share during the focus group discussion/interview will be kept private. The information will not be discussed with anyone. All information collected will be kept safe in locked filing cabinets, and on password-protected computers. When the results of the study become available, your name in the focus group discussion/interview will not be mentioned in the report. However, The Research Ethics Committees may inspect the research records if required

For the focus group discussions: If you agree to take part in the focus group discussion, you are asked to keep any information that is shared in the group private and not to share this with anyone outside of the discussion. We want you to know, however, that we cannot stop or prevent healthcare providers in the focus group from sharing information that should be private. The researcher will respect confidentiality of the healthcare providers by not revealing the names of those who take part in focus group discussion and will not repeat what was said in the group.

Right to refuse or withdraw

You do not have to take part in this research study if you do not wish to do so, and choosing to participate will not affect you in any way. You may stop participating in the focus group discussion/interview at any time that you wish. The researcher will give you an opportunity at the end of the focus group discussion/interview to review your comments. You can ask to change or remove parts of the information, if you do not agree with our notes or if we did not understand you correctly.

Who to contact

If you have any questions or concerns at any point during the study, you may contact either the UCT Research Ethics Committee (021 406 6492), Kim Tapscott (083 645 6424) or Prof Chris Colvin (021 406 6706).

This proposal has been reviewed and approved by University of Cape Town Human Research Ethics Committee, who are responsible for making sure that participants in the study are safe from harm.

You can ask us any more questions about study, if you wish to. Do you have any questions?

PART 2: CONSENT FORM

I _____ have been invited to participate in research study, which is about experiences with child disclosure. I have read the information sheet, or it has been read to me. I have had the chance to ask questions about the study, and any questions that I have asked, have been answered. I consent voluntarily to be a participant in this study.

Print name of participant/healthcare providers: _____

Signature of participant: _____

Date: _____

Day/month/year

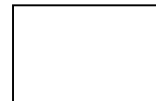
If illiterate:

I have witnessed the accurate reading of the consent form to the potential participant/healthcare providers, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness: _____

Thumb print of participant

Signature of witness: _____



Date: _____

Day/month/year

Statement by the researcher/person taking consent:

I _____, have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands that the information provided in these documents. I confirm that the participant/healthcare providers was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this consent form has been provided to the participant/healthcare providers.

Print name of researcher/person taking the consent: _____

Signature of researcher/person taking the consent: _____

Date: _____

Day/month/year

An informed assent form will ____ OR will not ____ be completed.

APPENDIX 7: Consent Form and Information Sheet for NGO Staff Members

The following consent form is for staff members working in NGOs in Khayelitsha, who are invited to participate in the following research study.

Principle investigator:	Kim Tapscott
Co-investigators:	Prof Chris Colvin, Alison Swartz & Ruth Mathys
Name of organization(s):	University of Cape Town (UCT) & Médecins Sans Frontières (MSF)
Name of project:	Caregivers' Readiness to Disclose: Experiences and Challenges of Child Disclosure in South Africa
Study site:	Khayelitsha

This consent form has two parts:

Part 1: Information Sheet (to share information about the study with you)

Part 2: Consent Form (for signatures if you choose to participate)

You will be given a copy of the full Consent Form.

PART 1: INFORMATION SHEET

Introduction

In South Africa, disclosure of HIV status is low with many HIV-positive children unaware of their diagnostic status. The World Health Organisation (WHO) suggests that child disclosure is a process, which should happen over a few years. But, disclosure of HIV for caregivers is difficult, because of stigma and discrimination, and caregivers often don't know how or when to talk to their children about HIV. There are also no guidelines available to help NGO workers to assist caregivers in learning about disclosure and how to talk to their children about HIV.

Purpose of the research

The purpose of study is to find out what you, as NGO workers, think about the process of child disclosure and what your experience of disclosure is. The researcher would like to talk to NGO workers to understand how they make decisions regarding disclosure and how they talk to caregivers about disclosing HIV to their children. The researcher would also like to find out about the difficulties caregivers face when trying to disclose to their children, and the factors that make this process easier. The researcher feels that your experience working at NGOs in Khayelitsha can contribute to the understanding and knowledge of child disclosure practices.

Voluntary participation

Your participation in this study is voluntary. If you wish to leave the study, you may do so at any time, without giving any reasons for doing so. The choice that you make will not affect your employment at _____. You may change your mind later and stop participating even if you agreed earlier. If you decide to leave the study, this will not affect your relationship with _____, University of Cape Town, or any other organisation.

Procedures

You are invited to participate in a **one-on-one interview**, which will be run by the main researcher at _____ (place) from _____ - _____ (time) on _____ (day & date). If you choose to accept, we will tell you about your role in the study. You may also be contacted in the future to participate in further interviews or focus group discussions after the first phase of the study. We would also like to share our results with you, so you may be contacted in the future and asked for your feedback and comments. You will be free to participate or not in these follow-up meetings and there will be a separate consent process for those future meetings.

The interview will begin with a brief explanation about the study. During the interview, we will not ask you to share personal beliefs, practices or stories and you do not have to share any information that you are not comfortable sharing. At the end of the interview you will be invited to ask the researcher any questions that you have about the discussion on child disclosure.

The interview will be tape-recorded, but you will not be identified on the tape. The tape will be kept stored in a safe cabinet at the University of Cape Town. The information recorded is private, and no one else except the main researcher will have access to the tapes. The tapes will be destroyed after _____ number of days/weeks.

The interview will be guided by us in English and a translator will be present to translate the interview into isiXhosa. You may respond to our questions in isiXhosa or English. The interview will take about 45 minutes to an hour.

Your participation will be important, as we believe it is valuable to learn about disclosure from NGO workers.

Risks

There will be no social or physical risks to you if you decide to participate in the study. We will ask you to share some personal information, and you may feel uncomfortable talking about some of the topics. You do not have to answer any questions or take part in the interview if you are uncomfortable. You do not have to give us any reason for not responding to any question, or for refusing to take part in the interview.

Benefits

If you decide to participate in the interview, this will help the researcher to collect information on disclosure and the experiences of NGO workers. This will help in the development of guidelines to help other NGO workers to be able to assist caregivers in the disclosure HIV status to their children and help them stay on their ARV treatment.

Reimbursements

You will not be provided any incentive to take part in the research study. However, refreshments will be provided during the interview.

Confidentiality & sharing of results

The information that you will share during the interview will be kept confidential. The information given will not be discussed with anyone. All information collected as part of the study will be kept secure in locked filing cabinets or offices, and on password-protected computers. When the results of the assessment become available, your name will not be mentioned in the report. However, The Research Ethics Committees may inspect the research records if required.

Right to refuse or withdraw

You do not have to take part in this research study if you do not wish to do so, and choosing to participate will not affect you in any way. You may stop participating in the interview at any time that you wish. The researcher will give you an opportunity at the end of the interview to review your comments. You can ask to change or remove parts of the information, if you do not agree with our notes or if we did not understand you correctly.

Who to contact

If you have any questions or concerns at any point during the study, you may contact either the UCT Research Ethics Committee (021 406 6492), Kim Tapscott (083 645 6424) or Prof Chris Colvin (021 406 6706).

This proposal has been reviewed and approved by University of Cape Town Human Research Ethics Committee, who are responsible for making sure that participants in the study are safe from harm.

You can ask us any more questions about study, if you wish to. Do you have any questions?

PART 2: CONSENT FORM

I _____ have been invited to participate in research study, which is about experiences with child disclosure. I have read the information sheet, or it has been read to me. I have had the chance to ask questions about the study, and any questions that I have asked, have been answered. I consent voluntarily to be a participant in this study.

Print name of participant/NGO worker: _____

Signature of participant: _____

Date: _____

Day/month/year

If illiterate:

I have witnessed the accurate reading of the consent form to the potential participant/NGO worker, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness: _____

Thumb print of participant

Signature of witness: _____



Date: _____

Day/month/year

Statement by the researcher/person taking consent:

I _____, have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands that the information provided in these documents. I confirm that the participant/NGO worker was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this consent form has been provided to the participant/NGO worker.

Print name of researcher/person taking the consent: _____

Signature of researcher /person taking the consent: _____

Date: _____

Day/month/year

An informed assent form will ____ OR will not ____ be completed.

APPENDIX 8: Letter of Approval – Health Sciences Human Research Ethics Committee



UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee



Room E52-24 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6336 • Facsimile [021] 406 6411
Email: shuretta.thomas@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

22 December 2015

HREC REF: 768/2015

A/Prof C Colvin
Public Health & Family Medicine
Falmouth Building

Dear A/Prof Colvin

PROJECT TITLE: CAREGIVERS OF HIV POSITIVE CHILDREN IN KHAYELITSHA: EXPERIENCES AND CHALLENGES OF PAEDIATRIC DISCLOSURE (MPH-candidate-Ms KM Tapscott)

Thank you for your response to the Faculty of Health Sciences Human Research Ethics Committee dated 15 December 2015.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until the 30th December 2016.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.

(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

Please quote the HREC REF in all your correspondence.

We acknowledge that the student, Kimberley Marie Tapscott will also be involved in this study.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE

Federal Wide Assurance Number: FWA00001637.

Institutional Review Board (IRB) number: IRB00001938

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH

2006), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI), and Declaration of Helsinki (2013) guidelines.

The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

APPENDIX 9: AIDS Patient Care and STDs – Instructions for Authors

PREPARATION OF MANUSCRIPT

Be sure these instructions are followed exactly.

We welcome contributions on topics of major significance in biotherapy, radiopharmaceuticals, and related fields that may be of the following types: (1) Reviews; (2) Research Papers; and (3) Short Communications. Each co-author accepts responsibility for the entire contents of the manuscript. Contributions to the journal are published at no charge to the author. Once a paper has been accepted for publication, it cannot be withdrawn. Authors will have the option to indicate one reviewer who should be excluded (non-preferred) from review of their manuscript. Authors will also have the option to suggest preferred reviewers during the submission process if they like.

Note: AIDS Patient Care and STDs does not publish Short Communications.

Abstracts

ABSTRACT should be capitalized and centred on the page and have one space below. The text of the abstract is single spaced and should be limited to 250 words. This should appear on a separate page.

Key words

Please provide a short list of key words to follow the Abstract. You will also be asked to enter keywords during online submission.

Tables and Figures

Each table should be prepared in a separate file. Tables should be cited in the text (see Table 1). Tables should be submitted in Microsoft Word.

Each figure should be prepared in a separate file with the figure number visible. Each figure should be cited in text (Fig. 1). Legends should be on a separate page from the figures.

Please follow these guidelines for submitting figures:

- Do NOT embed art files into a Word or PDF document.
- Line illustrations should be submitted at 1200 dpi.
- Halftones and colour should be submitted at a minimum of 300 dpi.
- Save as either TIFF or EPS files.
- Colour art must be saved as CYMK – not RGB.
- Black and White art must be submitted as grayscale – not RGB.
- Do NOT submit PowerPoint, PDF, Bitmap or Excel files.

Please name your artwork files with the submitting author's name i.e. SmithFig1.tif, SmithTable2.tif etc. Label figures and tables inside the files in addition to naming the file with the figure or table number. (i.e.: When figures or table files are opened, the figure or table number should appear inside the file.) Authors who do not follow these guidelines may have their submission returned to them without being reviewed.

You will be given directions on how to correct any files, which do not pass.

ADDITIONAL INFORMATION ABOUT ART FILES

Converting Word or Excel files: Perhaps the best and easiest way to convert Word or Excel files into a format, which is suitable for print, is to scan them using the guidelines below:

- All files should be scanned at 100% size.
- 300 dpi
- Final colour mode: cmyk
- save file as: .tif or .eps

If you need directions on how to convert a Power Point slide to acceptable format go to <http://www.liebertpub.com/MEDIA/pdf/ppconvert.pdf>

Footnotes

Footnotes should be typed single spaced at the bottom of the appropriate page and separated from the text by a 3-inch line starting from the left margin with one space above and below it. Footnotes should be used only when essential.

Acknowledgments

Collaborations, sources of research funds, and other acknowledgments must be listed in a separate section at the end of the text ahead of the REFERENCES section.

AUTHOR DISCLOSURE

All authors are expected to disclose any institutional or commercial affiliations that might pose a conflict of interest regarding the publication of a manuscript. Institutional affiliations, as indicated on the title page, should include all corporate affiliations and any funding sources that support the work. Other types of affiliation, including consultantships, honoraria, stock ownership, equity interests, arrangements regarding patents, or other vested interests should be disclosed in the Acknowledgments section.

References

Use order-of-citation format for references. Cite references within the text by a superscripted Arabic number as in the following example: [. . . as described previously.^{1,4}]. Provide a list of references, in numerical order, and in the order in which they appear in the text. Reference section should be double spaced.

For journal citations: (1) surname of author(s) and initials; (2) title of article; (3) journal; (4) year of publication; (5) volume number; (6) inclusive page range of citation.

For book citations: (1) surname of author(s) and initials; (2) title of book; (3) editor of book (if applicable); (4) edition of book (if applicable); (5) publisher; (6) city of publication; (7) year of publication (not in parentheses); and (8) page reference (if applicable).

For patents: (1) country of original registration; (2) patent number; and (3) month, day, and year of issuance. When data from an unpublished source are given, supply complete information (e.g., researcher's name and location). If work is in press, give journal in which it is to be published or publisher.

For book and journal references, if there are more than four authors, list only the first three, followed by et al.

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Correspondence

Be sure to provide the complete name and address to which correspondence should be directed.

Disclosures

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