

AN ASSESSMENT OF THE KNOWLEDGE, ATTITUDES AND PRACTICES OF CAREGIVERS OF HIV POSITIVE CHILDREN ON TREATMENT IN PRETORIA, SOUTH AFRICA: A CASE STUDY OF OUT-PATIENTS IN KALAFONG HOSPITAL, PRETORIA

by

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Assignment presented in fulfilment of the requirements for the degree of Master of Philosophy (HIV/AIDS Management) in the Faculty of Economic and Management Science at Stellenbosch



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DECLARATION

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ABSTRACT

This study examines the level of HIV and AIDS knowledge, attitudes, as well as practices amongst caregivers of HIV infected children in Pretoria, using Kalafong hospital as a case study. The study uses a questionnaire as survey instrument. A total of 30 respondents participated in the study, which took place in October of 2013. The respondents were selected via simple random sampling and the results were analyzed.

The results showed a remarkably high level of HIV and AIDS knowledge amongst the respondents, from which it was evident, that:

- A significant number of caregivers were aware of and able to take care of existing medical conditions arising from HIV in children.
- Most of the home-based care of children living with HIV was carried out by women in a very disproportionate ratio to men.

In this regard, the study offers a range of suggestions and recommendations as well as existing best practices, such as the UNAIDS booklet on caregiving within the context of HIV and AIDS.

The study was undertaken with the realization that generalizations cannot be made through extrapolation to the larger society because of limitations, such as the sample size of this study.

OPSOMMING

Hierdie studie ondersoek die vlak van MIV/VIGS kennis, houdings teenoor dieselfde, sowel as praktyke onder versorgers van MIV-besmette kinders in Pretoria, met behulp van Kalafong-hospitaal as 'n gevallestudie. Die studie maak gebruik van 'n vraelys as opname instrument. 'n Totaal van 30 respondente het deelgeneem aan die studie, wat in Oktober 2013 plaasgevind het. Die respondente is gekies deur 'n eenvoudige ewekansige steekproefneming en die resultate is ontleed.

Die resultate toon 'n merkwaardig hoë vlak van MIV en VIGS kennis onder die respondente. Hierdie kennis, houdings en praktyke opgedoen was voldoende om daarop te let:

- 'n beduidende aantal van die versorgers is bewus van en in staat om bestaande toestande in MIV-sorg in kinders te versorg.
- Die meeste van die tuisversorging van kinders wat met MIV leef is uitgevoer deur vroue in 'n baie oneweredige verhouding met mans.

In hierdie verband bied die studie 'n verskeidenheid van voorstelle en aanbevelings sowel as die bestaande beste praktyke soos die UNAIDS boekie oor versorging binne die konteks van MIV en VIGS.

Die studie is gedoen onder die besef dat veralgemenings nie gemaak kan word deur ekstrapolasie na die groter samelewing nie, as gevolg van beperkings soos die monster grootte van hierdie studie.

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OUTLINE OF CHAPTERS

- Chapter 1 introduces the study as well as provides an insight to key concepts that will be addressed, the objectives, scope as well as significance of the research.
- Chapter 2 reviews work undertaken by previous authors on care in respect of HIV and AIDS, including problems faced by caregivers, and the key knowledge and information needed to be a caregiver.
- Chapter 3 discusses the research methodology. The research planning and design, sampling techniques as well as the pros and cons of methodology employed are discussed.
- Chapter 4 provides a comprehensive analysis of the findings, as well as relevant discussions of the same.
- Chapter 5 summarizes the findings of the study, recommends ways of improving caregivers' knowledge and their impact on HIV infected children. Areas of future research are then suggested.

CHAPTER 1

INTRODUCTION

1.1. BACKGROUND

The concept of providing care in disease conditions is a fundamental aspect of human existence. From paid professional help, such as doctors, nurses and other allied health professionals to family members, or friends, caregiving, especially in chronic conditions introduces the dependence of the afflicted and their basic right to health and wellness.

For over three decades (from its first discovery in the early 1980s), the Human Immunodeficiency Virus (HIV) which eventually causes Acquired Immune Deficiency Syndrome (AIDS) has introduced new challenges in patient care and management. Principal among these challenges is that of overcoming stigma and discrimination (further discussed below). The main issues surrounding the propagation of stigma and discrimination are a basic lack of knowledge of HIV care and the (mainly) sexual aspects of its transmission, especially in predominantly conservative African communities. Besides contact with infected blood and body tissues, as well as from mother to child (see below), *“HIV is transmitted from one person to another through the most intimate of contacts-sexual intercourse. The virus is found in high quantities in the sexual fluids, semen and vaginal fluids of people with HIV infection”* (Evian, 2003).

In children, HIV management (otherwise known as Paediatric HIV Management) introduces the dual concept of dependence both in chronically ill patients, and also the fact that the children often times lack the mental and legal capacity to make decisions regarding their health, wellness and care. This latter aspect especially, introducing the all-important concept of *caregiving* in chronic conditions such as HIV/AIDS, which is the primary focus of this study. From transmission, prevention, diagnosis, antiretroviral treatment (ART) induction and compliance, to detection of side-effects of the same and general wellness, paediatric human immunodeficiency virus (HIV) management presents unique concepts which become relevant, especially in resource poor settings of sub-Saharan Africa, widely regarded as the epicentre of the global epidemic. For the purpose of clarity and emphasis, some of these issues presenting unique challenges will be briefly discussed below.

1.1.1. VULNERABILITY

Vulnerability refers to:

Unequal opportunities, social exclusion, unemployment, or precarious employment and other social, cultural, political, and economic factors that make a person more susceptible to HIV infection and to developing AIDS. The factors underlying vulnerability may reduce the ability of individuals and communities to avoid HIV risk and may be outside the control of individuals. These factors may include: lack of the knowledge and skills required to protect oneself and others; accessibility, quality, and coverage of services; and societal factors such as human rights violations or social and cultural norms. These norms can include practices, beliefs, and laws that stigmatize and disempower certain populations, limiting their ability to access or use HIV prevention, treatment, care, and support services and commodities. These factors, alone or in combination, may create or exacerbate individual and collective vulnerability to HIV (UNAIDS Terminology Guidelines, 2011:14).

In a nutshell, the simple fact that the general well-being of a child living with HIV depends on another person, be it a parent or an unrelated caregiver, only goes to underscore their vulnerability.

1.1.2. STIGMA AND DISCRIMINATION

Stigma is derived from the Greek meaning a mark or a stain. Stigma can be described as a dynamic process of devaluation that significantly discredits an individual in the eyes of others. Within particular cultures or settings, certain attributes are seized upon and defined by others as discreditable or unworthy. When stigma is acted upon, the result is discrimination that may take the form of actions or omissions. Discrimination refers to any form of arbitrary distinction, exclusion, or restriction affecting a person, usually but not only by virtue of an inherent personal characteristic or perceived belonging to a particular group—in the case of AIDS, a person's confirmed or suspected HIV-positive status—irrespective of whether or not there is any justification for these measures. The term 'stigmatization and discrimination' has been accepted in everyday speech and writing and may be treated as plural (UNAIDS Terminology Guidelines, 2011: 21).

1.1.3. HIV TRANSMISSION IN CHILDREN

Whilst the sexual route of transmission can also hold true for children, the widely recognised modes of transmission is still the "vertical" route. This vertical route simply refers to transmission from an infected mother to her child, either during pregnancy or childbirth, or after childbirth, during breastfeeding, especially when the mother (and baby) is not on any HIV treatment regimen. Other recognized modes of transmission, especially in South Africa, include sexual abuse, blood transfusion and insufficiently sterilized instruments, especially during traditional scarification (National Department of Health SA; 2010: 9).

1.1.4. HIV DIAGNOSIS IN CHILDREN

The diagnosis of children infected with the HIV virus significantly differs from that of an adult, at least for babies less than eighteen months of age. Whilst adults are usually diagnosed with rapid tests such as HIV-ELISA, babies aged less than 18 months, are usually diagnosed with the more complex Polymerase Chain Reaction (DNA PCR) because these babies still have their maternal antibodies in their systems (National Department of Health SA; 2010:14).

1.1.5. ANTIRETROVIRAL THERAPY IN CHILDREN

As with most medications in children, antiretroviral therapy (ART) is usually via syrups and mixtures, which have to be reconstituted with water to get the right dosage required. This therefore introduces the unique challenge of dosage, especially when the quantity of water is insufficient, or in excess. Secondly, from personal communication, it is widely established that the medications are usually bitter to taste, which makes children often reject them, leading to missed doses and issues with non-drug adherence. Thirdly, there may be no access to clean or portable water for drug reconstitution, as is prevalent in most parts of Sub-Saharan Africa. Another factor in paediatric ART is the attitude of the caregivers (CGs). Where the CGs are over-burdened or generally nonchalant with giving the children under their care the medications, the end result is sub-optimal treatment level, which result in increased morbidity and mortality patterns.

Commonly available ART in South Africa include Nucleoside Reverse Transcriptase Inhibitors (NRTI) with Abacavir and Zidovudine as common examples; non-Nucleoside Reverse

Transcriptase Inhibitors (NNRTI) with Efavirenz as a common example; and Protease Inhibitors (PI) with Ritonavir as a common example. Currently, the regarded optimal combination of ART is two NRTI combined with either one NNRTI or a PI.

1.1.6. ANTIRETROVIRAL (ARV) INDUCTION IN CHILDREN

According to the March 2013 Department of Health Guidelines, ART is mandatory for all children less than 5 years of age, regardless of their CD4 levels or clinical conditions, as against adults, who are initiated according to CD4 or clinical staging.

1.1.7. CAREGIVERS

For the purpose of this study, the caregivers being referred to will be adults (over 21 years of age), legally recognized as custodians of HIV-positive children between the ages of 0-5 years. These adults are further defined as providing ‘full-time’ care for the children living with HIV. However, the study takes cognizance of the fact that no one person can be responsible for ‘round the clock’ care of a sick child, hence account should also be taken of secondary (or tertiary) caregivers. Secondary caregivers, for emphasis, will be described as “those volunteering in the community to provide care such as home-based care” (Simpson, 2006).

1.1.8. HIV-POSITIVE CHILDREN

For the purpose of the purpose of this research, the HIV infected children whose caregivers will be assessed are those within the 0-5year age group. These are children who have been confirmed as HIV positive and who are on an approved treatment program from a reputable government health care establishment. This group is particularly relevant to the study as they are especially vulnerable to a host of childhood diseases and when immune-compromised, the morbidity (sickness) pattern is usually severe. Further discussed below, the World Health Organization (WHO) has developed a specific protocol for disease identification and management, namely the Integrated Management of Childhood Infections (IMCI), specifically for this group.

1.2. CAREGIVING: A UNAIDS PERSPECTIVE

Recognizing the importance of caregiving within the context of HIV, the Joint United Nations Programme on HIV/AIDS (UNAIDS) in 2008, prepared a booklet introducing key issues as well as identifying peculiar challenges and necessary interventions.

The paper commences by introducing the concept of home-based care (HBC), which is the focus of this study. According to the World Health Organization (WHO), HBC is described as “*any form of care given to people within their homes and includes physical, psychosocial, palliative and spiritual interventions*” (UNAIDS, 2008: 1). Elaborating further, AIDS related care therefore, forms part of the “*wider and largely invisible care economy, including childcare, elder care, and care for the infirm, which takes place largely in the home*” (UNAIDS, 2008:1). Forming an extension of formal (or hospital based care), it encompasses food provision, daily care and, of course, transportation to and from the hospital.

UNAIDS recognizes that most of the care provided to HIV infected people occurs in the home. The major reasons for this include the preference of patients (usually in response to a potentially stigmatizing disease condition) or a dearth of appropriate health infrastructure or personnel. Regarding the ‘economics’ of this care, the bulk of the care costs are borne by individuals and households, as well as volunteers in coordinated home-based care programs. For the most part, such care is undocumented and not recognized in macroeconomic planning strategies.

In Africa, where most of the care work concerning HIV/AIDS takes place, two thirds of caregiving is borne by women (and girls) and what is also of importance here is that the majority of these women are themselves living with HIV, poor and oftentimes illiterate. Added to this social burden is the undocumented physical, emotional and financial needs of caregivers. Caregivers generally, are most prone to burnouts from physical demands and the psychological stress of the demands of their activities, not forgetting their exposure to communicable infections, especially when not properly trained. This HIV and AIDS related care is therefore defined as “*care for people living with HIV and AIDS who fall ill, as well as care provided to children and/or families affected by HIV and AIDS. These distinct but overlapping care needs imply different strategies and tasks and many carers do both, often at the same time*” (UNAIDS,

2008:3). Of particular importance are caregivers of HIV infected children, who also become the sole (or principal) source of support, emotionally, materially and financially.

Still on the demographic distribution of caregivers, UNAIDS (2008: 3) identified the following gender distribution:

- In Southern Africa numerous studies reveal that two thirds of the primary caregivers in households surveyed are female, one quarter of these are over 60 years of age.
- In South Africa, a national evaluation of home-based care found that 91% of caregivers were women
- A survey of 62 organizations, deploying a total of 2,635 volunteers in three Ugandan districts, found that 68% of volunteers were female.
- Although the caregiving impact on women is most visible in Africa, the trend is growing across the developing world; in Thailand, two thirds of people living with HIV and AIDS are nursed at home by their parents, usually their mother.

Whilst there is a general consensus regarding the unequal distribution of care provided by females, there indeed exists a lesser, but significant number of men who provide care either at home or as volunteers in home-based care programmes. The reason for the lesser contribution of the men is not unrelated to the 'traditional gender stereotypes' of women being regarded as principal caregivers. Another reason is the social expectations of men to be 'economical providers' (tasked with being the bread winners in most societies) and women as 'care providers' in the home.

In summary, there is limited evidence of the role of men as primary caregivers, although emerging evidence points to more older, rather than younger men being actively involved in care of orphaned or vulnerable children. Lastly, as well as financial support, the more 'physical' aspect of care, such as transportation and lifting patients, for instance, is generally ascribed to the males as a rule, rather than the exception.

1.3. KALAFONG HOSPITAL PRETORIA: A BRIEF MOTIVATION

The proposed research will be undertaken in a place called Atteridgeville, situated about 12km west of the Pretoria Central Business District (CBD), specifically at an institute called Kalafong Hospital. It was an obvious choice for the research for 3 main reasons: firstly, it serves as a good catchment area for a diverse sample of respondents across all socio-economic spheres and races. Secondly, Pretoria is the administrative capital of South Africa, and a lot of government and non-governmental support has been received in the quest to mitigate the impact of HIV/AIDS. Therefore, an assessment of past and ongoing aspects of knowledge dissemination to the caregivers will be invaluable. Finally, Kalafong Hospital, which was opened in 1972, has a well-established Paediatric and Child Health Centre that is affiliated to the University of Pretoria, an equally world-renowned academic research institute. This factor will ensure the availability of trained and experienced personnel for research purposes.

1.4. THE RESEARCH PROBLEM AND RATIONALE FOR THE STUDY IN DETAIL

In an era where laudable achievements are being made towards HIV control, prevention and treatment, the fact that children are *indirect* recipients of any intervention programs and strategies can never be over-emphasized. It goes without saying that the health and general well-being of children depend on second, and at times, third parties. The knowledge, attitudes and practices of caregivers can therefore never be taken for granted if in-roads in paediatric HIV management are to be achieved. It should be pointed out that often, the caregivers are themselves living with HIV, and have the added burden of day to day existence and providing for their families. Being saddled with the 'extra' burden of ensuring ART compliance and wellbeing of their children and wards means their daily resources are increasingly being stretched to the limit.

Simply put, paediatric HIV wellness largely depends on someone else's, usually adult, HIV knowledge and wellness. Further discussed below, the aim of this study is to throw more light on how caregivers can be assisted, their existing knowledge improved and negative conceptions eradicated, so that the children dependent on them become eventual beneficiaries of any resultant positive behaviours or knowledge. Also of relevance is the issue of children orphaned by HIV/AIDS, where care is provided by people who are not the biological parents of the concerned children. It is therefore necessary to analyze the Knowledge, Attitudes and Practice (KAP) of not

only biological parents/caregivers but also ‘non-biological’ parents/caregivers, as it were. A scenario best expressed in South Africa, regarded as the ‘epicentre’ of the HIV/AIDS pandemic where most orphaned children have been placed in the care of grandparents (especially grandmothers, commonly referred to as ‘Gogos’ in local dialects), most of whom lack the essential information necessary to tackle the disease. According to SA Social Investment Exchange (SASIX):

In South Africa, HIV/AIDS is often referred to as the ‘grandmothers’ disease. Today, many grandmothers in impoverished communities are feeling the impact of the pandemic, nursing their sick and dying children and raising their orphaned grandchildren. According to Help Age International, two-thirds of people living with HIV/AIDS are cared for by their parents in their 60s and 70s. More than 60% of orphaned children in South Africa live in grandparent-headed households. (SASIX, 2011:1).

Going further, Kuo and Operario (2010: 1), in their abstract on ‘Caring for AIDS-orphaned children: an exploratory study of challenges faced by carers in Kwazulu-Natal, South Africa’, concluded that *“Fifteen million children have been orphaned because of AIDS and these numbers are expected to grow in the coming decade. Individuals providing non-institutional care for AIDS-orphaned children play a critical role in the capacity of communities to respond to the epidemic. However, a limited body of evidence exists on these carers”*.

It is a given that caregivers play an integral role in the care of HIV/AIDS in children, therefore, it is one thing to have all the technology, suitably trained health care personnel and new drugs such as those that South Africa is currently striving to attain, but it does indeed beg the question, “what are the knowledge, attitudes and practice of the caregivers tasked with delivering the all-important ‘end-user’ care to the needy children”?

The well-being of children living with HIV is dependent on the KAP of their caregivers. Simply put, this research aims to establish the relationship between children living with HIV (especially those on ART) and the Knowledge, Attitudes and Practices of the CGs, saddled with their care and wellbeing. As such, the Research Design will serve to measure both parameters, and determine the influence that the one (KAP of caregivers) has on the other (the wellbeing of HIV positive children). The end result will therefore aim to answer via analysis of the responses, the

specific Research Question, which is: *Are caregivers' knowledge, attitudes and practices towards HIV-positive children affecting the nature of care that such children receive?*

1.5. THE AIMS AND OBJECTIVES OF THE STUDY

The study aims to determine knowledge and beliefs of caregivers of paediatric HIV positive patients, in order to decrease morbidity and mortality in HIV/AIDS patients, as well as improve overall child health.

The objectives will be:

- To determine the various categories of caregivers in terms of demographics (such as age, sex, occupation) and relationship to HIV positive patients
- To establish existing knowledge of caregivers
- To establish caregiver attitudes towards their children
- To analyze existing mortality and morbidity patterns of HIV-positive children
- To suggest ways of improving caregiving outcomes
- To recommend ways of putting new knowledge to practice
- To suggest ways of improving outcomes in paediatric HIV, as well as general child health.
- Forming new bonds and strengthening existing ones with caregivers and health care workers, as partners with other stakeholders involved with HIV care in children.
- Reiterating to the various caregivers the important role they play in the issue of managing HIV in children.

1.6. RESEARCH METHODOLOGY

The research is an empirical study, involving the use of questionnaires to gather information from the sample population.

The target group is the adult primary caregivers (i.e. respondents over 21 years of age) of HIV positive children (patients between 0-5 years). Consent of participants was obtained verbally and in writing. There were 30 respondents, randomly selected from the day ART clinic of Kalafong Hospital, Pretoria. With the help of the nurses and other health care practitioners in the hospital, the primary caregivers were identified from case records and history of clinic/hospital attendance.

In order to attain a near accurate result as possible, which is representative of the general population, random sampling (as introduced above) will be employed. More specifically, simple random sampling, where from the outpatients, numbers were randomly assigned to the caregivers, and 30 numbers were called out at random from the total number which was placed in a hat. This method has the advantage of giving sampling results that are easily generalized to cater for the general population, and at the same time, having fewer sampling errors.

Regarding the survey instrument, respondents were asked to complete an anonymous self-administered questionnaire, comprising 35 closed and open-ended questions. A pilot study involving about 4 randomly selected caregivers was carried out at the initial stage of the research, to test the appropriateness and clarity of the questions, which went a long way towards determining the overall responses from the targeted sample of respondents. Respondents were informed at every stage on their rights to withdraw from the study, without fear of retribution, as well as informed that participation was wholly voluntary, for academic purposes, with no inducements or monetary compensation for participation. Confidentiality for the respondents was enabled by providing separate boxes where respondents were asked to place their completed questionnaires in one, and their signed and filled consent forms in the other, hence ensuring that no consent form was attached to the sample instrument, so the information remains 'blinded.'

1.7. SIGNIFICANCE OF THE STUDY

By assessing knowledge, attitudes and practices of caregivers, and taking cognizance of the dependence/vulnerability of HIV-positive children, who are for the most part totally dependent on these caregivers, it is hoped that any identified knowledge gaps will be adequately tackled with the appropriate education/health intervention. This will therefore benefit HIV positive children so that morbidity and mortality can be significantly reduced.

CHAPTER 2

LITERATURE REVIEW

2.1. THE CONCEPT OF A CAREGIVER

Drentea (2007) describes caregiving as the act of providing unpaid assistance and support to family members or acquaintances who have physical, psychological and developmental needs. The author goes further to distinguish caregiving from ‘paid work’ (as provided by nurses and social workers) and ‘parenting’ as undertaken by parents on a daily basis to their children. She asserts that the term caregiving implies morbidity and a concomitant voluntary assistance by another (the caregiver).

The concept of caregivers serves to underscore the debilitating nature of any illness/disease condition and this concept is further underscored in HIV/AIDS in children, where their vulnerability and dependence is further brought to the fore. Children as earlier noted, depend on caregivers for their welfare, and these caregivers also have psycho-social needs and indeed, they too may have medical issues to contend with (UNAIDS, 2008). Hence their (caregivers’) knowledge, attitudes and practices will need to be assessed, if positive inroads are to be made in childhood disease management especially HIV and AIDS.

2.2. HIV/AIDS CAREGIVERS

In line with Drenthea’s (2007) definition, The Merriam-Webster Dictionary (1993) describes a caregiver (CG) as “a person who gives help and protection to someone (such as a child, an old person, or someone who is sick)”. Furthermore, the concept of caregiving within the context of HIV/AIDS in general, and in paediatrics (childhood medicine) particularly, not only underscores the chronicity of the disease, but the overwhelming dependence of the infected child on an external loci of support-usually close family members (mothers, grandmothers, aunts, siblings and on some rare occasions, fathers too), as well as the fact that oftentimes, the CGs are themselves struggling with the effects of the disease itself (UNAIDS, 2008).

In the review of literature for this topic, a lot of glaring characteristics of HIV/AIDS caregivers were revealed. Cohen et al., (1997) found out that generally, CGs within the context of this disease represented a heterogeneous group involving of people comprising older parents and

grandparents, other relatives, gay partners and friends, HIV infected mothers, caring for their similarly infected children. Their paper goes further to cite Smith and Rapkin (1996) where it was reported that the category of CG varied according to the infected person. In this paper, the familial aspect of caregiving will be the main focus of interest.

There can both be positive as well as negative effects of caregiving. Although the negative effects are often more reported than the positive, Cohen et al (1997) similarly identified, as part of the positive aspects, the monetary savings to the family, as against institutionalized (paid) care for the individual. The reported 'negative' aspects of caregiving relate more to the burnout and fatigue resulting from not only the amount of chores done (cooking, cleaning, personal hygiene, financial, as well as emotional care), but also to the *paradoxical* negativity, as evident by the length of time spent caring. This is because often people with HIV/AIDS live longer due to the quality of care received, which further increases the burden on the CG. This no doubt introduces another concept of a needs assessment for CGs of HIV/AIDS infected people, which include stress relief and support, further discussed below.

2.3. HIV INFECTION IN CHILDREN

The statistics regarding HIV infection in children is a good focal point in informing further research on its care, treatment and prevention:

... The WHO estimate that about 630,000 children worldwide became infected with HIV, mostly through mother-to-child transmission during pregnancy, labour, delivery, or breast-feeding. More than 500,000 were in Sub-Saharan Africa and 50,000 in Asia. If this rate of infection continues, an estimated 5-10 million children worldwide will become infected with HIV over the next decade, and more than 90% of this will occur in the developing world...About one-quarter of infected newborns will die before their first birthday, and two-thirds before their second birthday. Most deaths occur in the under-5s (Sharland and Handforth, 2005).

More relevant to this research however, is caregiving as it relates to HIV in children. Despite advances in medical care, the high mortality and morbidity in HIV infected children is reason enough to focus attention on those tasked with providing ongoing care, love and support to the infected children especially in a familial setting.

A search of pertinent literature on the subject (caregivers of HIV-positive children) revealed certain distinct qualities/attributes of this group of care providers. Of particular importance is their relationship to the children, their needs, knowledge base, as well as their perceptions/attitudes.

2.4. CAREGIVERS' RELATIONSHIPS

In one study, it was found out that the CGs of HIV positive children were oftentimes the biological parents, foster or grandparents, relatives or significant others (Caldwell et al., 1992; Cohen et al., 1995; Joslin and Brouard, 1995). Nevertheless, a gender profiling of CGs revealed that women usually assumed this role regardless of their relationship to the infected children (Black et al., 1994). As discussed in Chapter 1, the majority of caregivers are female. Women, as informal caregiver, are estimated to be between 59 and 75% of the total number of caregivers (American Psychology Association, 2014).

2.5. NEEDS

Already introduced above, the needs assessment of CGs of HIV-positive children presented unique challenges. Reidy et al., (1991), found that the CGs needed help primarily with coping with stress and their personal life situations. Furthermore, they found out that the CGs also needed health education on protecting themselves and other family members from HIV, as well as financial assistance. As such, Eneh (2010) opines that stakeholders (policy makers and administrators) must proactively engage with caregivers, in decisions regarding their needs, so that adequate solutions can be developed.

2.6. PRACTICE AND ATTITUDES

The literature review identified that CGs perceptions associated with HIV/AIDS tended to focus on both physical and psychological issues. The physical issues comprised mainly of disease conditions, while social stigma formed the bulk of the psychological conditions. On 'attitudes', Poindexter and Linsk (1999) found out that the attitudes of the CGs were mixed between burden of care and honourable dimension in caring for their sick children, regardless of the presence of external support or inputs. Still on attitudes and perceptions D'Auria et al., (2006) discovered most mothers with HIV positive children became over-protective and obsessed about protecting

their children from catching diseases from playmates regardless of their (playmates') status. Others, it was found, adopted prayers, both as a form of internalized support, or as a way of dealing with the uncertainties of their children's conditions. By developing a sense of urgency in forming strong bonds with their children, or putting the children's needs before theirs, it was discovered as another form of attitudes and perception adopted by CGs (D'Auria et al., 2006). Horwood, et al., in their 2009 study of South African caregivers' attitudes discovered that mothers generally expressed positive attitudes towards routine disease screening and HIV testing for their children. This they (Horwood et al.) discovered was balanced against fears of stigma or discrimination from the nurses and other health workers, although no specific instances of such were identified. Pupradit (1998) summarized CG attitudes indicating that the majority of mothers reported satisfaction with care of newborns, took care of their babies with more love and tenderness and tried to prevent their babies from getting ill.

2.7. KNOWLEDGE

In line with an often quoted phrase about 'Knowledge is wealth, and wealth is life', it was discovered that positive knowledge had a proportionate influence on child rearing practices, especially as it relates to infection control and prevention and care of children with HIV and AIDS (Payaprom, 1996). Indeed assessing the knowledge base forms an integral component of any KAP study, which on the one hand influences the subjects' (CGs in this case) perceptions and attitudes. These perceptions and attitudes will, in turn, influence the areas of concentration of efforts in mitigating any anomalies detected. Abrams, et al. (2006) assert that improving HIV treatment-related knowledge and the self-efficacy of caregivers may help to improve the clinical outcomes of HIV-infected children. Pertinent areas of concentration of knowledge assessment in this regard will therefore be in areas of:

2.7.1. DISEASE RECOGNITION

Disease recognition in childhood HIV is an integral aspect of caregiving. The Integrated Management of Childhood Infections (IMCI) is a WHO/UNICEF initiative for improving morbidity and mortality in under-5 year old children, attending first level facilities in developing countries (Horwood et al, 2009). This IMCI protocol is essentially taught to health care workers and mothers (primary CGs) for easy identification of serious disease in children. Common

identifiable diseases in childhood include severe diarrhoea (more than 7 nappy changes per day), and a very high fever (temperature over 38 degrees celsius). Generally, however, mothers of HIV-positive babies tended to seek medical attention, confirmation, or reassurance even for relatively minor ailments (Lazarus et al., 2010).

2.7.2. ART INITIATION AND ADHERENCE

Prompt and effective initiation of antiretroviral treatment is the mainstay of HIV/AIDS treatment regardless of age or disease stage. This effective treatment with ART is dependent on the way the CGs (in particular, mothers) of children with HIV understand and engage with it (Lazarus et al., 2010). This CG factor becomes increasingly important due to the vulnerability of HIV-positive babies to illness and death, especially within the first year of life (Lazarus et al., 2010) following initiation of ART, the concept of adherence, which is described as at least a 95% compliance with ART or not more than 3 missed doses of medications per month plays an important role (SA National Department of Health 2010). This is however dependent both on the knowledge and perception (described above) and amount of support (described below) available to the CG. When adherence is sub-optimal, HIV infected patients usually present with poor response to HIV and a rapid decline in immune function. Lazarus et al., (2010) report that the initial period of commencement of ART was usually the most difficult regarding treatment compliance. In cases where other family members/friends were unaware of the child's (or mother's) status, giving the ARVs to the babies was a big challenge for the CGs. These concerns, they agreed, necessitated the need for a sound support system for CGs and their wards.

All in all, regarding ART, it was discovered that CGs were usually more optimistic when their children were on treatment, especially with observable positive results from the medications. Having a baby on ART, it was found, deflected attention from negative thoughts, although in some quarters it served to evoke ambivalent feelings of 'constantly reaffirming' the baby's HIV status.

2.7.3. NUTRITIONAL STATUS

Both in sickness and in health, the advantages of good nutrition are invaluable. HIV in children not only increases nutritional needs, but has the propensity to stunt growth and development, even in cases of optimal nutrition. It is in fact a sign of possible undiagnosed HIV infection. CGs

should be taught of the needs and principles of a balanced diet, taking into consideration their cultural and financial constraints (SA National Department of Health Guidelines, 2010). In addition CGs must be educated on recognizing signs of malnutrition in the children, as well as taught about the adequate use of nutritional supplements, especially for severely malnourished children.

2.8. SUPPORT AND COPING SYSTEMS AVAILABLE

The need for immediate and ongoing support for the CGs of HIV positive children can never be over-emphasized. Due to the chronic nature of the disease, the morbidity and eventual mortality of patients, there is a need to make adequate support structures available to people who routinely provide care for the infected. More so, when, as previously noted, they may be faced with similar or other disease conditions, along with their own day- to-day challenges.

A child with AIDS usually identifies a whole family at risk of infection. HIV can overwhelm already weak coping capacities and push a family into complete disorganization and crisis. More than one family member may be ill with AIDS at the same time. This puts strain on the family and increases vulnerability to psychosocial stress. Psychosocial stresses are heightened at the time of diagnosis, during episodes of illness and during terminal illness (SA National Department of Health Guidelines 2010: 68).

Regarding external support, it was discovered that support in relatively equal proportions was available to CGs from friends external to the family, both psycho-socially and financially (George et al., 2011). Regarding coping strategies, denial, concealment, isolation and crying were most often employed by the CGs (Hackl et al., 1997). As for coping styles, prayer and a desire to maintain some form of control over the situation were most utilized (Rose & Alexander, 1999).

2.9. DISCLOSURE TO CHILDREN

The public health advantages of HIV status disclosure to children far outweigh the effects of non-disclosure. From a legal perspective, the United Nations Convention on the Rights of Children (Article 12) states that children have the right to participate in their own health care (South Africa National Department of Health, 2010). The *process* of disclosure is one which

CGs have to make, preferably before the child attains the age of puberty. This is to avoid a population of sexually active young adults unaware of their disease status. When people know their status, they can therefore be in a position to make informed choices about their health. The legal and health implications of disclosure notwithstanding, many caregivers, either due to a lack of knowledge or adequate support systems or even because of fear of stigma/discrimination, fail to disclose the children's status to them. This is not in any way restricted to Sub-Saharan Africa (SSA). An estimated 20% of about 6000 HIV-infected children in Romania have not had their infection status disclosed to them (Ionescu, 2006).

Regardless of geographical location, guidelines as set in the Treatment Guidelines (SA National Department of Health 2010) for CGs to disclose to children include letting the children know they are loved and cared for; how HIV is transmitted; honesty; availability of adequate professional psychological help (if necessary) and lastly, an age-appropriate information dissemination process. This age-appropriate information concept simply refers to determining and catering to knowledge needs of HIV-positive children depending on their age and mental capacity.

Having looked at the issues affecting caregivers of children, as outlined in the literature, I now propose to explain how I sought to examine this issue. I shall look at the methodology that was employed, before proceeding to examine the results of the investigation that was undertaken.

CHAPTER 3

METHODOLOGY

The research methodology refers to the way and manner data is collected for research projects. It includes all the steps from planning and designing the study, to determining and constructing the survey instrument, culminating in sampling and data collection.

This study is an exploratory one, attempting to understand the phenomena of care as given to HIV infected children on treatment and to assess what factors (both medical and non-medical) best influence outcomes. For this reason, qualitative research was considered to be the most useful because it attempts to describe and understand their experiences, beliefs and actions as it impacts on the quality of care provided to children. As this is a non-experimental research, a survey method was adopted. From a large sample (the total number of caregivers of infected children in the Hospital, a target population of about 30 respondents was selected. This selected study sample was achieved by simple random sampling [see section 3.3 below].

As already stated, the research is a survey attempting to gauge the Knowledge, Attitudes and Practices (KAP) of HIV/AIDS caregivers, the ultimate objective of which is to suggest areas for possible improvement in HIV care. Following the relevant Ethics Committee and Institutional approval to conduct the research, the steps involved in the research methodology involved

- planning and designing the survey study;
- survey instrument construction; and
- sampling and data collection.

3.1. PLANNING AND DESIGNING THE STUDY

The primary factors considered were the time frame for completing the research (the research was meant to be completed over a few weeks/months); the sensitive nature of CGs disclosing details about their HIV positive children/wards and the need to get a heterogeneous group of respondents reflective of the total population. As such, a *cross-sectional* design was adopted as it fulfilled all the aforementioned criteria. It has been put forth that a cross-sectional study involves identifying representative samples of individuals that differ on some characteristics such as age,

gender, ethnic group, or religion, and measuring these different samples of individuals on the same variable or variable(s) at one point in time (Christensen et al., 2011: 50).

3.2. THE SURVEY INSTRUMENT

The survey instrument used was a questionnaire, which was answered by the research participants. The questionnaire consisted of 35 self-administered and anonymous questions in simplified English, with a Sesotho version for the non-English speaking respondents. This language preference determination was done following consultations with the nurses regarding what major languages were spoken in the clinic. The questions were a mixture of closed and open-ended questions, developed according to experience regarding issues encountered in medical practise, other appropriate and prior research on CGs, and the South African National Department of Health Paediatric HIV Care Manual (2010) with emphasis on the relevant sections on CGs. Areas covered in the questionnaires included:

- Demographic characteristics of caregiver;
- Knowledge about HIV transmission in children;
- Knowledge on appropriate nutrition and growth assessment for children with HIV;
- Assessment of knowledge of co-morbid diseases in HIV-positive children;
- Antiretroviral therapy (ART) adherence;
- Availability of HIV counselling and support structures;
- HIV status disclosure to children.

[See Annexures A and B for the respective English and Sesotho versions of the questionnaire.]

3.3. SAMPLE SIZE

Regarding the *sample size*, the first consideration was recognizing that all the CGs could not be studied, hence the primary consideration was in choosing as accurately representative sample size as possible. The target size was 30 respondents and random sampling (more specifically, simple random sampling) was employed. It has been maintained that random sampling ensures

an accurate depiction of the general population (Christensen et al., 2011). With simple random sampling as the specific method employed, the end result was a method with not only the least sampling error, but one which is most representative of all the total respondents.

A pilot study was conducted on 4 caregivers in an attempt to test the ease of use of the questionnaire so any potential problems could be identified. The entire survey was administered to the respondents (4) and their feedback was used as go-ahead for the survey proper. From this pilot study, the response time was identified to be a mean of 25 minutes each and no complaints were raised by the respondents.

Prior to the process of *data collection* from the sample population, the purpose of the research was explained to all the CGs who presented at the day clinic on the chosen day, with an opportunity for questions or clarifications. The respondents' right to participate or decline at any time (without coercion) was also explained and consent forms were provided and their importance elaborated. Respondents were also informed on the language choices (Sesotho and English), and all were assured of confidentiality at all stages of the research, and encouraged to seek clarity at any stage in the process. They were also informed that the study was purely for academic purposes; hence no monetary compensation for participants would be available.

All the CGs of under 5 children (on ART), presenting daily in the out-patient unit of the HIV/AIDS clinic of Kalafong Hospital were assigned numbers, which were folded and placed in a box, from which 30 were blindly and randomly drawn. The ease of choosing this sample from the population was made easy by the fact that Kalafong Hospital has a designated day clinic for under-5 children only. The selected CGs were assessed via a *group-administered questionnaire* method. This approach involved handing out questionnaires in a group to the selected CGs, so that they were subsequently quickly and efficiently completed. The response time was approximately twenty five minutes each (as evident by a prior pilot study with four randomly chosen CGs from same centre).

Lastly, confidentiality for the respondents was further ensured by providing separate boxes where respondents were asked to place their completed questionnaires in one, and their signed and filled consent forms in the other. This ensured that no consent form was attached to the

sample instrument, so that the information remained completely anonymous and unlinked to any one respondent in particular.

3.4. LIMITATIONS OF METHODOLOGY

This sub-section attempts to discuss some limitations in the methods employed and introduced in this chapter. As such the limitations of the employed methodology will be addressed as follows:

- Limitations involving the sample size;
- Limitations involving cross-sectional surveys;
- Limitations involving the use of questionnaires.

3.4.1. LIMITATIONS INVOLVING THE SAMPLE SIZE

Regarding the sample size, the population size (n=30) does not allow for generalizations to be made about caregivers' KAP in Pretoria. Although the study highlighted certain deficiencies regarding the knowledge and perceptions of certain caregivers studied, the sample size does not allow for statistically significant conclusions to be made. Regarding the sample size in random sampling, Christensen et al., (2011:160) explain that "*larger sample sizes make it less likely that you will miss an effect or relationship that is present in your population*". A larger sample size, they postulate, is indicated when the population is heterogeneous (the study attempted to analyze responses from a wide variety of CGs) and the response rate is likely to be low (see Limitations above).

"When simply describing the characteristics of a single group of subjects, the larger the study, the more reliable the results....the main results should have 95% confidence intervals (CI), and the width of this depends on the sample size: large studies produce narrow intervals, and therefore, more precise results" (Hackshaw, 2008, para 2). A CI, for emphasis refers to "*a range of numbers inferred from the sample that has a certain probability or chance of including the true population value*" (Christensen et al, 2011: 428). A 95% CI invariably has a 95% probability that the population parameter is included.

In summary, although small studies make for quick and easy collection and analysis of data, especially when data is collected in one or a few centres, the main issue with small studies is in the interpretation of results. This is illustrated with a simple equation:

Small studies (result in a large standard error) = Wide 95% CI (imprecise estimate of the effect) = No firm conclusions.

Finally, it is worth pointing out that there exists no rule regarding sample size determination. Despite not usually yielding reliable data, research with small sizes can and should form the template for designing larger studies, and may be used to identify other areas of further research.

3.4.2. LIMITATIONS OF CROSS-SECTIONAL STUDIES

Although easy to design and implement, cross-sectional studies are limited in use because they:

- Cannot determine causal relationships. They can only explain correlations between variables. Hence, they have limited in application.
- They may require very large sample sizes to be of maximum utility.
- They only measure existing (past and present) events. They are of limited use in new or projected events.

3.4.3. LIMITATIONS OF QUESTIONNAIRES USE

Questionnaires as used in this study are limited in the following ways:

- Results are usually biased, as participation is voluntary.
- The forced-response choice questions do not allow for freedom of expression by respondents.
- The response rate is usually low.

Having outlined the methodology that was employed, along with its pros and cons, I shall now undertake a detailed look of what the results revealed in respect of caregivers of children at Kafalong Hospital, Pretoria.

CHAPTER 4

RESULTS AND DISCUSSIONS

4.1. INTRODUCTION

This chapter endeavours to present the data collected in an easy to appreciate format. The analysis and interpretation of data from the questionnaire are discussed according to the sub-themes employed in the survey instrument (questionnaire). The questionnaire was distributed to the selected participants, for completion via a group-administered format (as described in Chapter 3). The participants met the eligibility criteria (21 years and older and caring for at least one HIV positive child who was not older than 5 years of age) and participation was voluntary. The data from the questionnaires were based on the respondents' personal experience and knowledge.

As previously stated, the results were depicted according to the questionnaire sub-themes, and as such, we have:

- Demographics;
- Caregiver characteristics;
- Knowledge of Nutrition;
- Disease Recognition;
- ART and Adherence;
- Counselling and Support;
- Disclosure to children;
- Stigma and Discrimination;
- Knowledge of ART Transmission;

4.2. DEMOGRAPHICS

The following demographics of caregivers and their wards at Kalafong Hospital were captured with the aid of the self-administered survey questionnaire.

4.2.1. AGE AND SEX OF CAREGIVERS

As shown in Table 1, the study comprised of 30 respondents of which 28 (93%) were found to be females with only 2 (7%) being males. The majority of the respondents were in the 21-35 year group, and there were no respondents in the >65years category. There were 5 respondents in the 36-50 years age group and only 2 in the 50-64 years group.

Age	Sex		Total
	Male	Female	
21-35	1	22	23
36-50	0	5	5
50-64	1	1	2
65+	0	0	0
Total	2	28	30

Table 1: Age and Sex of Caregivers

These results were in keeping with Folkman et al., (1994) who revealed that most CGs of people living with HIV/AIDS (PLWHA) were between the ages of 21-40 years. The fact that most CGs were females was also consistent with previous findings (Black et al., 1994 and UNAIDS, 2008) where it was discussed that women, possibly through gender stereotyping, are not seen as ‘traditional’ family breadwinners, and therefore usually stay at home to care for the infirmed. Men are traditionally regarded as the breadwinners/providers and, so they are expected to be working, rather than at home. Another significant finding here was the fact that there were no respondents in the >65 years age group. This contrasted sharply the notion of ‘grandmothers’ disease’ (SASIX 2011). However, a reason for this may be the fact that Pretoria is an urban area, so most of the ‘grandmother caregivers’ are confined to rural areas, outside of Pretoria. It should however be noted that one grandmother in this study was in the lower age groups.

4.2.2. LEVEL OF EDUCATION

Regarding the level of education, as depicted in Table 2, 14 respondents (representing 47%) had a high school ('matric') qualification; 9 (30%) had 'some high school' education, 3 (10%) had only a basic primary qualification, and 2 (7%) respectively had no education whatsoever. Some (6%) had college (and beyond) qualifications.

Age	Sex	Level of Education						Total
		None	Primary	Some School	High	Matric	College and above	
21-35	Male	0	0	0		1	0	1
	Female	2	1	8		10	1	22
36-50	Male	0	0	0		0	0	0
	Female	0	1	1		3	0	5
50-64	Male	0	1	0		0	0	1
	Female	0	0	0		0	1	1
65+	Male	0	0	0		0	0	0
	Female	0	0	0		0	0	0
Total		2	3	9		14	2	30

Table 2: The level of education level by age and gender

4.2.3. INCOME LEVEL

Table 3 shows that 28 respondents (representing 93%) were in the <R50, 000 per annum income category, whilst 2 (7%) were in the R50, 000-R100, 000) category. There were nil responses for the R150k-200k and >R200k categories.

Education level	<50k	50-100k	150-200k	<200k	Total
None	2	0	0	0	2
Primary	2	1	0	0	3
Some High School	9	0	0	0	9
Matric	13	1	0	0	14
College and above	2	0	0	0	2
Total	28	2	0	0	30

Table 3: Income Level

These findings are in keeping with the fact that most caregivers (especially the primary ones) of HIV positive children engage in rendering care on a full time basis, often only supplementing family income with petty trading and/or gardening. There was however no correlation between income level and level of education on the nature/quality of care given.

4.2.4. THE AGE OF THE CHILD BEING CARED FOR

The caregivers responded that they cared for 16 children (53%) between the ages of 4-7 years and 14 children (47%) in the 0-3 category as illustrated in Table 4 below. It would be recalled however that the study was targeted at children in the 0-5 age group (the significant group for infant mortality studies) so the lack of responses in the other age groups was not relevant for analyses.

Age of Child	Relationship to child of caregiver						Total
	Mum	Aunt	Grandma	Father	Brother	Other	
0-3	10	2	0	1	0	1	14
4-7	11	3	1	0	1	0	16
7-10	0	0	0	0	0	0	0
>10	0	0	0	0	0	0	0
Total	21	5	1	1	1	1	30

Table 4: The Age of the Child

4.3. CAREGIVER CHARACTERISTICS

Here, the relationship of the respondents to the children, as well as their roles (primary and secondary) was assessed. The definition of primary and secondary caregivers was introduced in Chapter 1. In this sub-section, the relationship of the respondents to the children was ascertained, as well as the level of care.

4.3.1. THE RELATIONSHIP TO THE CHILD

21 respondents (representing 70%) were found to be the mothers of the children being cared for, while 5 (17%) were the aunts, and 1 (3%) was a child's grandmother. 1 respondent respectively were the father and brother, whilst there was 1 respondent who was a house mother at an

orphanage (secondary caregiver). The significance of this was in keeping with the ‘more female to male’ ratio (approximately 13:1 from the study) of caregivers, as evidence by the UNAIDS manual on caregiving.

97% of the respondents had a familial relationship to the children being cared for, while there was only one non-family caregiver (3%). This is in line with HIV being regarded as a “family disease” (SA National Department of Health 2010: 32). Indeed as much as 86% of caregivers attend to a sick relative (Family Caregiver Alliance, 2012).

4.3.2. TYPE OF CAREGIVER

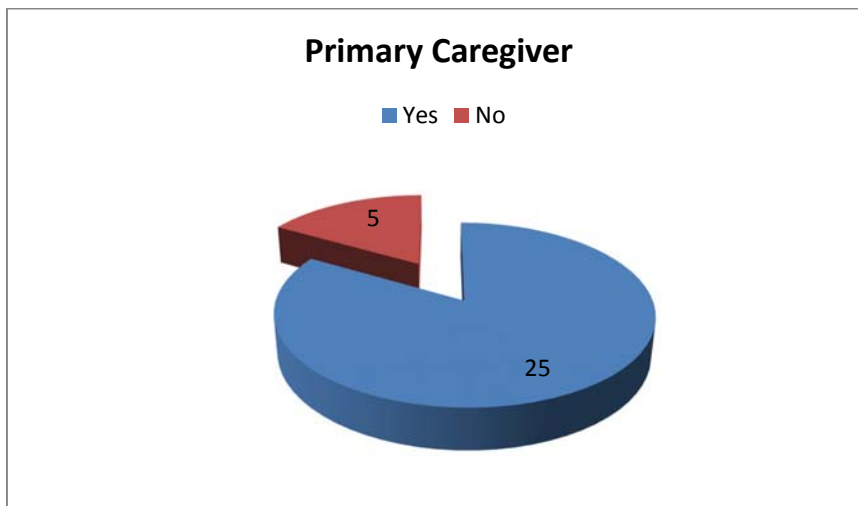


Figure 1: Type of Caregiver

The study unearthed that 25 (83%) of the respondents were discovered to be the primary caregivers of the children, with 5 (17%) claiming not to be the primary caregiver, as seen in Figure 1. No attempt was made to determine if these were secondary caregivers in this study. However, the bulk (14%) out of this 17%, were family members of the children. The assumption here is that the primary caregiver was temporarily indisposed, for one reason or another, so a close relative offered to bring the children for their routine check-ups.

4.3.3. THE NECESSITY OF A SECONDARY CAREGIVER

The responses in this section, as shown in Figure 2, were that 20 respondents (67%) were in favour of a secondary caregiver and 5 respondents (16.5%) each were either negative or unsure about this proposition, respectively.

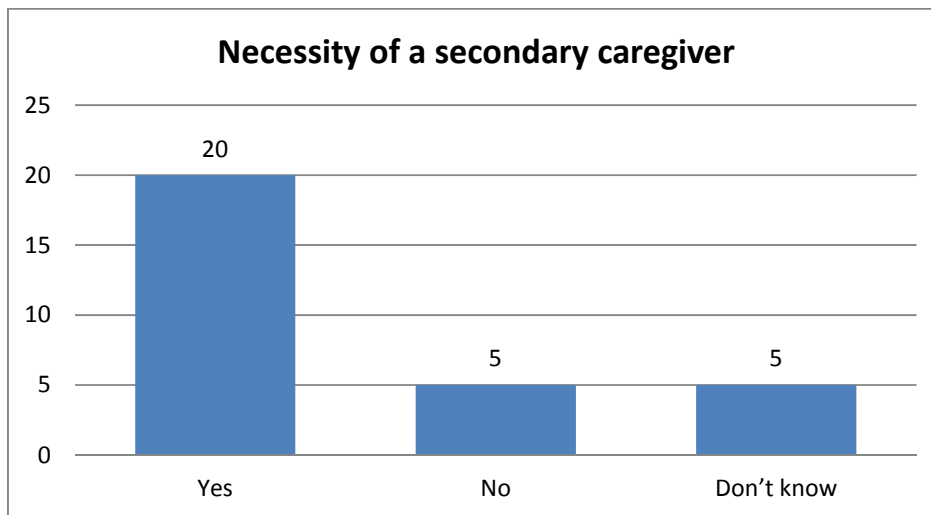


Figure 2: Secondary Caregivers

It is a given that no one person can provide round the clock care for a sick baby/child, either due to fatigue or stress from a burnout (see needs of caregivers in Chapter 2) or even because, as noted above, HIV could be a ‘family’ disease. The fact that 67% of respondents acknowledge this fact bodes well for the all-round care of HIV-infected children. The collective 33%, who either declined help from secondary caregivers or did not know if they were necessary were either responding to a negative scenario in the past (see next section) or might be putting themselves at risk of burnout, which will ultimately result in sub-optimal care.

4.3.4. THE REASONS FOR THE NEED FOR A SECONDARY CAREGIVER

Recognizing that caring for a sick child is indeed a stressful job for any one person, 10 (50%) of the respondents who identified the need for a secondary caregiver did so because they did not want to miss doses of ART for their children, whilst 40% and 10% said “in case I am not around” or “sick”, respectively, as seen in Figure 3. These are interpreted as positive responses that recognize the need for help (support systems) and ART adherence, further discussed below.

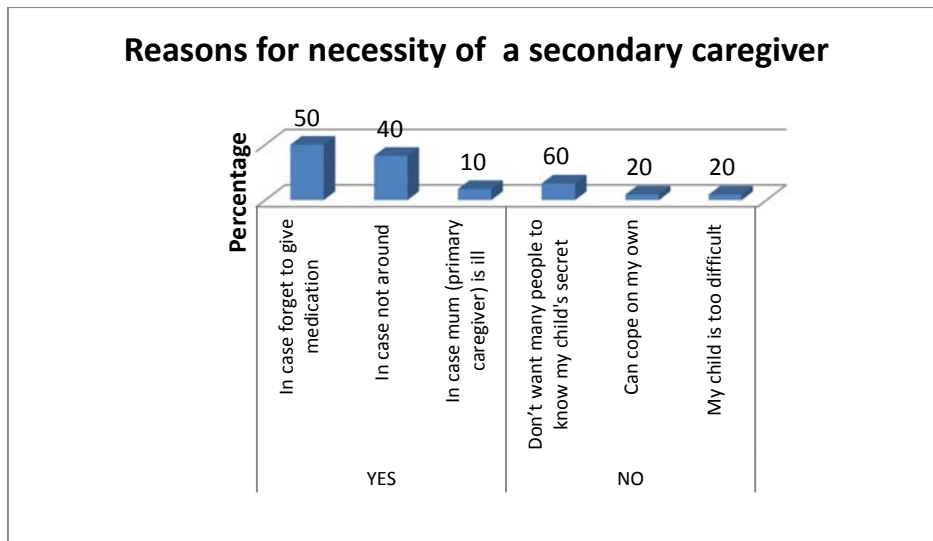


Figure 3: Reasons for the Need of a Secondary Caregiver

Of those respondents against a secondary caregiver, 3 ‘did not want people to know’, and 1 each felt they could cope on their own or had a “difficult child” respectively. These respondents represented, as previously, depicted a small portion of the whole.

4.4. KNOWLEDGE OF NUTRITION

The advantages of good nutrition especially in chronic diseases can never be over emphasized. During illnesses, energy requirements increase and depending on the nature of illness (diarrhoea, for instance) nutrient losses additionally follow. The need for balanced nutrition both in sickness and in health is of utmost importance.

4.4.1. GOOD NUTRITION AND IMPROVEMENT OF THE HEALTH OF THE CHILD

As shown in Figure 4, 28 respondents representing 93% of the total were of the opinion that good food will improve their child’s health, while 3.3% (1 respondent each) either did not believe this fact, or was unsure of the role of good nutrition in improving the efficacy of ART.

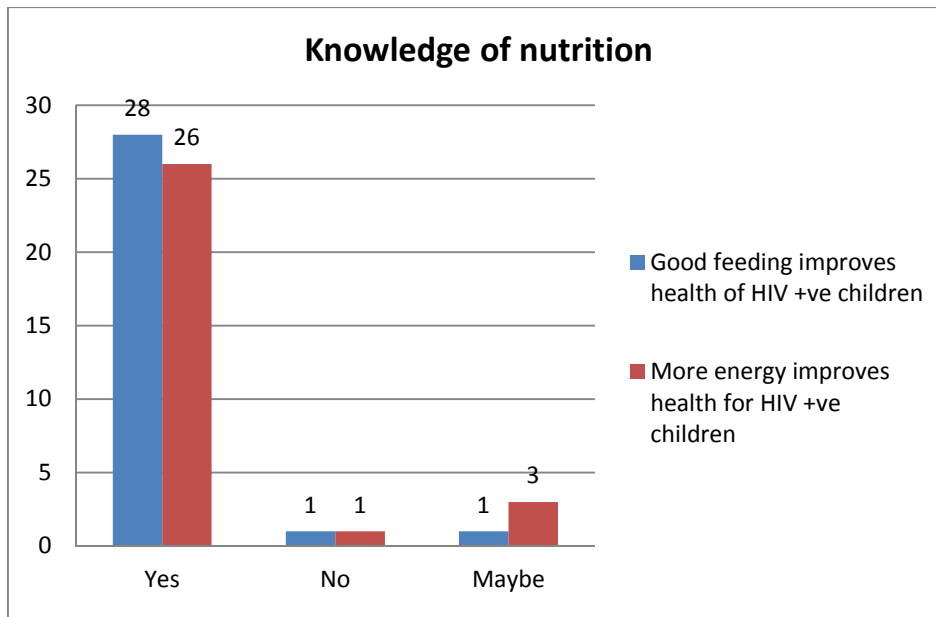


Figure 4: Knowledge of Nutrition

As much as ART remains the mainstay of treatment, children are also prone to nutritional deficiencies, more so than adults, this is because not only do nutritional requirements increase exponentially, malnourishment in a child will decrease the efficacy of ART even when given at the right times and the right amounts.

4.4.2. HIV POSITIVE CHILDREN NEEDING MORE ENERGY RICH FOOD

Chronic illnesses, like HIV, increase the energy requirements and indeed metabolism of infected patients. *“As soon as a child is infected with HIV they have an increased energy requirement of 10%. This needs to be taken into consideration when counselling the caregiver.”* (SA National Department of Health, 2010: 24).

The responses here were exactly similar to the above (93% for YES and 3.3% for the other 2 responses, signifying that the respondents had a good knowledge about the importance of good nutrition.

4.4.3. KNOWLEDGE OF EXAMPLES OF NUTRITIOUS FOODS

The responses here were a bit of a deviation from the already established knowledge of the role of good food in chronic diseases. As much as the respondents were almost unanimous in the

above mentioned knowledge, putting the same to practise was slightly different to the established pattern. Figure 5 shows that 60% of the respondents were of the opinion, and rightly so, that burgers were expensive and unhealthy. 40% of the respondents were wrong in their knowledge of healthy foods, which was worrying, as these are commonly found food items. A lot of attention needs therefore, to be placed on educating caregivers on cheap but healthy alternatives to feeding children, especially in resource poor settings. This is because malnutrition is implicated in most cases of child deaths as it increases susceptibility to severe diseases (WHO, 2013).

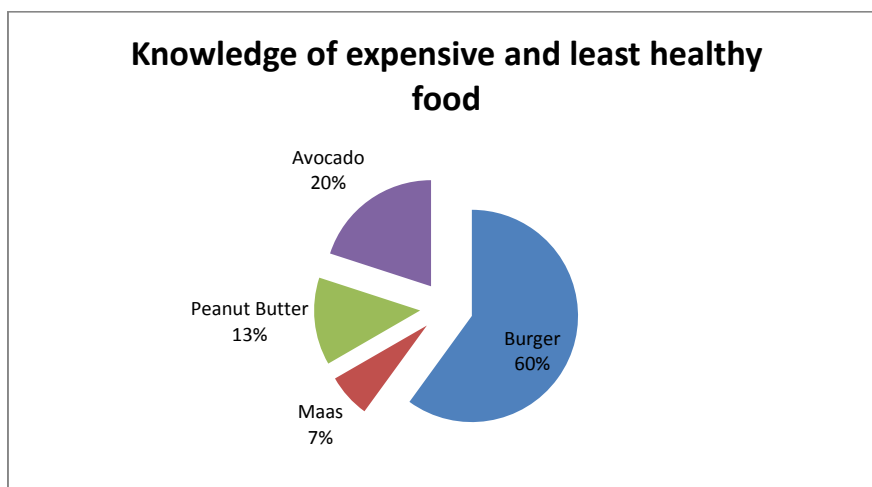


Figure 5: Nutritious Foods Examples

Burgers are generally made of meat and bread with lots of dressings, generally regarded as fattening and of low nutritious value. Maas refers to the Afrikaans for a sour milk-based product that is highly nutritious and can be used in supplementing nutrient loss in diarrhoea diseases in children. Avocados are highly nutritious fruit rich in carotene-a very potent antioxidant. Peanut butter is a highly nutritious protein rich food commonly used as a spread for bread, which is also rich in antioxidants. Antioxidants are nutrients that help improve the function of the immune system and are very advantageous in HIV infected children.

4.4.4. GROWTH AND DEVELOPMENT RECOGNITION

As Figure 6 indicates, 12 respondents, representing 40% of the total were able to correctly identify indicators of poor growth in children. The remaining 60%, whilst not entirely wrong,

only chose one indicator of poor growth from the list. Although it can be argued that more than half the respondents ‘failed’ this question (which would be somewhat worrying), the fact that they at least were able to recognize some form of growth retardation, was positive in itself. Comprehensive health education in this regard, will prove invaluable to the caregivers and ultimately, the children being cared for. This is more so because, “*monitoring of weight while on treatment is important as growth failure is often an indicator of treatment failure.*”. (SA National Department of Health, 2010: 22).

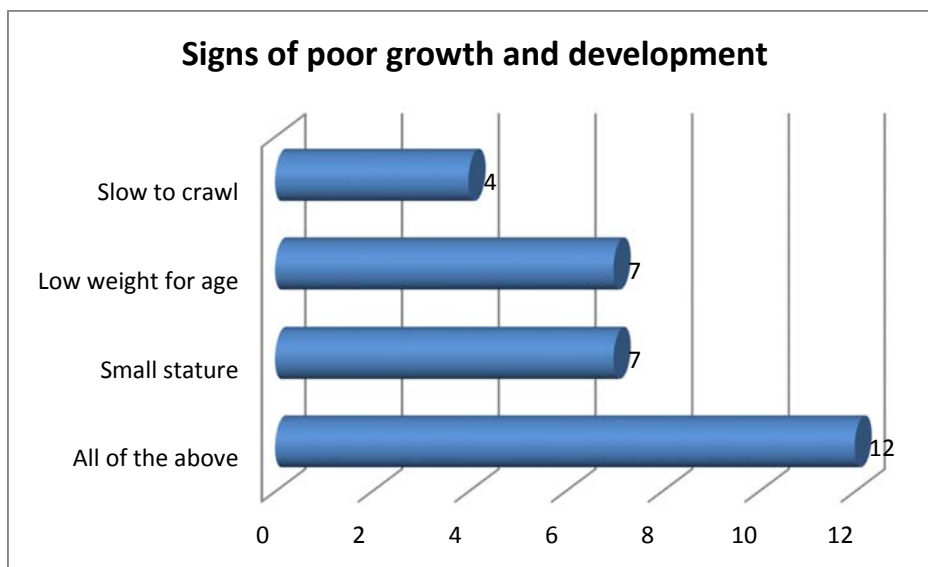


Figure 6: Signs of Poor Growth

4.5. DISEASE RECOGNITION

Disease recognition forms an integral part of care in childhood caregiver knowledge and attitude assessment. The IMCI initiative of the WHO/UNICEF has already been introduced in Chapter 2, where key disease and health indices are expected to be taught to and imbued into the caregivers of children, especially the HIV positive children under the age of 5 years (Horwood et al., 2009). For emphasis, a comprehensive list and disease recognition protocol is reproduced in this study (see Appendix C).

21 respondents, representing 70% of the total population, identified ‘vomiting everything’ as a sign of severe illness in a baby. Figure 7 provides a graphic representation of the findings.

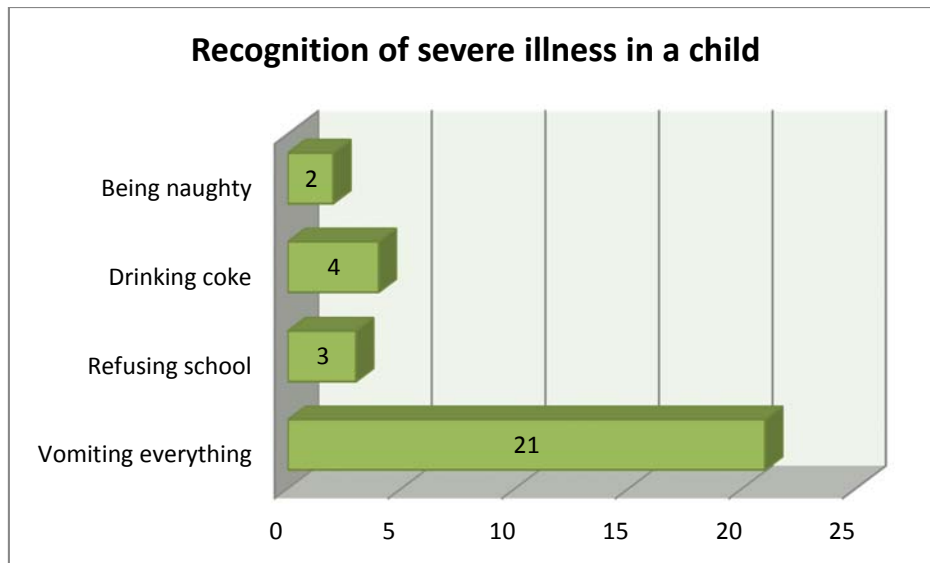


Figure 7: Signs of Severe Illness

A child who vomits everything will not only fail to retain the necessary medications (ART in this case), but is also prone to severe dehydration and death if left untreated. Whilst the other responses: refusing to go to school ((10%), drinking only coke (13%) and being naughty (7%) are also indicators of ‘something not quite right’ with the child, the focus of attention here is the standardized WHO/UNICEF disease recognition protocol. This is a necessity for all caregivers and the onus is on the healthcare workers to ensure this.

4.5.1. RESPONSE TO SEVERE ILLNESS IN A CHILD

As part of the IMCI protocol of disease recognition, the onus is on changing the attitudes of the caregivers, especially in response to the presence of severe disease in a child. 28 respondents (93%) were right in deciding to ‘rush their children to the nearest clinic/hospital’, whilst 7% decided to give ‘motswako’ to their children. There were nil responses for the other options: ‘give panado to the child’, and ‘call the neighbours’ as shown in Figure 8. Panado is a brand name for paracetamol, an over the counter medication used for treating aches and fevers.

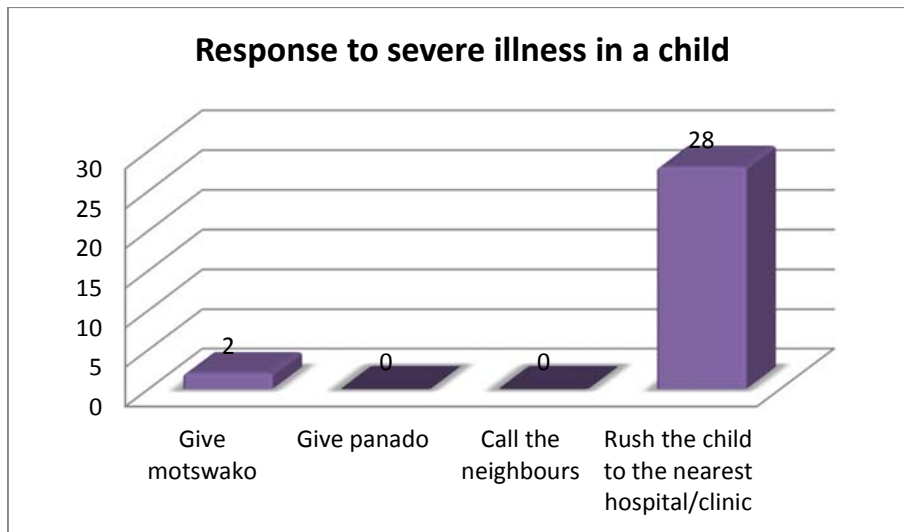


Figure 8: Response to Severe Illness in a Child

Health education forms an integral aspect of daily activities at the Kalafong ART clinic (and indeed most clinics across South Africa), so the 93% who responded correctly may be attributed to the efforts of clinics. Motswako is the Sesotho/Setswana nomenclature for the Oral Rehydration Therapy (ORT). In ORT, sachets of already prepared fluid replacement powders are given to mothers to use in case of dehydration/diarrhoea, or they are encouraged to mix sugar and salt with clean boiled and cooled water. While fluid replacement is essential and not in itself a wrong answer, it will be recalled that dehydration/diarrhoea is one of the markers of severe illness. The caregivers as part of the IMCI initiative should be able to recognize ALL the signs of severe illness and act appropriately by prompt clinic/hospital visit.

4.5.2. HIV AND DISEASE SEQUELAE

For emphasis, the term ‘sequelae’ is a New Latin adoption of the word ‘sequel’ which refers to after effects of a disease, condition or injury (Merriam-Webster Dictionary, 1993). Attempting to determine knowledge of HIV and associated diseases was one of the open-ended questions in the survey instrument. 11 respondents (37%) identified Tuberculosis (TB) as a disease an HIV positive child is prone to acquiring. 1 (3%) identified ‘AIDS’ as their choice of HIV disease, whilst 8 (27%) and 1 (3%) chose ‘diarrhoea’ and ‘measles’ respectively. 2 respondents (7%) each went with ‘Flu’ and vomiting respectively, and 3 respondents (10%) ‘did not know’ any

HIV- associated diseases. There were also 2 blank responses, meaning they could not identify any disease as illustrated in Figure 9.

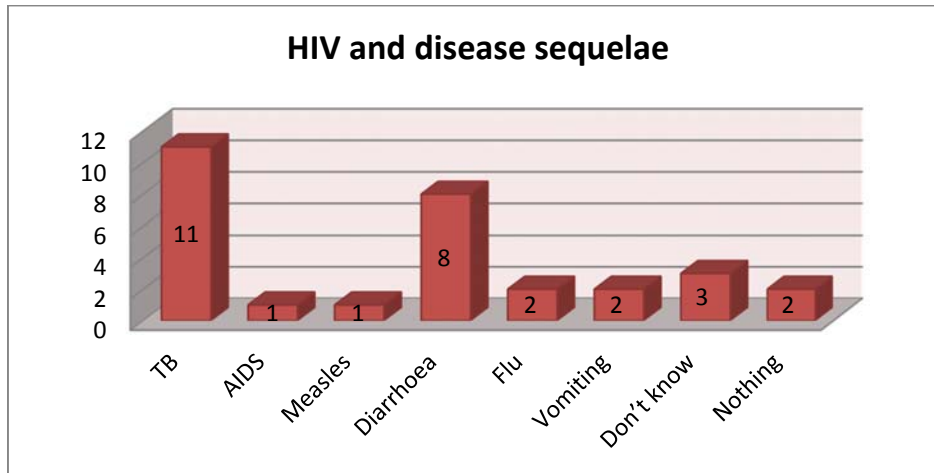


Figure 9: HIV and Diseases Sequelae

Commonly called TB, Tuberculosis is one of the major co-morbid diseases in AIDS, accounting for a high number of AIDS related morbidity, if left untreated. The other identified responses (measles and diarrhoea) were not specific to HIV, occurring commonly in the age group being studied: malaria and diarrhoea are identified as leading causes of death in under-five children (WHO, 2013).

The response of 'AIDS' deserves special mention here, as whilst not exactly wrong (HIV does lead to AIDS). AIDS however, is not a disease, but rather a syndrome of diseases, so on a technicality, it is a wrong answer. This is another identified case of knowledge gap requiring intervention.

4.6. ART AND ADHERENCE

Although there is no cure for HIV as yet, antiretroviral therapy (ART) is widely acceptable as the standard form of management. When rigidly adhered to, the medication has the propensity to significantly reduce the viral load (of HIV) thereby ensuring healthy, active children, free of diseases. Adherence (see definition in Chapter 1) to ART is arguably one of the most important steps in the management of HIV and caregivers attitude and practices in this regard are worth assessing. Good adherence prevents treatment (and virological) failure. Virological failure refers

to a rising viral load and is a common cause of mortality and morbidity in paediatric (and adult) HIV care. Virological failure is almost always due to poor adherence (SA National Department of Health, 2010: 20).

4.6.1. ART PERCEPTION AND KNOWLEDGE

Regarding ART perception, there was a unanimous agreement among all the respondents (100%) that ARVs are the best medicines for their children (Figure 10). This was indeed significant as it bodes well for adherence and eventual wellness when caregivers believe in what they give children.

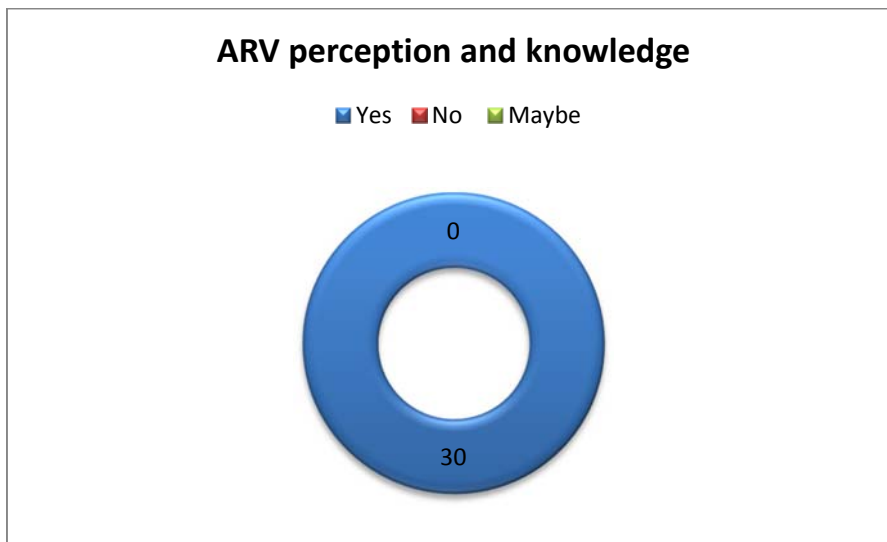


Figure 10: ARV Knowledge

4.6.2. DURATION OF ART

Regarding duration of ART, as shown in Figure 11, 27 respondents (90%) were right in saying that ART should be lifelong in duration, whilst 3 (10%) said 'until adulthood'. This 10% may be as a result of poor information dissemination or in-bred negative perception on the part of the caregivers. There were nil responses for 'one year' and 10 years.

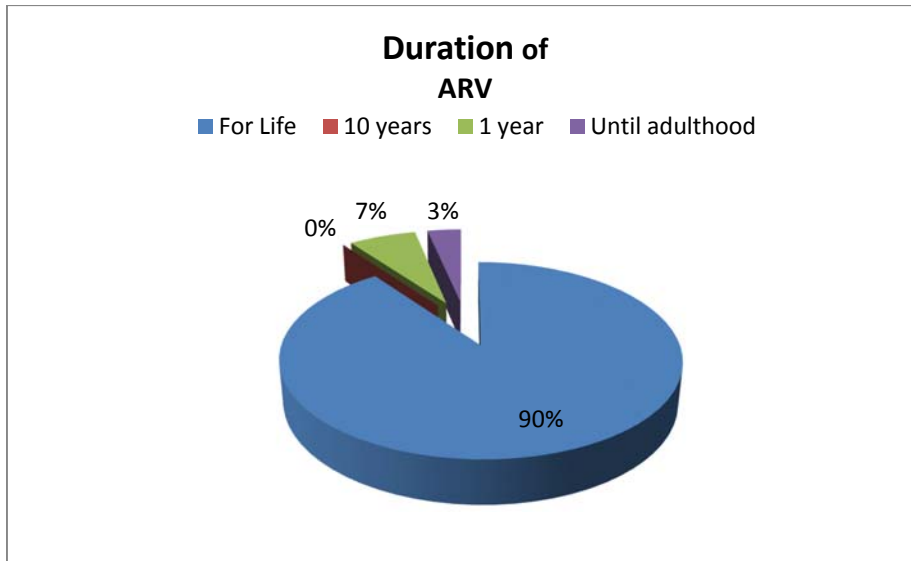


Figure 11: Duration of ARV

4.6.3. NAME OF ARV

It has been established that when patients can remember/know the name of their medications, they not only adhere, but it ensures continuity, in case they relocate and or lose their medical records. Figure 12 shows that of the 30 respondents, 14 (47%) said 'Kaletra', 10 (33%) identified 'Lamivudine', 3 (10%) indicated 'Abacavir', and a further 3 (10%) could not identify any ARV.

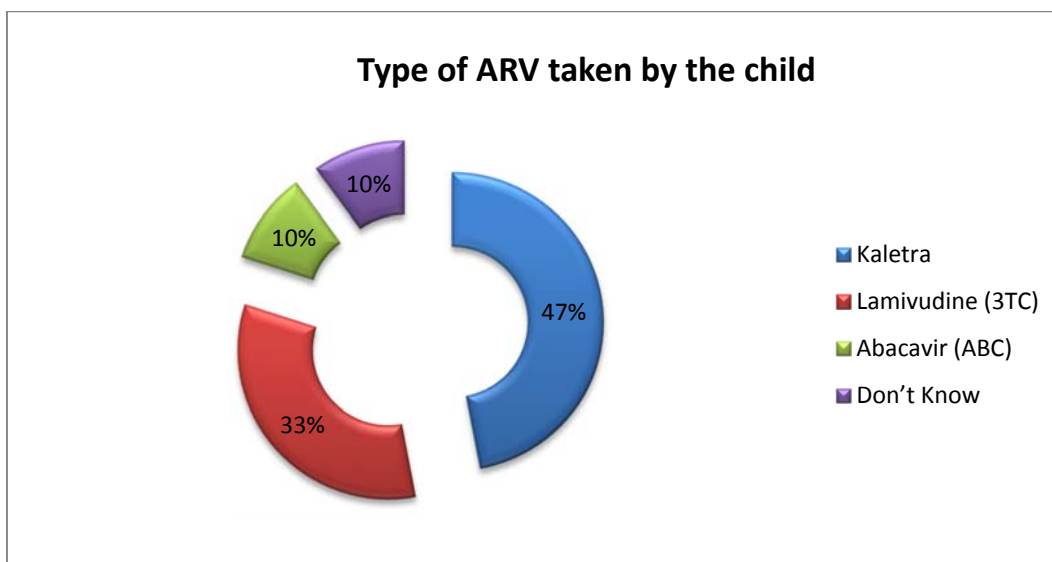


Figure 12: Name of ARV

It is worth pointing out here that Lamivudine and Abacavir are both Nucleoside Reductase Transcriptase Inhibitors (NRTIs), whilst Kaletra is not an ARV per se, but a brand name for a combination of Lopinavir/Ritonavir (two Protease Inhibitors). Kaletra is a highly efficacious ARV available in most ART clinics in South Africa.

4.6.4. ASSESSING ART ADHERENCE

18 respondents (60%) claim not to miss any doses of ART, giving the right amount of medication, at the right time, while 10 (33%) accepted that they ‘sometimes miss some doses’. 2 (7%) respondents ‘were not sure’ if they missed doses, opting to tick MAYBE (Figure 13).

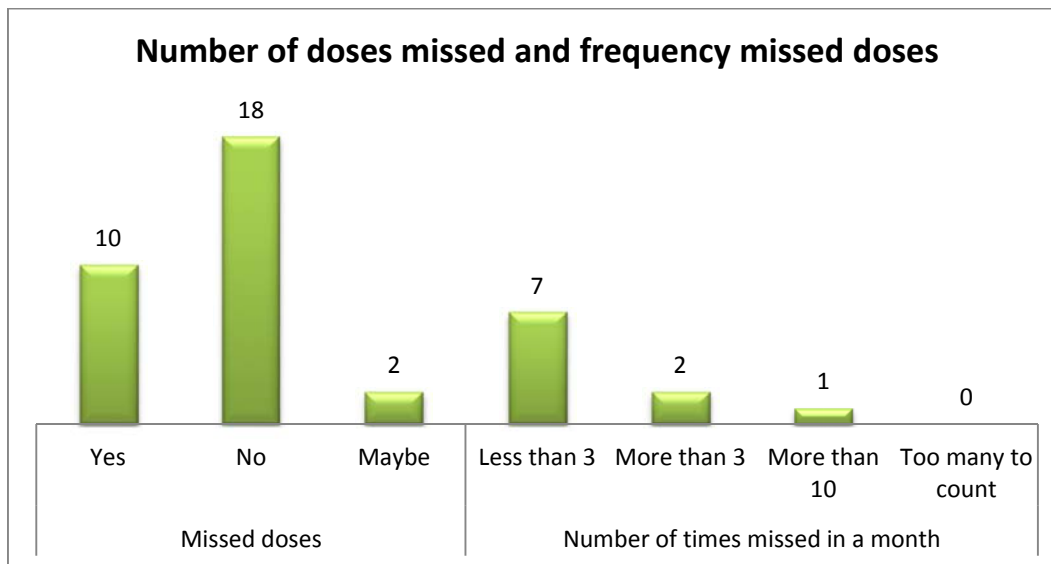


Figure 13: Assessing ART Adherence

Regarding frequency of missed doses, there were 10 responses (from the caregivers who admitted to missing some doses). 7 of these (70%) claimed to miss less than 3 doses per month (the maximum number of missed doses to maintain good adherence), and the remainder 30% missing more than 3 per month (sub-optimal adherence).

4.6.5. REASONS FOR MISSED DOSES

There were 12 respondents here, as shown in Figure 14, with 7 (58%) admitting forgetfulness, and 2 (17%) not giving the medicine because of the presence of ‘other people’. 3 respondents (25%) were ‘just too tired to give’.

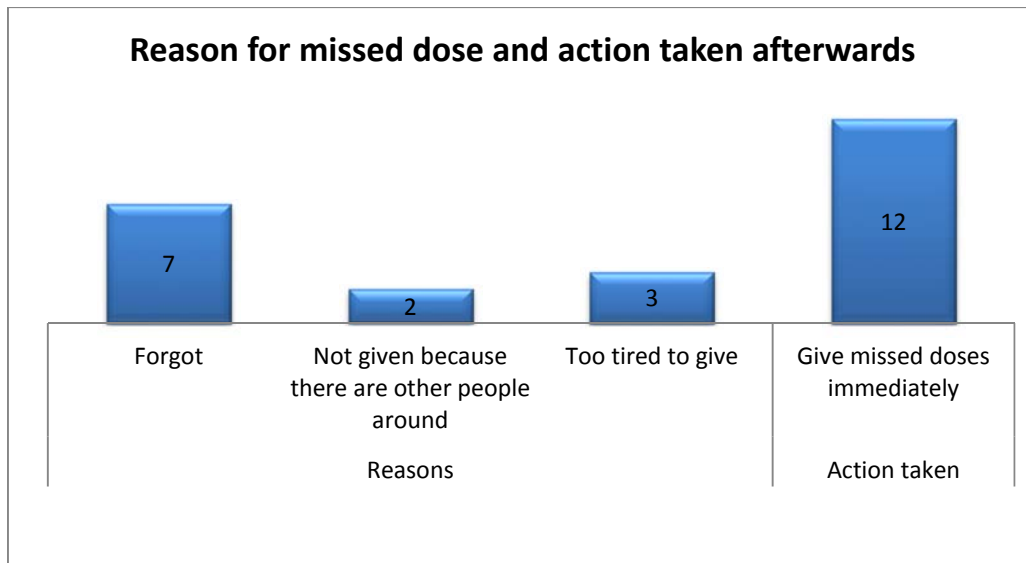


Figure 14: Reasons for Missed Doses

These responses allow ample opportunities for deliberations and deductive reasoning as to the reasons for the missed doses. The 17% mentioned above may have acted as a result of fear of stigma from people around (both real or perceived) hence they could not give the medications, while the 25% who claimed that they were “too tired”, may have been bogged down by the stress of caregiving (refer to stress and coping mechanisms in Chapter 1).

4.6.6. RESPONSE TO MISSED DOSES

All 12 respondents above admitted to ‘giving a single dose immediately and the next one at the right time’. This is the acceptable standard in response to a missed dose of medication. Although not impossible, 100% adherence is indeed difficult. The response to a missed dose is always worth analysing, as it tells a lot about the prognosis of the patient (corresponding to the attitude of the caregiver in this case).

4.6.7. IMPLICATIONS FOR FREQUENT MISSED DOSES

The caregivers’ response to implications of missed doses revealed much about the health education levels and needs. All 30 responded, with 8 (27%) stating that ‘the child will not grow well’, 6 (20%) said “the medication will stop working”, and 4 (13%) stating that “there will be other diseases affecting the child”. Without being too technical, this was a reasonable proportion

(70%) of caregivers with knowledge of implications of poor/non adherence to ART. The remaining 30%, whilst small in comparison, still represents a significant number of caregivers who should have further adherence counselling and/or health education (Figure 15).

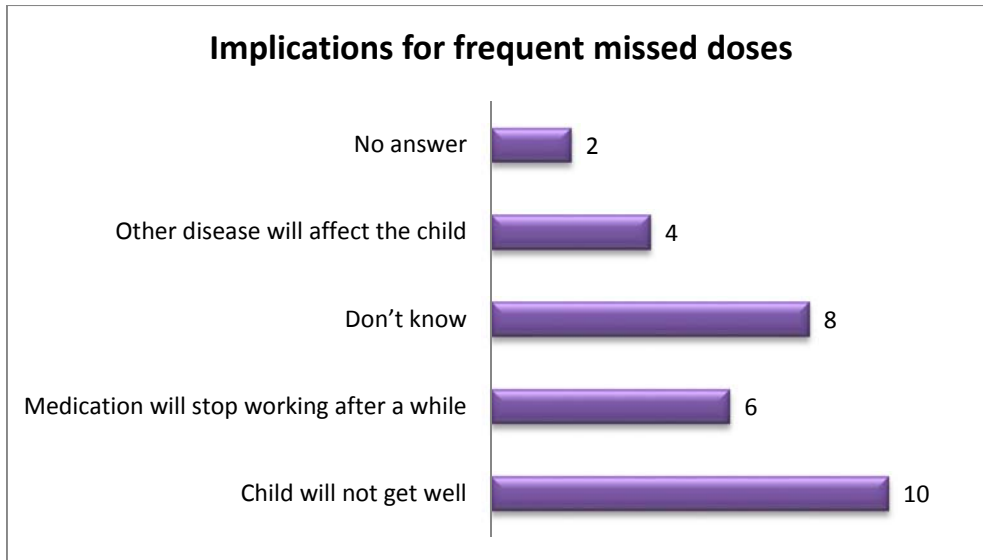


Figure 15: Implications for Frequent Missed Doses

4.7. COUNSELLING AND SUPPORT

Counselling, as well as support should be continuous, so long as a patient is on ART. Caregivers as earlier noted, battle with not only personal problems, but also the uncertain outcome regarding their HIV-infected children. Either from other family members or external support groups, there is a need for some form of support or coping mechanism for caregivers.

4.7.1. COUNSELLING FROM THE CLINIC (PRE-ART)

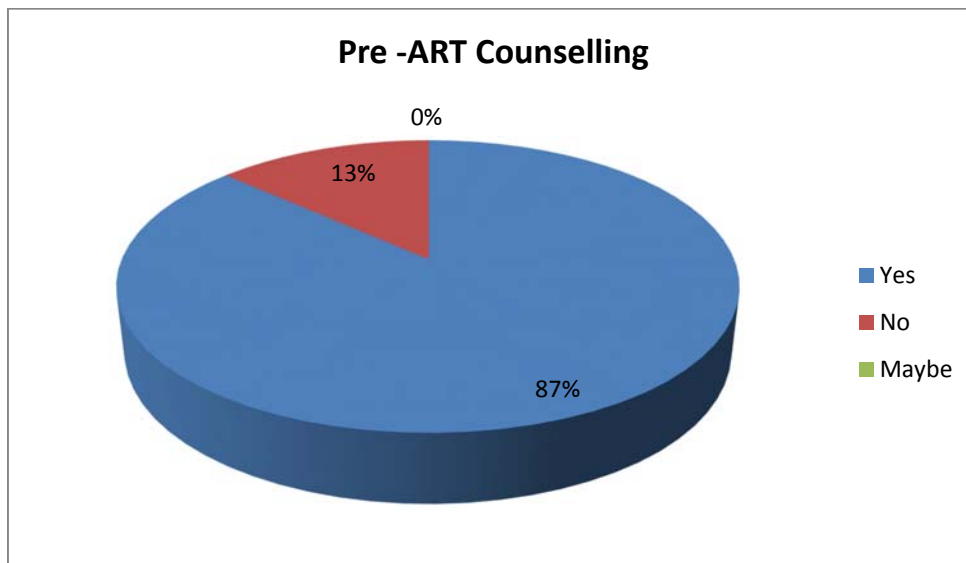


Figure 16: Counselling from the Clinic Pre ART

Counselling, including adherence and psychological counselling, is provided before and after tests results, as well as before commencing treatment on ARVs as shown in Figure 16. 26 respondents (87%) claimed to have received counselling before their children commenced treatment, while 4 (13%) did not. This was a bit worrisome because pre-ART counselling was essential before dispensing the medications for the first time. Either, it can be deduced, that the respondents were not physically present when counselling was given or it was done in a language they could not comprehend. Communication is essential towards ensuring compliance with instructions.

4.7.2. OTHER ISSUES TO BE ADDRESSED

14 respondents (47%) responded that there were still some issues that they were not exactly clear about and 16 (53%) claimed they were fully satisfied with their knowledge base regarding HIV in children (Figure 17).

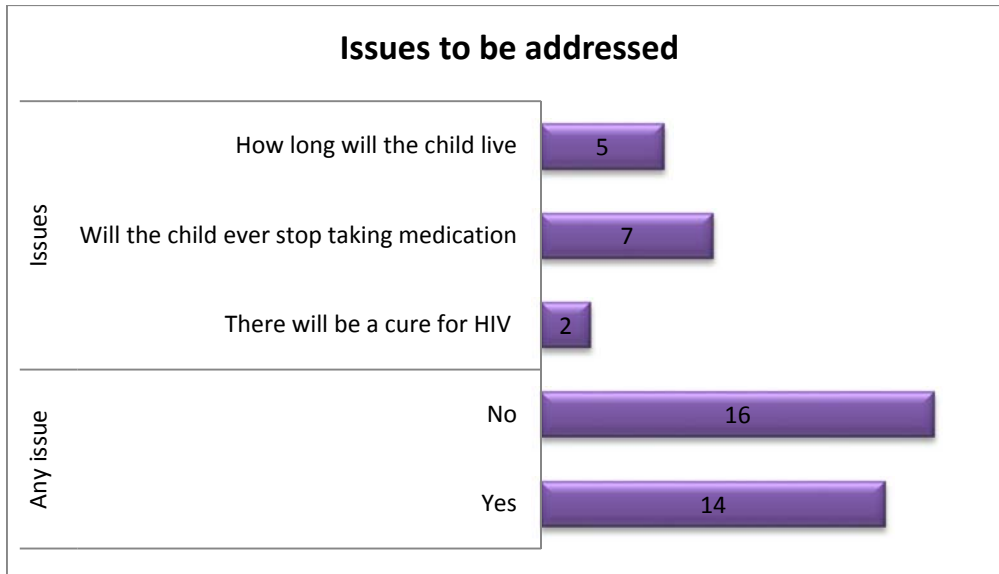


Figure 17: Issues for clarification

It is the norm to give patients (and caregivers in this case) information in a clear, concise manner and in a language they understand. Information dissemination is an integral part of healthcare delivery and efforts must be made to address any lingering issues to enhance uptake of clinical services.

4.7.3. ISSUES NEEDING CLARIFICATION

Of the 14 respondents above, 2 wanted to know if there will “ever be a cure for HIV”, 7 wanted to know “when their children will stop taking ARVs” and another 5 wanted to know “how long their children had to live”.

These are genuine concerns that should never be taken lightly. Caregivers should be educated that HIV is a lifelong infection, but the prognosis of a long, healthy life is assured with medication and good healthy practises.

4.7.4. SUPPORT GROUPS AND RELEVANCE

14 (47%) respondents belonged to a form of support group, where ideas and encouragement is shared, whilst 16 (53%) did not belong to any form of support group/mechanism. Of the 30 respondents, 19 (63%) felt a support group was necessary, while 8 (27%) did not see the

necessity of one. 3 (10%) were unsure of its relevance. Figure 18 gives a graphic representation of this.

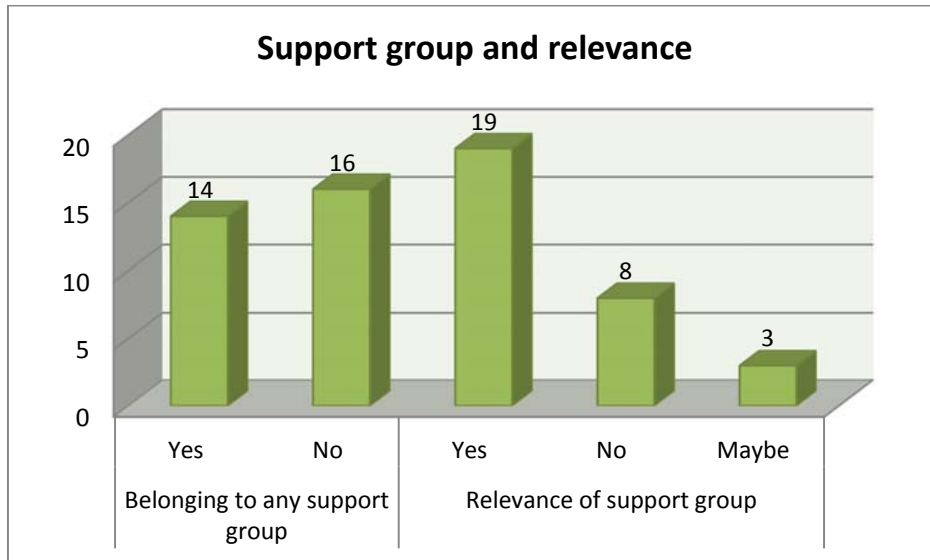


Figure 18: Support Groups and Relevance

Although support groups are necessary, their type and quality are also important. The fear of stigma and discrimination from the group or from other people is one major reason why support groups may be shunned by some. Some people would rather keep the knowledge of their child’s HIV status secret, than reveal ‘personal secrets’ to strangers. This may not be unconnected with the reason(s) given by the 17% of respondents who “did not see the necessity of a secondary caregiver” in section 4.2.3 above.

4.8. STIGMA AND DISCRIMINATION (S&D)

For ease of comprehension, an attempt was made to probe this issue by asking about negative behaviours. Already introduced in Chapter 1 above, they have the potential to derail advances made in the care of HIV positive patients, and can either be real or perceived. The main weapon against this is education. When people get more knowledgeable about HIV, especially on its transmission and treatment, the less likely it is thought, they will engage in S & D. 22 respondents (73%) “have not experienced any negative behaviours from anyone”, 1 (3%) was unsure, and 7 (23%) claimed to have experienced some form of negative behaviour from people as seen in Figure 19.

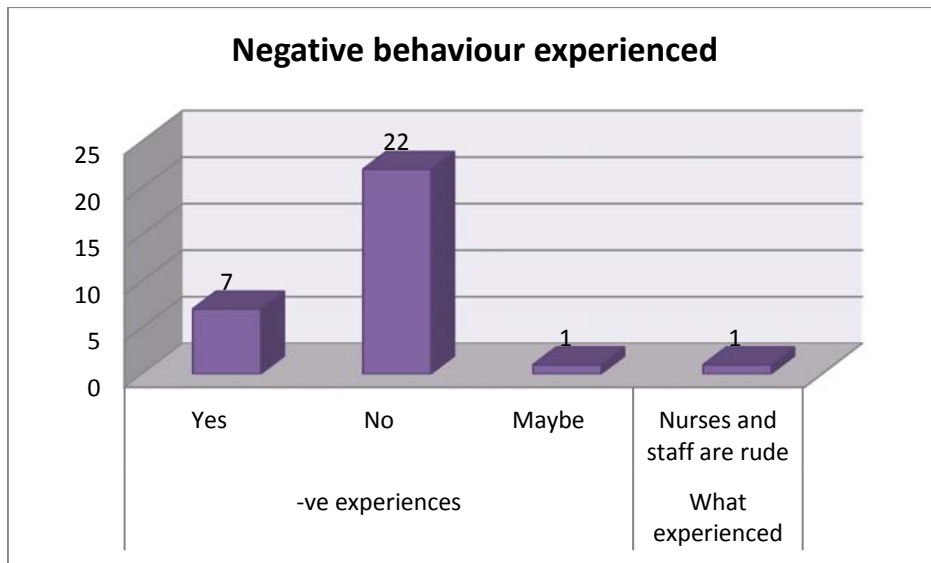


Figure 19: Stigma and Discrimination

When probed further, only one person responded that nurses and other hospital staff “are rude because of my child’s status”. No attempt was made to establish the veracity of the above claim or elicit responses from the other 6 (who also had similar experiences of negative behaviour). It may or may not have been true, but experiences of negative behaviours from healthcare workers have been reported in the past (Simpson 2006: 34).

4.9. DISCLOSURE TO CHILDREN

The general consensus is that people are prone to take positive actions when they know their health status (Payaprom, 1996). Disclosure to children of their HIV status should, out of necessity be made to children before adolescence. “*Disclosure needs to take place before adolescence....it is a process, not a once-off event*” (SA National Department of Health, 2010: 76). This is not only when they have the mental capacity to grasp the full extent of the disease, but also to enable them to make better and informed sexual choices for themselves and their partners, when they progress into puberty/adulthood.

Of the 30 respondents, 19 (63%) were of the opinion that disclosure should be made, 10 (33%) did not agree, and 1 respondent was unsure about disclosure (Figure 20).

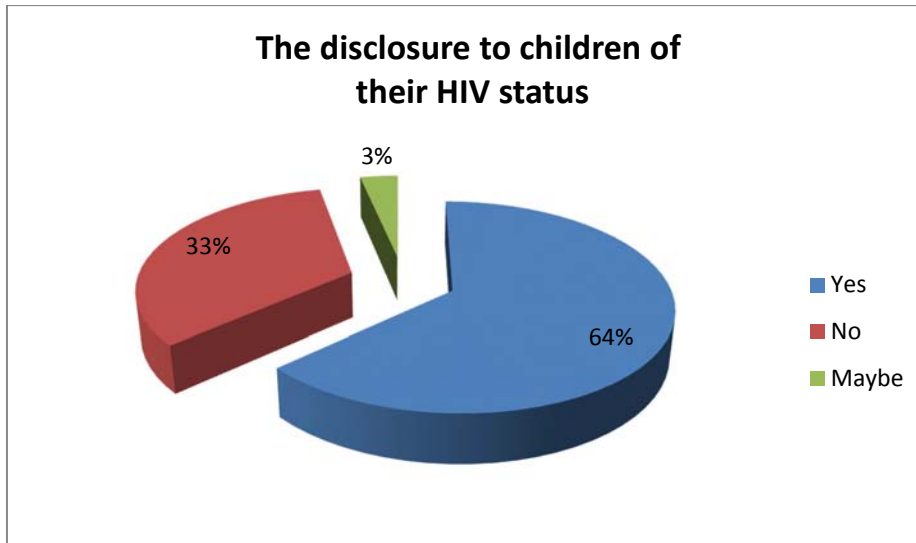


Figure 20: Disclosure to Children

Regarding timing, the 19 in favour of disclosure, all were somewhat vague in their responses, with statements such as “when they are bigger” (10) and ”when they get to high school” (5), and 4 respondents opting for “when the time is right”.

The 10 respondents who were against disclosure, were unanimous in saying that their “children were too young” to fully understand the scope of their disease. This is true. However, it is important that the caregivers recognise the need for disclosure on or before adolescence or early adulthood (Figure 21).

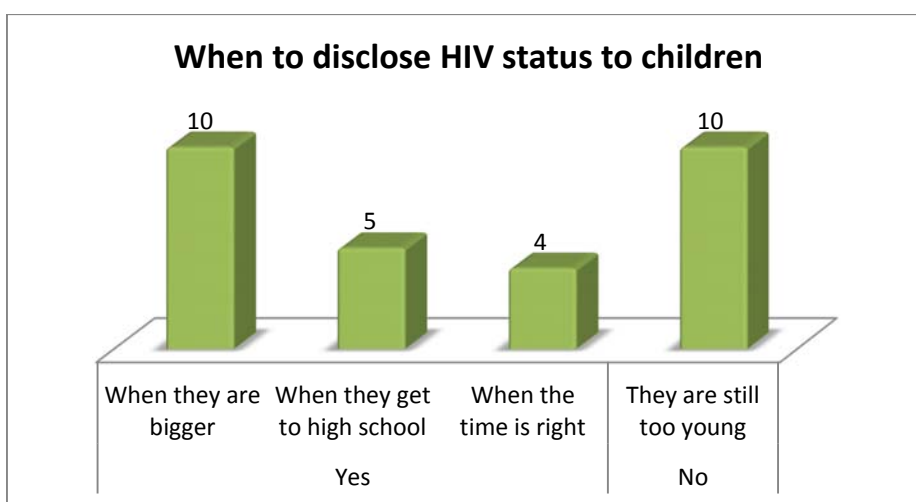


Figure 21: Timing of Disclosure

4.10. KNOWLEDGE OF HIV TRANSMISSION

HIV transmission in children and adults differs in terms of main mechanisms of infection (see Chapter 1). An attempt was made to assess if the caregivers (adults) were aware of these differences. 11 (37%) correctly identified all the options as important in transmitting HIV to children, while 8 (27%) went with “breastfeeding” only, 3 (10%) opted for “during delivery” only and 8 respondents did not answer at all, as seen in Figure 22. It is important to point out here that although HIV can be transmitted by sexual contact even in children and also by Intravenous Drug Use (IDU), the focus here was on the main modes of transmission. The latter two identified, occurred commonly in cases of child neglect/abuse, which was not the focus of this study.

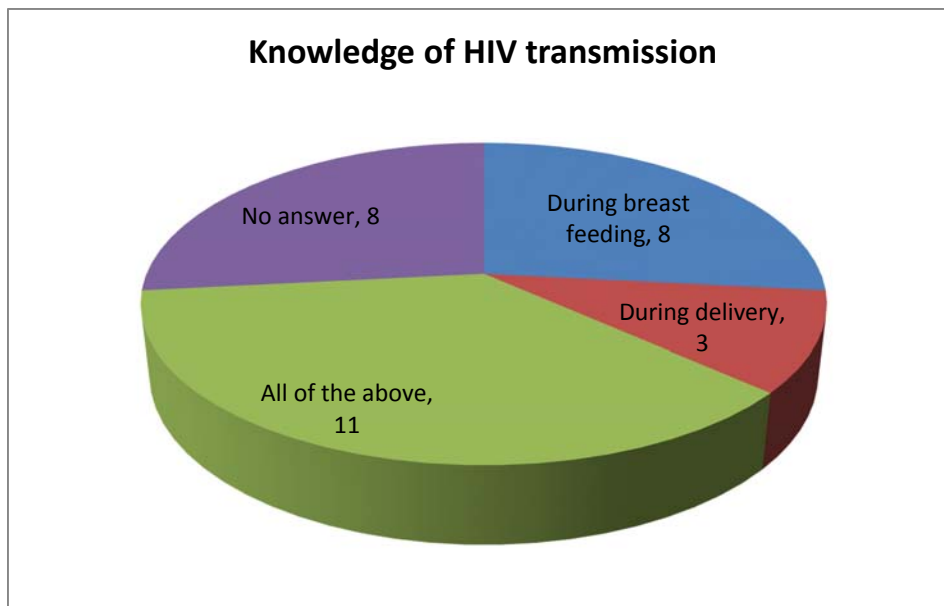


Figure 22: Knowledge of HIV Transmission

As most caregivers are parents, aspiring (HIV positive) parents, these results revealed that much more in terms of education will need to be done, so that positive health decisions can be made not only for caregiver, but for the children being cared for.

In conclusion, from the analysed results, it is evident that CGs of HIV infected children displayed adequate information that will no doubt impact on the care they receive. The responses

clearly identified knowledge gaps from which appropriate recommendations will be made as discussed in the next chapter.

CHAPTER 5

CONCLUSION AND RECOMMENDATIONS

From the research that has been undertaken, it is clear that there is a significant positive relationship between knowledge of caregivers and the outcomes, in terms of care, of HIV positive children, especially in the 0-5 age group. The research question: *Are caregivers' knowledge, attitudes and practices towards HIV-positive children affecting the nature of care that such children receive?* Has been answered in the affirmative, as is evidenced by the indices itemized below.

The study, although not without limitations (see below) in terms of scientific representation of results, acknowledges the important role caregivers can and do play in HIV management, especially in children. Regardless of the type of relationship (biological or non-biological) or gender, the fact that adults are willing and able to provide the necessary care augurs well for the children of today and generations unborn. The study commenced with identifying the demographic profile of the caregivers and then went on to assess their KAP regarding HIV in children. Based on these objectives, the following conclusions were arrived at:

- Most caregivers were female family members, and the majority of care in HIV/AIDS in children took place at home, with a few (one orphan in this study) taking place outside the home.
- The majority of these family members were also the primary caregivers, who also recognized the need for inputs of secondary caregivers.
- Overall knowledge in terms of nutritional needs, growth and development, disease recognition, and attitudes towards common morbidity patterns in children living with HIV was generally good.
- The perception of caregivers to ART and its usage was found to be positive, as a means of rendering HIV care. Also adherence patterns were positive in relation to both the practices and attitudes of caregivers.

- The availability of counselling and support for caregivers was noted to be reasonably good, although some work still needs to be done regarding the duration and chronic nature of the disease.
- The perception of stigma and discrimination was found to be low amongst caregivers. Stigma and discrimination are reduced by improved knowledge, and this can and will augur well for care of HIV infected children.
- Caregivers were largely amenable to disclosure of the child's HIV status, but clearly there needs to be further work undertaken in this sphere.
- Knowledge of HIV transmission was also quite high. Besides treatment, this will enhance care and preventative measures.
- HIV is a disease of care and support, as revealed in the literature and further buttressed by relevant findings in the research study. Improving the knowledge of the caregivers not only means that the children are better cared for, but it could also positively impact on the CGs outlook to life. Positive knowledge also means positive attitude and practice, which can filter down to the children.

5.1. SUGGESTED AREAS OF FURTHER RESEARCH

The study on caregivers KAP in Pretoria, South Africa, has made it imperative to focus more attention on the following areas:

- Comparative studies on the differences (if any) on the KAP of primary and secondary caregivers. Whilst this study essentially focused on home-based care, as depicted by primary caregivers (usually family members), there is a need to assess the nature of care as received by children in orphanages and other non-familial settings.
- The KAP of children caregivers. Whilst an attempt was made here to focus on adult caregivers, it is a known fact that some child-headed households exist. Such caregivers, albeit children themselves, are directly responsible for the care of their HIV infected younger siblings. Research is required in this area.

- A rural versus urban caregiving perspective. The study was carried out in Pretoria (the administrative capital of South Africa). Any highlighted deficiencies in caregiving, can and should be compared or contrasted with rural areas, so that further government (and non-governmental) interventions can be identified.

5.2. RECOMMENDATIONS

As minimal knowledge gaps were identified from the research, the recommendations here, will essentially borrow from the UNAIDS booklet on caregiving in HIV and AIDS and reinforce the recommendations made therein.

5.2.1. RECOMMENDATIONS FROM THE UNAIDS MANUAL ON CAREGIVING

Already introduced above (see literature review), the Joint UNAIDS paper on caregiving recognises the importance of caregiving (especially on the home front). A summary of its recommendations, especially in the sphere of capacity development will be discussed. These recommendations involve strategies adapted to various contexts and societies, which serve to address the financial and psychosocial burden of caregiving to individuals and groups-both families and the community at large. The paper also goes on to introduce the importance of the *continuum of care*, especially as it relates to “social protection and poverty reduction, promoting gender equality, and increasing the knowledge and research on caregiving and its economic and social impacts” (UNAIDS, 2008: 9). This continuum, encompasses HIV counselling and testing, clinical and nursing management, as well as community-based social support. It emphasizes the concept of care in a cyclical pattern, commencing from the home, to the hospital (through various networks and levels) and back to the home again.

As such, the recommendations which can ultimately be adopted or modified into the South African context will be:

- Recognize and value care work and its impact on women: Key here is recognizing and attempting to quantify the value of unpaid care provided by caregivers and involving them in any decision-making process to ease their burdens and proffer solutions. This is a form of *stakeholder* involvement.

- Promoting stronger cross-sector linkages to create a continuum of care: this involves recognizing the importance of home-based care (HBC) *vis a vis* volunteer care, as well as hospital-based care. Appreciating the importance of HBC, and providing care and support for caregivers is the way forward here.
- Support carers and reduce poverty through social protection: providing both cash and non-cash incentives to caregivers, supporting women and girls of HIV infected households, especially in areas of poverty alleviation and job creation, as well as entrepreneurship development.
- Increase household access to HIV related services and resources: as evidenced by the results of this research, “*caregivers still require adequate and appropriate HIV related services and information to operate effectively*” (UNAIDS, 2008: 11). Paramount here are initiatives that scale up access to services, such as reduced (or eradicated) fees, bringing health care closer to the people, by siting more clinics and health centres nearby, as well as improving transportation and other social amenities. Besides ART, the “care” aspect of *treatment and care* should focus on providing caregivers with food and income generating activities.
- Facilitate the greater involvement of men in caregiving roles and the equal sharing of care work between women and men: initiatives that increase male participation in providing care for HIV infected people, not only reduces the burden on women and girls, but can, in turn, result in an increase in men accessing HIV testing and other facilities. Education and awareness-creation is the way to go in this regard.
- Promote women’s rights and address broader gender inequalities, including employment: of relevance here is improving women’s rights and empowerment as well as greater recognition and valuing the care work that they provide.
- Develop policies and programmes which are informed by a full gender and ageing analysis and integrate programmes which address caregiving into National AIDS Strategies.

- Promote the participation and involvement of home-based care networks and caregivers in shaping national policies and solutions.
- Invest in operational research to better understand caregiving in the context of HIV and AIDS, and to generate strategic information to inform programming. Already introduced above, other areas as identified by the UNAIDS booklet (2008) include, but is not limited to analyzing the impact of antiretroviral therapy provision on caregiving.

It is hoped that in undertaking this research and in making these recommendations, caregiving in respect of children will be more effective and yield better health outcomes, especially when multi-sectoral and collaborative initiatives are adopted.

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ANNEXURUES

ANNEXURE A

QUESTIONNAIRE ASSESSING CAREGIVER KNOWLEDGE, ATTITUDES AND PRACTICE REGARDING HIV IN CHILDREN

DEMOGRAPHICS

1. How old are you?

a) 21-35yrs?	<input type="radio"/>	
b) 36-50yrs?	<input type="radio"/>	
c) 50-64yrs?	<input type="radio"/>	
d) 65yrs+?	<input type="radio"/>	

2. What is your gender?.....

3. What is your level of education?

a) None?	<input type="radio"/>	
b) Primary School?	<input type="radio"/>	
c) Some High School?	<input type="radio"/>	
d) Matric?	<input type="radio"/>	
e) College and beyond?	<input type="radio"/>	

4. What is your income level per annum?

a) Less than R50 000?	<input type="radio"/>	
b) R50 000-R100 000?	<input type="radio"/>	
c) R150 000-R200 000?	<input type="radio"/>	
d) >R200000?	<input type="radio"/>	

5. What is your relationship to the child in question?.....

6. How old is the child you are caring for? (Choose the youngest if more than one child)

a) 0-3yrs?	<input type="radio"/>	
b) 4-7yrs?	<input type="radio"/>	
c) 7-10yrs?	<input type="radio"/>	
d) >10yrs?	<input type="radio"/>	

CAREGIVER CHARACTERISTICS

7. Are you the Primary caregiver of the child?

a) Yes	<input type="radio"/>	
b) No	<input type="radio"/>	

8. Do you think a secondary caregiver for this child is necessary?

a) Yes	<input type="radio"/>	
b) No	<input type="radio"/>	

9. Explain the reason for your answer in Q 8

above.....

KNOWLEDGE OF NUTRITION

10. Will good feeding improve the health of HIV positive children?

a) Yes	<input type="radio"/>	
b) No	<input type="radio"/>	
c) Do not know	<input type="radio"/>	

11. Do HIV Positive children need more energy rich foods than HIV negative children?

a) Yes	<input type="radio"/>	
b) No	<input type="radio"/>	
c) Do not know	<input type="radio"/>	

12. Which of the following is an expensive and least healthy feeding choice for HIV positive Children?

a) Burgers?	<input type="radio"/>	
b) Maas?	<input type="radio"/>	
c) Peanut butter?	<input type="radio"/>	
d) Avocado?	<input type="radio"/>	

13. How can you tell if a child is not growing well?

a) Small stature for age?	<input type="radio"/>	
b) Low weight for age?	<input type="radio"/>	
c) Slow to crawl, walk or run?	<input type="radio"/>	
d) All of the above?	<input type="radio"/>	

DISEASE RECOGNITION

14. Which of the following is a sign that a child is SERIOUSLY ill?

a) Refusing to go to school?	<input type="radio"/>	
b) Drinking only coke?	<input type="radio"/>	
c) Vomiting everything?	<input type="radio"/>	
d) Being naughty?	<input type="radio"/>	

15. When a mother suspects a serious illness in her child, which is the best response?

a) Give <i>motswako</i> to the child?	<input type="radio"/>	
b) Give panado?	<input type="radio"/>	

c) Call the neighbours?	<input type="radio"/>	
d) Rush the child to the nearest hospital/clinic?	<input type="radio"/>	

16. Name one major disease an HIV positive child is at risk to acquire.....

.....

.....

ART AND ADHERENCE

17. Do you believe ARVs are the best medicines for HIV for your child?

a) Yes	<input type="radio"/>	
b) No	<input type="radio"/>	
c) Maybe	<input type="radio"/>	

18. How long should ART be for?

a) One year?	<input type="radio"/>	
b) 10yrs?	<input type="radio"/>	
c) Until adulthood?	<input type="radio"/>	
d) For life?	<input type="radio"/>	

19. Can you name **ONE** ARV your child is taking presently?.....

.....

20. Do you sometimes miss doses when giving your child ARV?

a) Yes	<input type="radio"/>	
b) No	<input type="radio"/>	
c) Maybe	<input type="radio"/>	

21. If the answer to Q20 is YES, how many times in a month do you miss?

a) Less than three (3) times?	<input type="radio"/>	
b) More than three (3) times	<input type="radio"/>	
c) More than ten (10) times a month?	<input type="radio"/>	
d) Too many to count?	<input type="radio"/>	

22. What is the reason(s) for the missed doses?.....

23. What do you do after a missed dose?

a) Give double dose immediately?	<input type="radio"/>	
b) Give single dose immediately and the next one at the right time?	<input type="radio"/>	
c) Give supplements?	<input type="radio"/>	
d) Do nothing?	<input type="radio"/>	

24. What do you think is the implication for frequent missed doses of ART?.....

COUNSELLING AND SUPPORT

25. Did you get any counseling from the clinic before your child started ART?

a) Yes	<input type="radio"/>	
b) No	<input type="radio"/>	
c) Maybe	<input type="radio"/>	

26. Are there still certain issues you will like to know more about?

a) Yes	<input type="radio"/>	
b) No	<input type="radio"/>	

27. If YES to Q19, please elaborate

.....

28. Do you belong to any support groups?

a) Yes	<input type="radio"/>	
b) No	<input type="radio"/>	

29. If YES, do you think the support group is relevant?

a) Yes	<input type="radio"/>	
b) No	<input type="radio"/>	
c) Maybe	<input type="radio"/>	

30. Have you ever experienced any negative behaviours from people because of your child's status?

a) Yes	<input type="radio"/>	
b) No	<input type="radio"/>	
c) Maybe	<input type="radio"/>	

31. If YES, please specify.....

.....

DISCLOSURE TO CHILDREN

32. Do you think disclosure to children of their HIV status is ok?

a) Yes	<input type="radio"/>	
b) No	<input type="radio"/>	

c) Maybe	<input type="radio"/>	
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33. If YES, when is the right time?.....

34. If NO, why?.....

KNOWLEDGE OF ART TRANSMISSION

35. In children, which of the following are the commonest HIV transmission routes from an infected mother to child?

a) Breastfeeding when mother is not on treatment?	<input type="radio"/>	
b) During delivery?	<input type="radio"/>	
c) Mixed feeding (both formula and breastfeeding?)	<input type="radio"/>	
d) All of the above?	<input type="radio"/>	
e) None of the above?	<input type="radio"/>	

THANK YOU FOR YOUR TIME AND PATIENCE IN COMPLETING THIS QUESTIONNAIRE!

KEALEBOHA!!

ANNEXURE B

FOROMO HO BATLISISA TSEBO, BOITSHWARO LE MEETLO YA BAHLOKOMEDI BA BANA BA NANG LE KOKWANA YA HIV

TSA PHOBELO BA HAO

1. O dilemong tsefe?

a) 21-35 yrs?	<input type="radio"/>	
b) 36-50 yrs?	<input type="radio"/>	
c) 50-64 yrs?	<input type="radio"/>	
d) 65 yrs+?	<input type="radio"/>	

2. Seemo sa hao ke se fe?

a) Mosadi?	<input type="radio"/>	
b) Monna?	<input type="radio"/>	

3. Bo emo bathuto ya hao ke bofe?

a) Letho?	<input type="radio"/>	
b) Primary School?	<input type="radio"/>	
c) High School?	<input type="radio"/>	
d) Matric?	<input type="radio"/>	
e) College le hofeta?	<input type="radio"/>	

4. Boemo ba mokgolo wa hao selemong ke bofe?

a) Tlaseho R50000?	<input type="radio"/>	
b) Mahareng a R50000-R100 000?	<input type="radio"/>	
c) Mahareng a R150000-R200 000?	<input type="radio"/>	
d) Hofeta R200 000?	<input type="radio"/>	

5. Kamano ya hao mabapi le ngwana oo ke efe?

6. Ngwana oo mohlokomelang o na le dilemo tse kae? (Kgetha e monyenyanane ho bona kao feela, ha bana ba le bangata)

a) 0-3yrs?	<input type="radio"/>	
b) 4-7yrs?	<input type="radio"/>	
c) 7-10yrs?	<input type="radio"/>	
d) >10yrs?	<input type="radio"/>	

CHARACTERISTICS TSA MOHLOKOMEDI

7. O mohlokomedi wa ngwana a kasehlohong?

a) Ee	<input type="radio"/>	
b) Tjhe	<input type="radio"/>	

8. O nahana ho re motho wa bobedi wa hlokahala ho hlokomela ngwana?

a) Ee	<input type="radio"/>	
b) Tjhe	<input type="radio"/>	

9. Kakopo hlalosa mabaka a hao ka karabo ya hao hopotso 8

.....

.....

.....

TSEBO DIJO TSE HLOKO

10. Ana dijo tse hloko di ka phahamisa bophelo ba bana banang le kokwana ya HIV?

a) Ee	<input type="radio"/>	
b) Tjhe	<input type="radio"/>	
c) Ha ke tsebe	<input type="radio"/>	

11. A bana ba nang le kokwanaya HIV bahloka haholo dijo tse fanang ka mafolofolo ho feta bana ba senang kokwana ya HIV?

a) Ee	<input type="radio"/>	
b) Tjhe	<input type="radio"/>	
c) Ha ke tsebe	<input type="radio"/>	

12. Ho tsena tse lateng, ke eng e phahameng ka tjhelete empa e le tlase ka hoba sejo se loketseng bana ba nang le kokwana ya HIV?

a) Burgers?	<input type="radio"/>	
b) Maas?	<input type="radio"/>	
c) Peanut butter?	<input type="radio"/>	
d) Avocado?	<input type="radio"/>	

13. O kgona ho bona jwang ho re ngwana ha a hole hantle?

a) Mmele o monyenyanengwaneng?	<input type="radio"/>	
b) Boimabammelebotlase?	<input type="radio"/>	
c) Ha ngwana a nka nako ho kgasa kappa ho tsamaya kappa ho matha?	<input type="radio"/>	
d) Tsohle tse ka hodimo?	<input type="radio"/>	

KELELLO YA MAHLOKO

14. Ke tsefeng ho tsena tse bontshang ho re ngwana o kula hahola?

a) Ha a hana ho ya sekolong?	<input type="radio"/>	
b) Ha anwa coke feela?	<input type="radio"/>	
c) Ha a hlatsa tsohle tseo a dijang?	<input type="radio"/>	
d) Ha a sena tsebe?	<input type="radio"/>	

15. Ha mme a belaela ho re ngwana w ahae o kula haholo, bohato bo loketseng maemo ke bofe?

a) Hofa ngwana <i>motswako</i>?	<input type="radio"/>	
b) Ho fa ngwana Panado?	<input type="radio"/>	
c) Ho bitsa ba ahisane?	<input type="radio"/>	
d) Ho potlakisetsa ngwana sepetleleng kappa kliniki	<input type="radio"/>	
e) ng e haufinyana?		

16. Fana ka bohloko bo BOHOLO bo le bong boo ngwana a nang le kokwanaya HIV a kaba tsietsing ya ho bo fumana?

.....

ART LE MAMELLO

17. Ana oa dumela ho re diARV kemoriana wa sebele ho thusa ngwanawa hao a nang le kokwanaya HIV?

a) Ee	<input type="radio"/>	
b) Tjhe	<input type="radio"/>	
c) Mohlomong?	<input type="radio"/>	

18. ART etlamehile ho nkwa nako e kae?

a) Selemo?	<input type="radio"/>	
b) 10 yrs?	<input type="radio"/>	
c) Ho fihlela ngwana eba motho e moholo?	<input type="radio"/>	
d) Bophelo ba motho kao feela?	<input type="radio"/>	

19. Fanaka ARV e le NNGWE eo ngwana hao ae nwang motsotsong wa hona jwale.....

20. Hona le mohla o lebalang ho fa ngwana diARV?

a) Ee	<input type="radio"/>	
b) Tjhe	<input type="radio"/>	

c) Mohlomong	<input type="radio"/>	
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21. Ha ebe karabo ya hao hopotso 20 ke EE, ke ha kae kgweding o lebalang ho fa ngwana diARV tsa hae?

a) Ka tlase ho mehla e meraro (3)?	<input type="radio"/>	
b) Ho feta mehla e meraro (3)?	<input type="radio"/>	
c) Ho feta mehla e leshomekgweding?	<input type="radio"/>	
d) Mehla e mengatangatafeelahoka e bala	<input type="radio"/>	

22. Mabaka a hao a holebala ho fepa ngwana diARV ke afe?.....

23. O etsaeng ha hoile wa lebala ho fepa ngwana diARV tsa hae?

a) O fana ka tokelo (dose)tsepedi hang-hang?	<input type="radio"/>	
b) O fana ka tokeloe le nngwe hang-hang, ebe o fana ka etshwanetseng ka nako?	<input type="radio"/>	
c) O fanaka di aha mmele (supplements)?	<input type="radio"/>	
d) Ha holetho leo ole etsang?	<input type="radio"/>	

24. O nahana ho re moputso wa ho lebala ho fepa ngwana tokelo (dose) ya hae ya ART keeng?

.....

KELETSO LE TSHEHETSO

25. O ile wa fumana keletso ho tswa kliniking pele o fepa ngwana moriana wa ART?

a) Ee	<input type="radio"/>	
b) Tjhe	<input type="radio"/>	

c) Mohlomong	<input type="radio"/>	
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26. Hona le dintho tse ding tseo ontse o lakatsang ho tseba haholo ka tsona mabapi le HIV?

a) Ee	<input type="radio"/>	
b) Tjhe	<input type="radio"/>	

27. Ha o arabile EE hopotso 9, kakopo hlalosa

.....

.....

.....

28. Oteng mokgatlo oo tshehetsang?

a) Ee	<input type="radio"/>	
b) Tjhe	<input type="radio"/>	

29. Ha o arabile EE hopotso 28, o nahana ho re mokgatlo ona o tshehetsang wa hlokahala?

a) Ee	<input type="radio"/>	
b) Tjhe	<input type="radio"/>	
c) Mohlomong	<input type="radio"/>	

30. E teng mehla eo o ileng wa thola boitshwaro bo bobbe ho tswa ho batho mabapi le maemo a bophelo ba ngwana hao?

a) Ee	<input type="radio"/>	
b) Tjhe	<input type="radio"/>	
c) Mohlomong	<input type="radio"/>	

31. Ha o arabile EE, kakopo hlalosa.....

.....

.....

HO NTSHA BOEMO BA BOPHELO HO BANA

32. O nahana ho bolella bana ka boemo ba bona ba HIV holokile?

a) Ee	<input type="radio"/>	
b) Tjhe	<input type="radio"/>	
c) Mohlomong	<input type="radio"/>	

33. Ha o arabile EE, kenako efeng e lokileng ho bolella ngwana?

.....

.....

34. Ha o arabile TJHE, kakopohlalosa.....

.....

.....

TSEBO KA FITISETSO YA ART

35. Baneng, ke tsefeng ho tsena e leng tsela tse tlwailehileng ho fitise tsa kokwana ya HIV ho tswa ho mme ho ya ho ngwana?

a) Lebese la matswele ha mme a sa nke moriana wa ARV?	<input type="radio"/>	
b) Ka nako ya pelehi ya ngwana?	<input type="radio"/>	
c) Ha ngwana a fepwa lebese la formula le lebese la matswele ka nako e lenngwe?	<input type="radio"/>	
d) Tsohletsekahodimo?	<input type="radio"/>	
e) Ha ho le enngwe ho tsena?	<input type="radio"/>	

KE LEBOHELA NAKO LE MAMELLO YA HAO HO TLATSENG HA FOROMO ENA!

ANNEXURE C

WHAT IS IMCI?

IMCI stands for Integrated Management of Childhood Illness. It is a strategy that has been developed by WHO's Division of Child Health and Development and UNICEF, and has been introduced in more than 30 countries around the world. The strategy focuses on the child as a whole rather than on a single disease or condition. Sick children often present with a number of sicknesses to the primary care practitioner and thus need to be managed in an integrated manner at home and in the primary health care facility.

WHY DO WE NEED IMCI?

In developing countries, many children die from these illnesses:

- Pneumonia
- Diarrhoea
- Malnutrition

In South Africa measles and malaria have become less of a problem. However HIV/AIDS is killing more and more children.

Many of these conditions can be prevented or treated with simple case management, including HIV/AIDS.

Why then do we still have these childhood conditions? There may be inadequate living conditions, such as poor water supply and sanitation, which promote the rapid spread of disease. If children are sick, parents may not recognise that their children are dangerously ill and not take them for appropriate treatment. When treatment is sought at a health care facility, the health care workers treating the child may lack drugs, equipment or training to provide good care. Health workers may also not recognise that a child may have more than one condition in need of treatment. For example, a child with pneumonia may also have malnutrition, an ear problem and symptomatic HIV infection.

IMCI IS AN INTEGRATED APPROACH

IMCI takes into account the variety of factors that put children at serious risk. It ensures the combined treatment of the major childhood illnesses. It speeds up urgent treatment of seriously ill children. It involves parents in effective care of their children at home where possible. It emphasizes prevention of disease through immunization, improved nutrition and exclusive breastfeeding. IMCI supervision and support of the health facilities is also integrated into the drive to support and monitor primary health care.

IMCI IS COST EFFECTIVE

IMCI reduces wastage of resources by identifying and promoting the most appropriate medicines and treatments. E.g. There are definite guidelines of when and when to not use an antibiotic. IMCI avoids duplication of effort from a series of separate disease control programs.

WHAT DOES THE IMCI CLINICAL PROCESS CONSIST OF?

- Assessment and classification of the illness
- Treatment of the child
- Counselling the caregiver
- Advice on follow-up of the patient

STANDARD CASE MANAGEMENT (SCM)

Sick children are assessed according to their symptoms and signs. This process uses reliable clinical signs to classify the illness according to the level of intervention required:

- Severely ill, requires urgent hospital referral.
- Moderately ill, requiring specific treatment at PHC facility and at home.
- Mildly ill, requiring supportive therapy and counseling at home.

Health care practitioners are taught to rationalize treatment, prescribing the minimum number of essential medicines.

IMCI focuses on pneumonia, diarrhea, fever and malnutrition, but other childhood illnesses are also identified and treated using the guidelines. In South Africa, HIV/AIDS and tuberculosis is an increasing problem, and the guidelines have been adapted to cover this. Anemia and micronutrient deficiencies are dealt with, and there are sections on intestinal parasite control, identification and treatment of ear conditions and asthma.

THE 3 COMPONENTS OF IMCI

IMCI - CASE MANAGEMENT

This consists of training health professionals who function at primary level in standard case management skills through an 11 day IMCI Clinical Course. Training includes support, mentoring and other activities to promote the use of IMCI case management skills.

IMCI - SUPPORT AND SUPERVISION

This involves ensuring:

- Follow-up visits within 6 weeks of doing the course
- Essential drugs are available
- The quality of supervision and support of practitioners is high
- Effective monitoring and evaluation
- Efficient stock control of medicines
- Efficient transport systems for quick referral to hospitals



Source: Western Cape Department of Health

ANNEXURE D

APPENDICES

Appendix 1: WHO Clinical Staging

CLINICAL STAGE 1

- Asymptomatic
- Persistent generalized lymphadenopathy

CLINICAL STAGE 2

- Unexplained persistent hepatosplenomegaly
- Papular pruritic eruptions
- Extensive wart virus infection
- Extensive molluscum contagiosum
- Fungal nail infections
- Recurrent oral ulcerations
- Unexplained persistent parotid enlargement
- Lineal gingival erythema
- Herpes zoster
- Recurrent or chronic upper respiratory tract infections (otitis media, otorrhoea, sinusitis or tonsillitis)

CLINICAL STAGE 3

- Unexplained moderate malnutrition not adequately responding to standard therapy
- Unexplained persistent diarrhoea (14 days or more)
- Unexplained persistent fever (above 37.5°C intermittent or constant for longer than one month)
- Persistent oral candidiasis (after first 6–8 weeks of life)
- Oral hairy leukoplakia
- Acute necrotizing ulcerative gingivitis or periodontitis
- Lymph node tuberculosis
- Pulmonary tuberculosis
- Severe recurrent bacterial pneumonia
- Symptomatic lymphoid interstitial pneumonitis
- Chronic HIV-associated lung disease including bronchiectasis
- Unexplained anaemia (< 8 g/dL), neutropaenia ($< 0.5 \times 10^9$ per litre)
- And/or chronic thrombocytopenia ($< 50 \times 10^9$ per litre)

CLINICAL STAGE 4

- Unexplained severe wasting, stunting or severe malnutrition not responding to standard therapy
- Pneumocystis pneumonia
- Recurrent severe bacterial infections (such as empyema, pyomyositis, bone or joint infection or meningitis but excluding pneumonia)
- Chronic herpes simplex infection (orolabial or cutaneous of more than one month's duration or visceral at any site)
- Extrapulmonary tuberculosis
- Kaposi sarcoma
- Oesophageal candidiasis (or candidiasis of trachea, bronchi or lungs)
- Central nervous system toxoplasmosis (after one month of life)
- HIV encephalopathy
- Cytomegalovirus infection: retinitis or cytomegalovirus infection affecting another organ, with onset at age older than one month
- Extrapulmonary cryptococcosis (including meningitis)
- Disseminated endemic mycosis (extrapulmonary histoplasmosis, coccidiomycosis)
- Chronic cryptosporidiosis
- Chronic isosporiasis
- Disseminated non-tuberculous mycobacterial infection
- Cerebral or B-cell non-Hodgkin lymphoma
- Progressive multifocal leukoencephalopathy
- Symptomatic HIV-associated nephropathy or HIV-associated cardiomyopathy
- HIV-associated rectovaginal fistula