

CHAPTER FIVE

DISCUSSION

5.1 INTRODUCTION

According to Pietkiewicz and Smith (2014), IPA consists of double interpretation. First, it allows the researcher to present his or her understanding of the participants' meaning, i.e. the researcher tries to explain the world of the participants from the participants' perspective. Second, the researcher documents her own interpretation about the participants' interpretation as portrayed in the findings. In this chapter, the findings are considered in the light of the objectives and discussed in relation to existing literature. In doing so, emphasis is placed firstly on the adjustment of families after discovering the HIV status of the loved one; secondly, this chapter will look at the understanding that the families had on being identified as HIV affected families, and thirdly it will explore the meaning participants as family members attached to their situation as they identified as an HIV/AIDS affected family.

5.2 FAMILIES' ADJUSTMENT TO HIV/AIDS DISCLOSURE IN THE FAMILY

5.2.1 Emotional turmoil expressed by families during adjustment.

Participants struggled with the adjustment process as they progressed through a phase of emotional turmoil after their loved one's HIV/AIDS status was disclosed to them. As the participants were interviewed, their responses reflected unpleasant emotions experienced during the time of disclosure. Hall (2014) states that individuals who experience emotional turmoil undergo a series of painful emotions during this process. Likewise, Bor, Miller and Goldman (1993) confirm the ripple effect that HIV has on families and that it could threaten

the ability of the family to adjust to the new HIV situation. The findings of this study revealed that, while adjusting as an HIV/AIDS affected family, the participants experienced a series of emotions such as pain, shock and hurt because of the way in which society perceived HIV/AIDS. This was also evident in the manner in which the participants hoped that their family members would test negative for HIV even though they suspected an HIV positive result. Nomthetho from family four - had hope while she was awaiting the HIV results of her daughter although she was suspecting that she was HIV positive.

It is clear that an HIV status does not affect the person diagnosed with HIV only, as Susser (2009) states that people who are infected with HIV experience emotional pain as they start to think about the future, coupled with the fact that there is no cure for HIV/AIDS. These feelings were also experienced by the participant family members or those close to the person living with HIV. Susser (2009:108) further states that “it is painful to hear that your loved one is infected with the virus which will later progress to a deadly illness that is incurable”. The findings of the study highlighted that these feelings were severe not only for the participants as immediate family members, but also for anyone that was close to the HIV positive person. Vuyisile from family one explained that when he disclosed the status of his daughter to the extended family, it was not easy for them. Jane also mentioned how hurt she was when she heard that Vivian tested positive for HIV/AIDS. Other participants also reflected feelings of shock as probably they did not expect the news. These feelings were expressed by the family members and extended family. Fine (2007) confirms that emotions of shock are to be expected after the HIV diagnosis. Mary explained her shock after she was made aware of her daughter’s status. These are the intense feelings expressed by the participants of this study after learning about the HIV positive status of their loved one. The research findings clearly indicate that the diagnoses of the HIV status do not only affect the infected, but that it has a ripple effect.

Families and those close to the person living with HIV undergo a series of unpleasant emotions after disclosure. These emotions ranged from shock to a loss of hope and feelings of anger as highlighted by the findings of this study.

5.2.2 A loss of hope and feelings of anger during adjustment

The process of adjustments to the disclosure of HIV within their families was accompanied by feelings of losing hope. This was as a result of the struggle and deterioration in health that the participants observed in some of their family members diagnosed with HIV/AIDS. Others were already suffering from AIDS related illnesses such as tuberculosis, wasting illness such as diarrhoea, vomiting, loss of appetite, pneumonia, cancers and other illnesses as other participants mentioned that their loved one suffered from some of these illnesses. For example, Lihle also highlighted that her mother's weakness, inability to walk and eat and difficulties she experienced meant she lost hope that her mother would survive that year. The loss of hope expressed by the participants was spurred on by them witnessing the suffering that their family members experienced, leading them to feel unsure that the family members would survive. According to Bor et al. (1993), anticipation of loss through witnessing physical illness in the family can disturb the functioning of each family member who may be immobilized by the fear of dread of facing the loss. As reflected in the findings of this study, this resulted in the participant families feeling hopeless and helpless. Bor et al. (1993) also state that HIV/AIDS affected families will experience feelings of fear and helplessness as the HIV positive family member progresses through the different stages of the virus. The journey back to health is a most difficult journey especially for the parents and it is coupled with emotions of pain, as, depending on the state of the sick person, family members tend to lose hope that the person will get better and be healthy again (Bor et al., 1993). This means they will even do the smallest

thing to hang on, especially when they notice they are on the verge of losing the person. This was reflected by Portia and Nomthetho who related waking up in the middle of the night to check if their loved ones were still alive. Portia checked on her daughter's heartbeat, whereas for Nomthetho coughing and sneezing of her daughter was a sign of hope. Bor et al. (1993) also state that anticipation of loss through physical illness in the family can disturb the current functioning of each family member who may be immobilized by the fear of facing the loss. This meant that families were forced to deal with two different situations at the same time, that is, the disclosure and the illness that the individuals experienced. The findings show that the intense emotions experienced by the participants as a result of dealing with the disclosure as well as their loved one's illness, resulting in a loss of hope, contributed to making the adjustment process a challenging journey for them.

The findings further show that, for the participants, adjustment meant that families needed to learn to cope with the new situation that they found themselves in. Susser (2009) mentioned that the manner in which HIV/AIDS was initially introduced to people projected it as a shame as it is mainly transmitted through sexual intercourse. The findings show that some participants acted out their frustrations differently from others, as they expressed anger which was reflected in fights and insults. The findings revealed that these participants, as they came to terms with the presence of the virus in their family, experienced emotions of fighting with and swearing at each other. The anger exhibited could, however, also have been a means of showing grief in response to their family situation by the participants. According to Kubler-Ross (1969), anger becomes part of the grief process and has no limits. She also confirms behaviours that accompany anger as fighting and swearing at each other as was exhibited in some of the participant families, as in the case of family two where Linda mentioned some people will be rude and swear at her and there was nothing, she could do to avoid the mistreatment (Kubler-

Ross, 1969). This reflects that the process of adjustment to a dreadful illness like HIV/AIDS was a difficult one for the participants of this study. These feelings probably resulted from the fear of social stigma, as there is a high possibility of being discriminated against once identified HIV positive as illustrated in the findings from Nomvuzo from family two who was subjected to fights and discrimination from her siblings when it was revealed that she was HIV positive. Furthermore, these feelings did not surface only in a verbal manner. In some instances family one experienced withdrawal as Portia mentioned that after she disclosed the status of her child to her sister-in-law, she observed that the sister-in-law distanced herself from Portia's family. This concurs with the view of Bor et al. (1993) who state that family members will tend to distance themselves from the person living with HIV with the view that they will infect them or for not wanting to be associated with an infected person. The findings highlighted that the participants experienced that extended family members and friends distanced themselves after discovering that one of their family members was living with HIV/AIDS. Thus, it could be concluded that the isolation they were subjected to was because of a lack of knowledge or stigmatisation.



5.3 FAMILIES FINDING MEANING IN HIV/AIDS DISCLOSURE

5.3.1 Families finding meaning within religion and spirituality.

It emerged from the findings that for the participants the adjustment process to disclosure created a realization that a higher power, as informed by either their religion or sense of spirituality, guided them as an important force on their journey of adjusting to disclosure. The participants related how they depended on their religion and/or sense of spirituality while they were coming to terms and tried to cope with the HIV status of their loved ones. Accordingly, Walsh (2012) asserts that spirituality can be of assistance to families in dealing with

misfortunes and physical illness and provide explanations and understanding of the situation that the family is facing due to illness. Related to this, Vuyisile from family one indicated that God provided him with the necessary HIV knowledge as he learnt that his children were infected with HIV. As the participants were trusting God in the situations that they found themselves in, this clearly indicates that in dealing with the HIV/AIDS disclosure the strength of their sense of spirituality was a contributing factor. It would seem that their spirituality was consequently strengthened due to the nature of their experience of adjusting to the disclosure.

HIV can be viewed as a disaster that disrupts family equilibrium by placing dark and frightening clouds over their future (Paul & Premaraj, 2013). Yet, participants in this study, although initially finding themselves in a position where they were unable to define what was happening in their lives, were later able to support their loved ones while relying on their trust and dependence on God to carry them along their journey. This process allowed them to find meaning in their situation. These findings concur with Dalmida, et al's (2011) affirmation that spirituality could be a positive strategy to assist families to deal with illness and adjust to uncertainties associated with chronic illness. The findings reflected that the participant family members consoled themselves by believing that there is a higher power beholding them while they deal with HIV/AIDS in their midst. This is also confirmed by the qualitative study conducted by Van Deventer and Wright (2017) where the researchers found that faith in God increased due to the presence of illness in families. This was an important feature of the journey to adjustment to disclosure experienced by the participant families in this current study, where, in the midst of what they were experiencing, participants were also in the process of making sense of their situation. What transpired was that, in doing so, they found a sense of meaning in their situation. Consequently, for example, as Mary mentioned, she managed to deal with HIV/AIDS because she trusted God and he is everywhere and in everything. Spencer (2012)

defines spirituality as the recognition of a feeling or sense or belief that there is something greater than oneself, something more to being human than sensory experience, and that the greater whole of which we are part is cosmic or divine in nature. The spirituality of the participants allowed them to adjust to and accept that they were HIV affected families, concurring with Safranski's (2017) view that an increased sense of spirituality can lead to people beginning to view life more positively.

5.3.2 Families assigning importance to family support.

As the participant families were trying to adjust to the disclosure of the HIV status of one of their family members and all the challenges along with that like caring for a brother, sister, son or daughter, the participants found that extended family members were also there to provide emotional and financial support to ease their burden. Through this they began to understand what it meant to be a family. According to Paul and Premaraj (2013) the problems associated with people living with HIV and AIDS such as stigma, discrimination, social and economic problems puts pressure on families. Paul and Premaraj (2013) further state that HIV/AIDS has a negative impact on people's lives as they will lose their forms of employment and have a burden of health and transport expenses to take care of. This was reflected in the findings, but extended family members were providing the participants with financial support in an attempt to assist them in taking care of those living with HIV. Nomthetho from family four mentioned that her in-laws send food to assist in taking care of her sick daughter. The importance of family support was also reflected when extended family members provided emotional support to the person living with HIV/AIDS and encouraged the individual or collected medication and assisted with administering the medication. As the family becomes aware that one of them was diagnosed with HIV/AIDS, they unite in providing support to the infected individual until she

or he becomes better (Susser, 2009). This was related by Nwabisa from family three who indicated that she would take on the responsibility of fetching and administering medication as a way of providing support to her sister. This indicates how family support provided by extended family members to the family affected by HIV members strengthened family bonds. Furthermore, Bor et al. (1993) state that as much as social support is a buffer against stress for people living with HIV, caregivers may themselves require support to carry out their task. It thus emerged from the findings that the journey that the participant families were on allowed them to understand and appreciate important aspects of life such as family support and its meaning when they experience difficulties in life.

5.4 THE MEANING OF BEING IDENTIFIED AS A FAMILY AFFECTED BY HIV

5.4.1 Families accepting their HIV/AIDS status

The findings highlighted that the participants reached a phase of acceptance after they dealt with the emotions that accompanied the disclosure and after reaching a level of understanding of what the presence of the HIV/AIDS meant in their lives. This meant that families got to a realization that HIV/AIDS is part of their lives, and that they needed to embrace it. Hall (2014) states that being HIV/AIDS affected meant a new beginning of their lives as families based on something which was never there before and redefining their relationships. As Portia from family one mentioned, you cannot change HIV and Zama from family two said that HIV is already in his family and there was nothing he could do to change it. It appears that the participants felt coerced into the situation as they felt there was nothing they could do about it. As part of acceptance it was reflected that as family members, they ended up making a joke out of HIV to cope with it. Nomthetho reflected her acceptance of the HIV status as she mentioned that she even forgets that Andile is HIV positive. This statement reflects a journey

where the participant families came to a point of accepting that HIV will be part of their lives and that they needed to find a means to accommodate HIV in their families. This process of meaning making is also confirmed by Susser (2009) and Maane (2009) who describe coming to terms with HIV as an intimate process of naming it as a sign of attachment to it and a way of moving forward with her life and they need to treat each other right. Maane further explains that even with her own brother it took time to accept the HIV status, and later on the brother was able to inform their parents.

The acceptance stage as mentioned above reflects a point where the participant families discovered another means of coping with their status of being a family affected by HIV . As mentioned by Hall (2014), families have no choice but to build new relationships with HIV as it is something they have no control over. For Kubler-Ross (1969) finding acceptance also means accepting the new situation and the permanent reality of being assigned as a family affected by HIV . It transpired in the interviews that acceptance moved the participants to live like there is no HIV in their families. In other words, acceptance fostered a situation where the participant families lived as normal as possible even though they were assigned the status of being a HIV positive family.

5.4.2 Families affected by HIV/AIDS educating and supporting others.

As participant families identified as HIV/AIDS affected, some of them were inspired to educate and support others who found themselves in a similar situation. For the participants, it meant that they did not want other people to experience what they did without support. This was motivated by the participants' experiences when dealing with disclosure as they felt that they

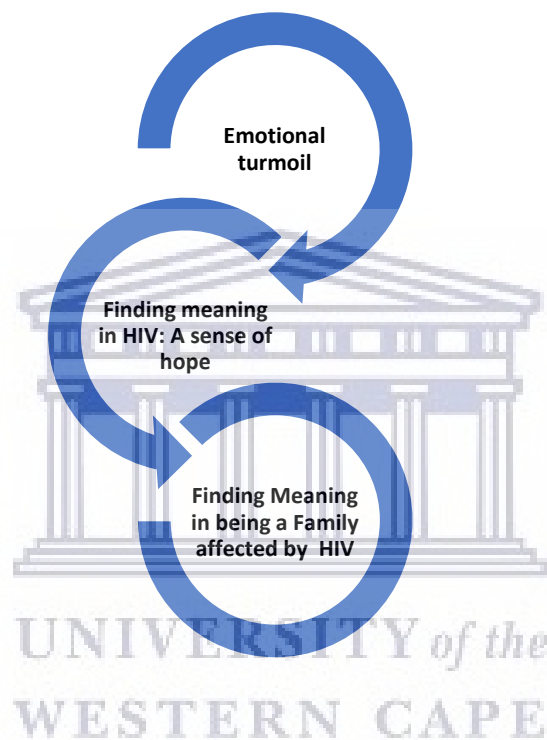
were now equipped to encourage others to better deal with HIV disclosure in their respective families.

The United Nations Children's Fund (2006) states that providing support to families affected by HIV is vital so they can be united. Portia from family one and Nwabisa from family six reflected that they did not only avail themselves to provide education, but they also opened their homes where they allowed individuals with questions around HIV to come to their homes to attend to their questions. As much as the families were providing support to community members, programmes developed to deal with HIV/AIDs are more focused on the infected person. Thus, UNICEF (2006) mentions that current programmes need to accommodate supporting HIV/AIDS families as it is evident from the findings that they can play an important role in supporting others. Therefore, Thurmam et al. (2017) state that conducting home visits can be part of providing support needed by families. At the same time the infected individuals from the family also played a role in educating others and providing support. Thus, Nomthetho mother to Andile from family one and Mary mother to Nomvuzo from family two also explained how Andile was of assistance to the rest of the family when they had questions about the virus. To the families this process was also part of healing as they were able to provide support to those who were suffering from the same situation and also highlighted that they are able to bring change to others. Maane (2009:85) further states that, being infected herself, providing support to the newly infected person "allowed her to see the anguish that comes with being newly diagnosed with HIV and lying ill". She then became comfortable talking about HIV and encouraging newly diagnosed people to accept themselves.

5.5 THE LIVED EXPERIENCE OF FAMILY MEMBERS ADJUSTING TO HIV/AIDS DISCLOSURE

5.5.1 The journey of adjustment from HIV/AIDS negative family to finding meaning in being a Family affected by HIV/AIDS.

Figure 1: Families adjusting to HIV positive status.



This study has shown that HIV/AIDS has a major impact on the participants whose lives have been affected by it. A study conducted by Van Deventer and Wright (2017) showed that caregivers of people living with HIV and AIDS suffered from significant psychosocial problems such as depression, anxiety, anger and stigmatization and other difficulties. It is thus not surprising that the findings of this current study highlighted that families experience a similar emotional burden that is experienced by people living with HIV and AIDS. As the participants were narrating their stories, they reflected on challenges they encountered in dealing with HIV disclosure within their families and acknowledged that adjusting to this status as a family could be overwhelming. Portia of family one shared that she felt like she was losing

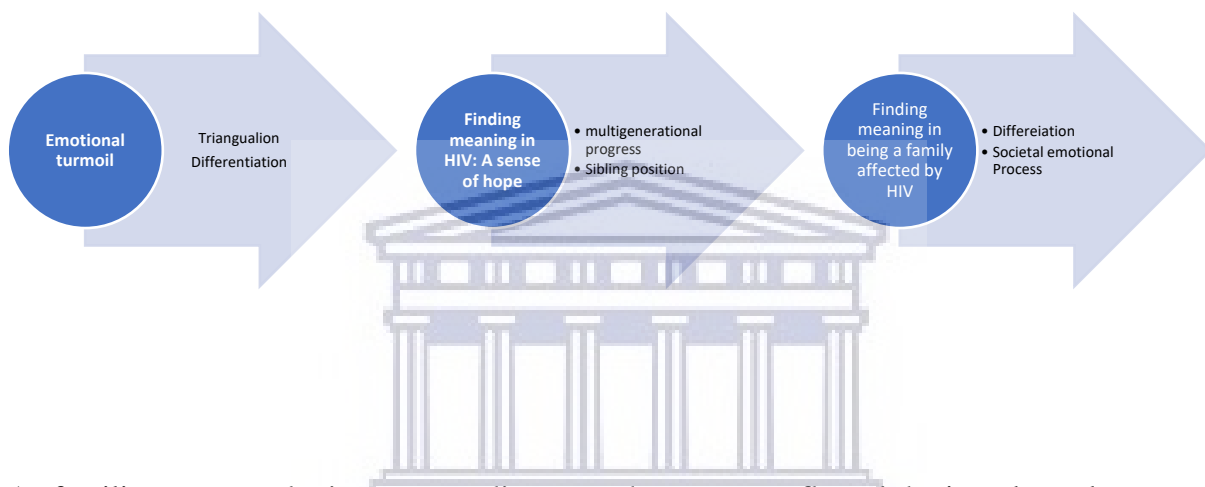
her mind as she was taking care of her daughter and dealing with issues that accompanied her disclosure, such as taking care of her grandchildren. Thus, Smith (2007) asserts that each family responds differently to challenges brought by disclosure of HIV. However, it is clear that most families experience huge strain from the impact of HIV/AIDS. However, most programmes implemented to provide HIV/AIDS support are tailored for people living with HIV/AIDS (Bor et al., 1993). Thus Susser (2009) states that programmes such as counselling services are not provided for the affected families in equipping them on how to better handle the situation after disclosure and how to cope when the loved one is diagnosed with HIV/AIDS. This gap in services available for affected families is particularly significant as the study findings reflected that the participants of this study had to deal with overwhelming emotions after HIV was disclosed in their families and in some instances needed to suppress those emotions in order to care for their HIV infected loved ones.

Disclosure of the HIV/AIDS status meant that families had to go through these experiences and emotions so that they could support the person living with HIV. What transpired during the interviews was, although the family members were experiencing the emotional turmoil, they were not giving up on their loved ones. Instead, they found meaning in their experiences in that it created a sense of hope that was given momentum through their belief system which created a platform for them to be stronger to pull through the situation until the adaptation phase. Utey and Wachholtz (2011) state that being diagnosed with HIV status allows people to reflect on their spirituality as part of their coping strategy, indicating the importance of families having opportunities to practice their spirituality as they participate in various supportive interventions that may be available to them. Of further significance is that the families' experiences allowed them to support other families who were going through the same

situation or to journey alongside those families who were struggling to come to terms with their status post disclosure.

5.5.2 Family systems theory and adjustment to HIV status

Figure 2: Understanding adjustment process using Bowen’s interlocking concepts



As families were on the journey to adjustment the process reflected the interdependence and interconnection of family and the ripple effect that occurs within the family (Bowen, 1978). Therefore, in this section Bowen’s (1978) interlocking concepts will be applied in understanding family systems theory and HIV/AIDS adjustment (see figure 2 above).

During emotional turmoil in the family the process of differentiation took place. This became evident as some families in the study reflected anger and were fighting and insulting each other. Thus, level of differentiation determines how family think, act and feel and their level of vulnerability (Brown, 1999). Thus, a well differentiated family is able to withstand any negative stressors (Haefner, 2014). As families, such as families two and three, learned about the status of the loved one, the study reflected low level of differentiation as they experienced some conflict during this time. Families reflected the process of triangles. This meant that as

they were experiencing emotions of hurt, pain and shock their attention was more on the family member infected with the virus. This meant that stressors that were experienced by families were stabilized by attending and taking care of the ill family member. Brown (1999) states that in triangulation any form of stress between two people can be stabilized by a third person.

The multi-generational transmission process looks at how people relate to each other and it is passed down to other generations. This study echoed the same understanding as explained by this concept. Family composition of the participants had people playing different roles in the unit and different relationships such as grandparents, parents, children and grandchildren. As parents were taking care of their children, their grandchildren were part of the process, meaning that the information and knowledge of taking care of the HIV/AIDS infected person was filtered down to the next generation. Haefner (2014) states that this process can be either detrimental or supportive to the next generation. As Brown (1999) mentions, information passed down has more impact on the future generation than the past generation. At the same time, the grandchildren in these families are also the elder children to their parents who are infected with HIV/AIDS. This speaks to the concept of sibling position as Kott (2014) states that number of children and their gender determine their role in family functioning. Furthermore, Haefner (2014) stated that elder children tend to assume more serious roles and younger ones will follow. Therefore, the study reflected older children of the infected person assuming supportive roles by fetching and administering medication for their parents.

As a family reached a phase where they accept being identified as an family affected by HIV , it means that the family has reached some level of differentiation. This means that families are at the phase where their emotional and cognitive level is stable to understand their HIV status. Haefner (2014) emphasises that well differentiated families are able to deal with

stressors without overlooking the importance of the family. This can be extended to the society, as the concept of societal emotional process, the manner in which family functions, society can do the same (Kutt 2014). Families involved in the study reflected some level of influence on the society as they aided external families that were dealing with HIV/issues.

5.5.3 Effect of HIV disclosure on the family system

The findings reflected a clear understanding of the effect of HIV disclosure on the life of the participant families in this study and the economic conditions of the household. Bowen's (1978) family systems theory explains that family members are connected, and each family member has a role to play. Therefore, this creates interdependence amongst family members. Family systems theory defines family members as being interdependent and interconnected to each other, with each family member having a role to play (Bavelas & Segal, 1982). At the same time this theory looks at how people behave when they have contact with each other as family members. Family systems theory places primary focus on exchanges of behaviour that take place in a given moment of interaction between members of the family (Johnson & Ray, 2016). Once the structure is affected it has a ripple effect on the whole family. The presence of HIV in the participant families had an effect on the survival of the families and their functioning. It emerged from the findings of this study that this is clear in three areas that will be further discussed, namely 1) role adjustment, 2) loss of income and 3) survival of the family (Sealy, Kajura, Backengana, Okongo, Wagner & Muller, 1993).

Role adjustment

The presence of HIV/AIDS disclosure in this study reflected that participants had to adjust their roles within their families in order to accommodate the HIV infected family members. Role

adjustment in this study was reflected in two ways. Firstly, parents, for example, were taking care of their daughters and sons who were HIV positive. Vuyisile, Portia, Mary and Nomthetho are the parents who had to take care of their sick children. Kalomo and Liao (2018) state that caregivers are normally those who are 50 years of age and older. The participants in this study who adopted a caregiving role to those infected were, however, above the age mentioned by Kalomo and Liao (2018). For example, Vuyisile and Portia from family one, Mary from family two and Nomthetho from family four reflected the age where they were supposed to be taken care of by their children; however, the situation was different for them.

Secondly, the study also reflected that the children also took care of their parents instead of their parents looking after them as they were of school going age. Therefore, these children could be subjected to stress as they are witnessing their parents' conditions. As Pillay (2015) mentions, the conditions that the children are in due to HIV means that they can experience social, psychological and educational challenges. Namhla from family three and Lihle from family four were both in their teenage years and assisting family members in taking care of their mothers. Coupled with that they also assisted in taking care of their younger siblings as their mothers could not fulfil the role due to HIV/AIDS. This reflects new roles that HIV/AIDS has brought about in the family. As Bor, Miller and Goldman (1993) state, given the nature and the intensity of the illness, families are obliged to relocate family roles amongst themselves.

Family systems theory explains the family as a unit that is connected and members are dependent on each other (Bowen, 1978). Therefore, family roles in the family regulate how family members function with each other. As a result, it will influence the rest of the family. Gunindi, Sahin and Demircioglu (2012) state that family is the unit that is bound together with different roles that fulfil psychological, social and economic needs. Therefore, if the role of

one person is disrupted, it means the whole system is disrupted. The need to evolve is required in order for the family to survive and to bring about the state of equilibrium. To maintain the stability of the family it means roles must be redefined in the family to accommodate the needs of the family. This reflects the interconnectedness of the family and the ripple effects of any changes that happen in the family. The study has shown that members of the family such as the elderly and adolescent are now expected to take care of the middle-age who were supposed to take care of them. This concurs with Smith's (2007) assertion that South African families have been perceived as adaptive systems.

Economic adjustment

The study also reflected the negative economic impact of HIV, where individuals who are living with HIV had to stop their economic contribution to the family as they could no longer work due to the illness. According to Page, Louw and Packer (2006) the nature of HIV takes its toll on people as it is hard for an infected person to work as due to the illness, coupled with that the fact that the family has to bear the economic cost of taking care of the loved one. The participants of the study reflected that all the infected loved ones were active in making financial contributions to the household. Jane from family three mentioned that Lilian had to stop working due to the illnesses she was experiencing and was no longer coping at work. Smith (2007) states that HIV/AIDS has a dire impact on household economic status as it reduces the household income and the expenses increase due to the needs of the HIV infected person as illustrated in the findings of this study. This confirms a situation where the household funds are redirected towards taking care of the infected person. Bor et al. (1993) asserts that if the bread winner of the family becomes sick other family members are expected to fulfil his or her role in providing for the family. This can lead to the family being subjected to poverty as

most funds are focused on taking care of the loved one, especially if the sick person was the only one who qualified in the labour sector.

Family systems theory asserts that each member of the family has different roles that they need to fill to ensure the functioning of the family (Bowen, 1978). Therefore, economic contribution is one of those clearly defined roles as it contributes to the maintenance and the stability of the household. Thus, in the family there are individuals who are breadwinners solely for the smooth running of the household. Once a member of the family is infected with HIV/AIDS, it means the family is faced with the challenge of meeting the needs of the individual and also household economic needs. Smith (2007) states that the presence of HIV has come with some challenges in the family. Firstly, the person who is infected might be too sick to work and, secondly, the remaining income of the household might be redirected to the needs of the HIV infected person. This can leave the family as a unit under enormous stress financially which can be difficult to resolve. In some families, depending on how differentiated they are, they could overcome these challenges but it will depend on the emotional and intellectual maturity of the family (Brown, 1999). Furthermore, the manner in which they handle the negative impact of HIV/AIDS in the family economy can be passed into future generations. This can create a cycle of poverty. Bachman and Boysens (2003) in their study into the economic and social conditions of Families affected by HIV in South Africa discovered that most HIV/AIDS affected families are poor households. The multi-generational transmission process of poverty can be evident in these families (Haefner, 2014).

Survival of the family and family relationships

Oktem (2015) states that HIV is perceived as a major obstacle in fulfilling family related expectations which were seen as normal and desirable social functions, such as getting married, having children and earning money to maintain the family. Living with HIV challenges the expected way of living among the society where each individual is fulfilling his or her role in the family or society. According to Bor et al. (1993) HIV/AIDS is common amongst the individuals of childbearing age which challenges the survival of families. This means that should the loved one succumb to HIV the grandparents are too old to bear children and the children are still very young to bear children which threatens the survival of the family. Vuyisile and Portia from family one are both parents and they reflected the fear of the family surviving as three of their children were infected with HIV/AIDS. However, with the presence of ARVs they had hope that the situation will be better.

The study revealed that at some point some family relationships were shaken and some were strengthened after disclosure. According to Van Deventer and Wright (2017) sometimes this virus can create tension amongst the household that leads to isolation of family members. The findings highlighted a situation where Linda and Mary's family members would fight and swear amongst each other during the period of disclosure and Portia explained that her sister-in-law distanced herself after she disclosed the status of her daughter to her. As much as some family members experience some tensions, for others this period allowed for strengthened family bonds. Bor et al. (1993) state that as much as support strengthens people with HIV, it is also required for those taking care of the sick. Therefore, support provided by the family members during this period strengthened family relationships. For example, Nomthetho from family four mentioned how she could depend on her family members for support.

5.6 CONCLUSION

Following IPA this chapter provided interpretation of the participants from the researcher's perspective. Therefore, it has explained and described in detail the process of adjustment after the disclosure of an HIV/AIDS positive status of the family based on the themes that were generated. Bowen (1978) was used as a theoretical framework providing a grounded explanation of the impact of HIV/AIDS on families, reflecting the ripple effect that it brings to families and how families manage to cope with being affected with HIV.



CHAPTER SIX

CONCLUSIONS AND RECOMMENDATIONS

6.1 INTRODUCTION

In this chapter, a summary of the study with regard to its objectives and main conclusions is presented. The limitations of the study are discussed and recommendations that emerged from the findings are presented.

6.2 CONCLUSIONS

HIV/AIDS has brought about many challenges to families affected by HIV/AIDS, but most attention has been placed on individuals living with HIV/AIDS. Therefore, the rationale for the study was to generate insight into how families adjusted to disclosure and their experiences. Furthermore, it aimed to understand how families can be supported in dealing with their psycho-emotional needs through proposing relevant services that will meet their needs. Thus, the aim of the study was to explore the lived experiences of family members adjusting to HIV/AIDS disclosure within their families. The objectives were: 1) To explore how family members adjust to HIV/AIDS disclosure in the family; 2) To explore how family members understand their experiences of adjusting to HIV/AIDS disclosure in the family and 3) To explore the meaning family members assign to being an HIV/AIDS affected family. Interpretative phenomenological analysis was utilised as research design, as it was suitable for the needs of the study.

This research study generated three themes and below is a summary of the main conclusions that arose from each theme:

Theme one: Emotional turmoil

The emotions of the family participants after the family member had disclosed to the family about his or her HIV/AIDS status ranged from pain to hurt and shock. At the same time as family members were dealing with an infected family member, they also experienced feelings of losing hope due to the nature of the illness. During this process some members displayed feelings of anger as adjustment process was a challenge for them. This was an emotional process for the family members as they were experiencing different negative emotions associated with any bad news.

Theme two: A sense of hope

Family participants gained some hope as they processed their own meaning and understanding of being a family affected by HIV. In doing so, families were able to discover aspects that brought the meaning and understanding why they were experiencing what they were going through as a family being HIV affected. Meaning was derived through support from family and extended family that assisted the families to deal with the virus. The support was in the form of financial, emotional and physical support from the family members. The experience with HIV/AIDS allowed them to have an understanding that in dealing with such a difficult situation there is a need for people whom you are able to depend on. Spirituality also played a central role in providing families with a sense of understanding why they were experiencing HIV/AIDS in their families. It provided a sense of hope to them as they used it to explain what seemed to be a mystery or unexplainable to them.

Theme three: Identifying as a family affected by HIV

Family members eventually accepted that they are an HIV/AIDS affected family and became comfortable with being identified as an HIV/AIDS affected family. The nature of the illness as

it is not curable allowed them to understand that HIV/AIDS would be with them for the rest of their lives. Some participants now understood that there was nothing they could do to change the status so they might as well accept it. Furthermore, other participants mentioned that they even forget that they have a family member infected with HIV. These experiences motivated them to educate other families who were experiencing the same situation about HIV/AIDS and provide support to them on how to deal with it and the importance of taking treatment. They mentioned that the source of their motivation was that they did not wish for other families to undergo the same experience they had when they discovered that the family member was HIV positive.

As family systems theory was used as an underpinning theoretical framework of the study, it was evident, through role allocation, that the elderly and the younger members of the family were now obliged to take care of the young adults while the situation was supposed to be vice versa. Economic adjustment also occurred as the infected family members had to stop working and some of the funds of the household had to be redirected towards fulfilling the medical needs of the HIV/AIDS infected person.

6.3 RECOMENDATIONS

The following recommendations to government and non-government sectors involved in HIV/AIDS programming are made in respect of:

6.3.1 HIV/AIDS counselling programmes

It is recommended that families be granted the opportunity to attend counselling programmes after learning about the HIV positive status of a loved one. This will allow families to process

the emotions and provide support to channel them constructively. This can be implemented through providing individual counselling programmes for family members which could then extend to integrated family counselling sessions. Individual counselling sessions will allow each family member to deal with his/her emotions after being disclosed to as people react differently to situations. An integrated family counselling programme will offer counselling to the family as a unit equip families on how to adapt to being an HIV/AIDS affected family. Furthermore, it could be a platform to learn how to manage family conflict and to further deal with any emotional trauma that they experience as they are adjusting to the HIV/AIDS status.

6.3.2 Structured HIV/AIDS educational support programmes

The implementation of a structured educational support programme is further recommended. This programme can assist families' understanding of the illness itself and they could be provided with skills and knowledge of taking care of ill individuals. The educational support programme should also equip families on managing stress associated with taking care of ill family members.

6.3.3 Programmes fostering spirituality

Spirituality was reflected as one of the coping mechanisms in the study that brought about a sense of hope to families. Therefore, it is recommended that spiritual programmes that will aid families in coping with their HIV status be implemented. This could be promoted at a personal and group level as people's spiritual needs differ.

6.3.4 Asset based community development

It is recommended that community involvement in supporting families that are dealing with HIV/AIDS be strengthened in all HIV/AIDS programmes implemented. Families affected by

HIV are clearly an asset in communities and could be utilised within an asset-based community development approach to build community and family resilience in coping with the challenges presented by HIV/AIDS.

6.3.5 Future research

This study has illuminated areas that needs further exploration through research. Accordingly, it is recommended that the role that can be played by families in preventing the spread of HIV/AIDS and coping with psychosocial and emotional challenges in taking care of HIV/AIDS affected individuals be explored through research.

As spirituality emerged as a key dimension of families' process of positive adjustment to HIV/AIDS disclosure, an exploration of how spirituality could be integrated into mainstream HIV/AIDS programmes would also be worthy of future research.

6.4 LIMITATIONS OF THE STUDY

In this research study the following limitations were identified:

The participants of the study were Xhosa and English speaking people from rural and urban areas in the Western Cape. However, the researcher cannot generalize the findings of the study to the Western Cape in its totality. Initially, the researcher reported on the sample size of twelve from four families, three participants in each family. However, the study ended up with ten participants with two participants from two families and three participants from two families. These families did however provide dependable information for the study.

REFERENCES

Asuquo, E.K., Etowa. B.J., Margaret, I. and Akpan, M. 2017. Assessing Women's Caregiving Role to People Living with HIV/AIDS in Nigeria, West Africa. *SAGE Open*. Volume 7, Issue 1, pp.1-10. DOI: 10.1177/215824401769201

Azhar, A.A., and Aboul-Hosn, N.K. 2015. Subcultural Narratives of Paediatric Chronic Illness in the Arab Community. *Procedia - Social and Behavioural Sciences*. Volume 165, pp. 116-120 . <http://www.sciencedirect.com/science/article/pii/S1877042814067512>

Babbie, E. and Mouton, J. 2011. *The Practice of Social Research*. Southern Africa: Oxford University Press.

Baran, M. and Jones, J. 2016. *Mixed Methods Research for Improved Scientific Study*. Hershey: IGI Global.

Bavelas, J. and Segal, L. 1982. Family Systems Theory: Background and Implications: *Journal of Communication*. Volume 32, pp. 99-107. 10.1111/j.1460-2466.

Biggerstaff, D. and Thompson, A. 2008. Interpretative Phenomenological Analysis (IPA): A Qualitative Methodology of Choice in Healthcare Research. *Qualitative Research in Psychology*. Volume, 5, pp. 214-224. 10.1080/14780880802314304

Bor, R., Miller, R. and Goldman, E. 1993. HIV/AIDS and the Family: A Review of Family in the First Decade: *Journal of Family Therapy*. Volume 15, Issue 2, pp. 187-204. 0163-4445

Bowen, M. 1978. *Family Therapy in Clinical Practice*. New York: Aronson.

Brown, J. 1999. *Bowen Family Systems Theory and Practice: Illustration and Critique*.
Australia: The Family Systems Institute.

Chidziva, V., and Heeralal, P.J.H. 2016. Circumstances leading to the establishment of child-headed households. *International Journal for Innovation Education and Research*. Volume 4, Issue 10, pp. 91-102 <https://doi.org/10.31686/ijer.vol4.iss10.601>.

Chih-Hui, L. and Sapphire, L. 2017. Systems theory. In: Scott, C.R and Lewis, L. (eds) *The International Encyclopaedia of Organizational Communication*. John Wiley and Sons, Inc.
DOI: 10.1002/9781118955567.wbieoc203

Chipanta,D., Lynch, V., Muñoz Sanchez, H., Nadkarni,V., Semigina, T. and V Sewpaul:
Getting to Zero: Global Social Work Responds to HIV: UNAIDS and IASSW, pp. 16-38.

Colman, A. 2009. *Oxford Dictionary of Psychology*. Third Edition. Oxford: Oxford University Press.

Connelly, L.M. 2016. Trustworthiness in qualitative research: *MedSurg Nursing*. Volume 26, Issue 6, pp. 435-436. Accessed 27 Sept. 2020.

Creswell, J.W. 2003. *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*. California: Sage Publications.

Dalmida, S., Holstad, M., Diiorio, C. and Laderman, G. 2011. Spiritual Well-Being and Health-Related Quality of Life among African American Women with HIV/AIDS. *Applied Research in Quality of Life*. Volume 6, pp. 139-157. <https://doi.org/10.1007/s11482-010-9122-6>.

Deacon, H., Stepheney, I. and Prosalendis, S. 2005. *Understanding HIV/AIDS Stigma: A Theoretical and Methodological Analysis*. South Africa: Human Sciences Research Council.

D'Cruz, P. 2004. *Family Care in HIV/AIDS: Exploring Lived Experience*. India: Sage Publications.

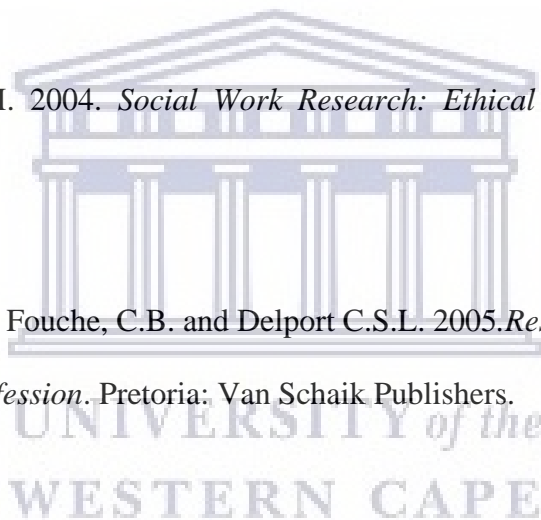
D'Cruz, H. and Jones, M. 2004. *Social Work Research: Ethical and Political Contexts*. London: SAGE.

De Vos, A.S. Strydom, H., Fouche, C.B. and Delpoit C.S.L. 2005. *Research at Grass Roots: A Primer for the Caring Profession*. Pretoria: Van Schaik Publishers.

Dickson, A., Emad, H. and Adu-Agyem, J. 2018. Theoretical and Conceptual Framework: Mandatory Ingredients of a Quality Research. *International Journal of Scientific Research*. Volume 7, Issue 11, pp. 438-441. [Accessed 20 November 2020].

Fine, D. 2007. *Clouds Move: My Journey of Living Openly with HIV*. South Africa: The Openly Living Trust.

Gilbert, L. and Walker, L. 2002 HIV/AIDS in South Africa: An overview. *Cadernos de Saúde Pública*. Volume 18, Issue 3, pp. 651-660.



Ghafouri, R. and Ofoghi, S. 2016. Trustworthy and Rigor in Qualitative Research. *International Journal of Advanced Biotechnology and Research (IJBR)*. Volume 7, Issue 4, pp. 1914-1922. <http://www.bipublication.com>. [accessed 21 November 2020]

Golics, C.J., Basra, M.K., Finlay, A.Y. and Salek, S. 2013. The impact of illness on family members: A critical aspect of medical care. *JRSoc Med*. Volume 106, Issue 10, pp. 399-407. doi:10.1177/0141076812472616.

Goundar, S. 2012. Cloud Computing : Understanding the Technology Before Getting “Clouded”. In F Goal, eds., *Recent Progress in Data Engineering and Internet Technology*. Volume 157, pp.217-222. https://doi.org/10.007/978-3-642-28792-5_30.

Guest, G., Bunce, A. and Johnson, L. 2006. How many Interviews are Enough? An Experiment with Data Saturation and Variability. *Field Method*. Volume 18, pp. 59-82. 10.1177/1525822X05279903.

Günindi, Y., Şahin, F. and Demircioğlu, H. 2012. Functions of the Family: Family Structure and Place of Residence. *Energy Education Science and Technology Part B: Social and Educational Studies*. Volume 4, pp. 549-556.

Hadi, A.M. and Closs, S. J. 2015. Ensuring rigour and trustworthiness of qualitative research in clinical pharmacy. *International Journal of Clinical Pharmacy*, Volume 38, pp. 641-646.

Hall, C. 2014. *Bereavement Theory: Recent Developments in our understanding of Grief and Bereavement*. Australia: Centre for Grief Management.

Haefner, J. 2014. An Application of Bowen Family Systems Theory. *Issues in Mental Health Nursing*. Volume 35, pp. 835-841. doi10.3109/01612840.2014.921257.

Hancock, B., Ockleford, E. and Windridge, K. 2005. *An Introduction to Qualitative Research*. Yorkshire and Humber: National Institute for Health Research.

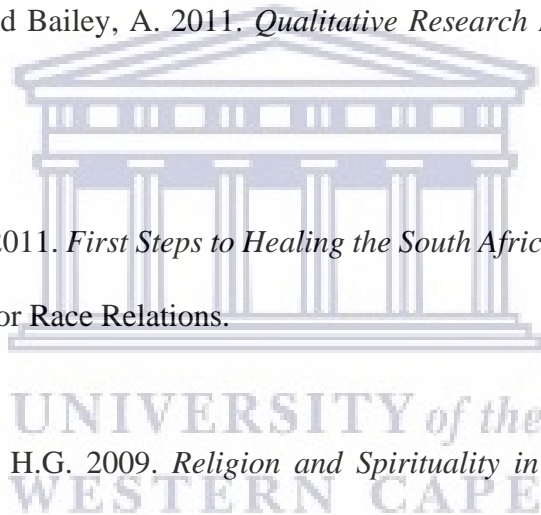
Hennink, M., Hutter, I. and Bailey, A. 2011. *Qualitative Research Methods*. London: Sage Publication.

Holborn, L. and Eddy, G. 2011. *First Steps to Healing the South African Family*. South Africa: South African Institution for Race Relations.

Huguelet, P. and Koenig, H.G. 2009. *Religion and Spirituality in Psychiatry*. New York: Cambridge University Press.

Human Science Research Council. 2014. *South African National HIV Prevalence, Incidence and Behaviour Survey 2012*. South Africa: HSRC Press.

International HIV/AIDS Alliance. 2003. *Supporting Community Action on AIDS in Developing Countries*. Building Blocks. USAID.



Iwelunmor, J., Airhihenbuwa, C. O., Okoror, T. A., Brown, D. C., and BeLue, R. 2006. Family systems and HIV/AIDS in South Africa. *International Quarterly of Community Health Education*. Volume 27, Issue 4, pp. 321–335. doi.org/10.2190/IQ.27.4.d

Jackson, R., Drummond, D. and Camara, S. 2007. What is Qualitative Research? *Qualitative Research Reports in Communication*. Volume 8, pp. 21-28. 10.1080/17459430701617879.

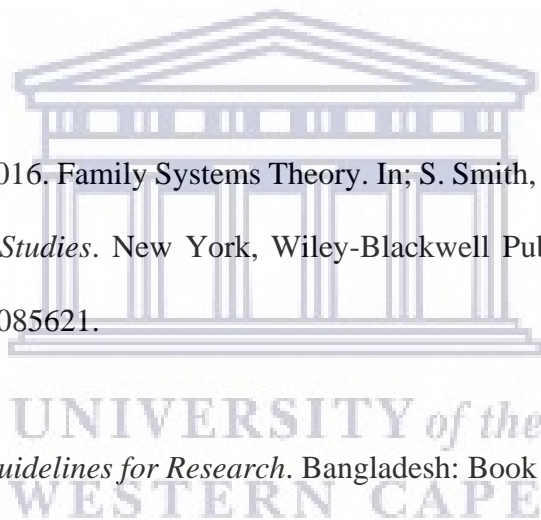
Jacobs, A. 2013. Spirituality: history and contemporary developments: An evaluation. *Koers – Bulletin for Christian Scholarship*. Volume 78, Issue 1. <http://dx.doi.org/10.4102/koers.v78i1.445>

Johnson, B. and Ray, W. 2016. Family Systems Theory. In; S. Smith, ed., *The Wiley Blackwell Encyclopaedia of Family Studies*. New York, Wiley-Blackwell Publishing, Volume, 2, pp. 782-787.10.1002/9781119085621.

Kabir, S.M. 2016. *Basic Guidelines for Research*. Bangladesh: Book Zone.

Kalomo, E.N. and Liao, M. 2018. Burden of Care among Caregivers of Persons Living with HIV/AIDS in Rural Namibia: Correlates and Outcomes. *Social Work Public Health*. Volume 33, Issue 1 pp.70-84. doi:10.1080/19371918.2017.1415180.

Karim, A.S.S. and Karim, A.Q. 2005 *HIV/AIDS in South Africa*. Cape Town: Cambridge University Press.



Kathuri-Ogola, L.N., Mugenda, O. and Kerre, P. 2014. Challenges Faced and the Coping Strategies Adopted by Family Caregivers in Dealing with People Living with HIV/AIDS in Thika District, Central Province, Kenya. *International Journal of Humanities and Social Science*. Volume 4, Issue 6, pp. 184-193.

Kerr, M., and Bowen, M.1988. *Family Evaluation: An Approach Based on Bowen Theory*. New York: Norton.

Kerr, E., 2000. *One Family's Story: A Primer on Bowen Theory*. The Bowen Centre for the Study of the Family. <http://www.thebowencenter.org> (Accessed 20 October 2020).

Kielmann, K., Cataldo, F. and Seeley, J. 2002. *Introduction to Qualitative Research Methodology: A Training Manual*. United Kingdom: Centre for International Development. .

Kohli, R., Purohit, V., Karve, L., Bhalerao, V., Karvande, S., Rangan, S., Reddy, S., Paranjape, R., and Sahay, S. 2012. Caring for Caregivers of People Living with HIV in the Family: A Response to the HIV Pandemic from Two Urban Slum Communities in Pune, India. *Plus One*, Volume 7, Issue 9 . <https://doi.org/10.1371/journal.pone.0044989>. [Accessed 10 August 2020].

Kubler-Ross, E. 1969. *On Death and Dying*. New York: Macmillan.

Kott, K. 2014. Applying Bowen Theory to Work Systems. *Od Practitioner*. Volume 46, Issue 3, pp. 76-82.

Maane, E. 2005. *Umzala: A woman story of living with HIV*. South Africa: The Openly Positive Trust.

Maman, S., van Rooyen, H. and Groves, K.A. 2013. *HIV Status Disclosure to Families for Social Support in South Africa (NIMH Project/Accept HPTN043) AIDS Care*. South Africa: Routledge Taylor and Francis Group.

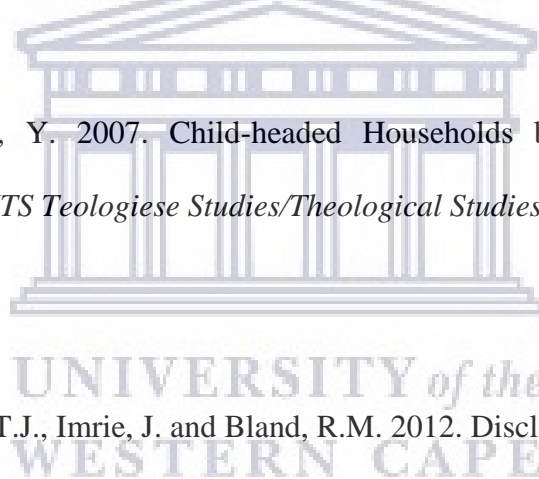
Mathambo, V. and Gibb, A. 2008. *Qualitative Accounts of Family and Household Changes in Response to the Effects of HIV and AIDS: A Review with Pointers to Action*. South Africa: Joint Learning Initiative on Children and HIV/AIDS.

Maqoko, Z. and Dreyer, Y. 2007. Child-headed Households because of the Trauma surrounding HIV/AIDS. *HTS Teologiese Studies/Theological Studies*. Volume 63, Issue 2, pp. 717-731.

Mkwanazi, N.B., Rochat, T.J., Imrie, J. and Bland, R.M. 2012. Disclosure of Maternal HIV Status to Children: Considerations for Research and Practice in sub-Saharan Africa. *Journal of Future Virology*. Volume 7, Issue 12, pp.1159–1182.

McNeill, F.G. 2009. *Venda: Magic: Talking about Treatment in M.Crewe*. AIDS Review. Pretoria: Centre for the Study of AIDS.

Miller, R. and Murray, D. 1999. The Impact of HIV Illness on Parents and Children with particular reference to African Families: *Journal of Family Therapy*. Volume 21, pp. 208-302, 0163-4445.



Moradi, G., Mohraz, M., Gouya, M.M., Dejman, M., Seyedalini, S., Khoshnavesh, S., and Malekafzali, A.H. 2014. Health Needs of People Living with HIV/AIDS: From the Perspective of Policy Makers, Physicians and Consultants, and People Living with HIV/AIDS. *Iranian Journal of Public Health*, Volume 43, Issue 10, pp. 1424–1435.

Oktern, P. 2015. The Role of Family in Attributing Meaning to Living with HIV and its Stigma in Turkey. *SAGE Open*. Volume, Issue 4, pp. 1-15. DOI: 10.1177/2158244015615165

Oxford English Dictionary. (2007). Vol2. 6th ed. Oxford: Oxford University Press.

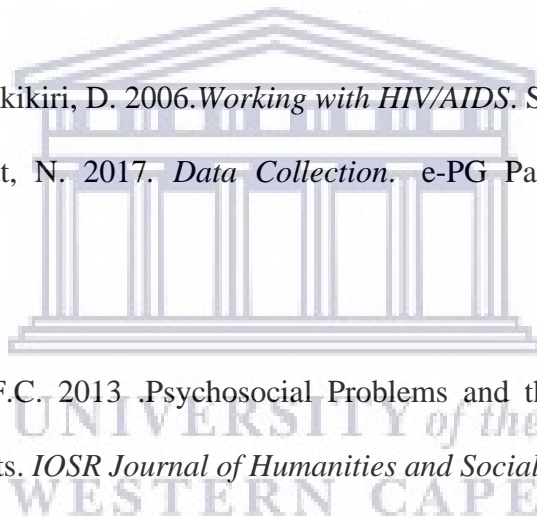
Page, J., Louw, M., and Pakikiri, D. 2006. *Working with HIV/AIDS*. South Africa: Juta.

Parveen, H. and Showkat, N. 2017. *Data Collection*. e-PG Pathshala Aligarh Muslim University: India.

Paul, A.A. and Premaj, F.C. 2013. Psychosocial Problems and the Impact Faced by the HIV/AIDS infected Patients. *IOSR Journal of Humanities and Social Science*. Volume 13, pp. 40-45.

Patton, M. Q. 2002. *Qualitative Research and Evaluation Methods*. Beverly Hill, CA: Sage Publications.

Patton, M.C. and Cochran, M. 2002. *A Guide of Using Qualitative Research Methodology*. Medecens Sans Frontiers.



Papero, D., Frost, R., Havstad, L. and Noone, R. 2018. Natural Systems Thinking and the Human Family. *Systems*. Volume 6, Issue 19. DOI:10.3390/systems6020019.

Peterson, R. and Green, S. 2009. *Families First-Keys to Successful Family Functioning. Family roles*. Virginia Estate: Virginia Cooperative Extension.

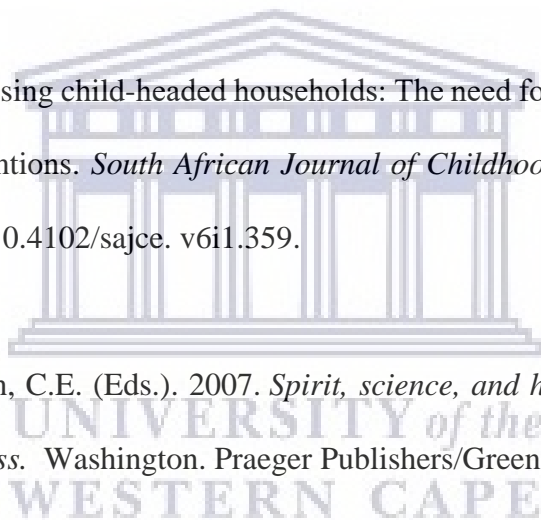
Pietkiewicz, I. and Smith, J.A. 2014. A Practical Guide to Using Interpretative Phenomenological Analysis in Qualitative Research. *Psychological Journal*. Volume 20, Issue 1, pp. 7-14.

Pillay, J. 2016. Problematising child-headed households: The need for children's participation in early childhood interventions. *South African Journal of Childhood Education*. Volume 6, Issue 1. [http:// dx.doi.org/10.4102/sajce.v6i1.359](http://dx.doi.org/10.4102/sajce.v6i1.359).

Plante, T.G., and Thoresen, C.E. (Eds.). 2007. *Spirit, science, and health: How the spiritual mind fuels physical wellness*. Washington. Praeger Publishers/Greenwood Publishing Group.

Poston, D.J. and Turnbull, A. P. 2004. Role of Spirituality and Religion in Family Quality of Life for Families of Children with Disabilities: *Education and Training in Developmental Disabilities*, Volume 39, Issue 2 pp, 95-108. <http://www.jstor.org/stable/23880059>.

Preda, M., Mareci, A., Tudoricu, A., Talos., A., Bogan, E., Lequeux-Dincă, A.I. and Vijulie J. 2020. Defining the Concept of Family through the Lens of Fertile-Aged Women in Bucharest, Romania—between Traditionalism and Inclusion, Faculty of Geography. *Sustainability*. Volume 12, Issue 7. <https://doi.org/10.3390/su12072691>.



Rabstejnek, C. 2009. Family Systems and Murray Bowen Theory. *Schizophrenia and Family Systems* [Accessed 23 October 20202].

Reimien, R.H. and Rabkin, J.G. 2001. Psychological Aspects of Living with HIV Illness: A Primary Care Perspective: *Western Journal of Medicine*. Volume 175, Issue 5, pp. 332-335.

Rotheram-Borus, M.J.D., Flannery, E., Rice and P.Lester. 2005. Families living with HIV: *AIDS Care*. Volume 17, Issue 8, pp, 978-987, DOI: [10.1080/09540120500101690](https://doi.org/10.1080/09540120500101690).

Sapsford, R. and Jupp, V. 2006. *Data Collection and Analysis*. Thousand Oaks, CA: Sage Publications.

Sharma, R. 2013. The family and family structure classification redefined for the current times. *Journal of Family Medicine and Primary Care*. Volume 2, Issue 2, pp. 306-310. <https://www.jfmpe.com/text.asp?2013/2/4/306/123774>

Shenton, A. 2004. Strategies for ensuring trustworthiness in qualitative: *Education for Information*. Volume 22, pp. 63-75. UK: IOS Press.

Sher, L.C., Cluver, L.D., Betancourt, T.S., Kellerman, S.E., Ritcher, L.M. and Desmond, C. 2014. Evidence of Impact: Health, Psychological and Social Effects of adult HIV on Children. *AIDS*: Volume 28, pp. 251-259 doi:10.1097/QAD.0000000000000327. PMID: 24991898.

Shields, S. A.2002. *Speaking from the Heart: Gender and the Social Meaning of Emotion*. New York: Cambridge University Press.

Shorter Oxford English Dictionary.2007. Sixth Edition. Volume 2. Oxford : Oxford University Press.

Smith, R. 2007. Living in an Age of HIV and AIDS: Implications for Families in South Africa: *Nordic Journal of African Studies*. Volume 16, Issue 2, pp. 161–178.

Smith, J.A., Flowers, P. and Larkin, M. 2009. *Interpretative Phenomenological Analysis: Theory, Method and Research*. Los Angeles, CA: Sage.

Smith, J.A. and Osborn, M. 2008. Interpretative Phenomenological Analysis. In: Smith, J.A., Ed., *Qualitative Psychology: A Practical Guide to Research Methods*, Sage, London, pp.53-80. <http://dx.doi.org/10.1002/9780470776278>.

Smith, J.A. and Osborn, M. 2015. Interpretative Phenomenological Analysis as a Useful Methodology for Research on the Lived Experience of Pain: *British Journal of Pain* 2015. Volume 9, Issue 1, pp. 41–42.

Statistics South Africa. 2011. Census 2011: *Profile of PWD in South Africa*. (Census No.03-01-59). Pretoria, SA: Statistics South Africa.

Spencer, M. 2012. *What is spirituality? A personal exploration*. Loyal College of Psychiatrist.

Susser, I. 2009. *AIDS, Sex and Culture: Global Politics and Survival in Southern Africa*. USA: Wiley-Blackwell Publishing, pp. 107-117.

Szaflarski, M. 2013. Spirituality and Religion among HIV-infected Individuals: *Current HIV/AIDS Reports*. Volume 10, Issue 4, pp. 324–332. doi.org/10.1007/s11904-013-0175-7

Tam, B., Findlay, L. and Kohen, D. 2017. Conceptualization of Family: Complexities of defining an Indigenous Family: *Indigenous Policy Journal*. Volume 28. <http://indigenouspolicy.org/index.php/ipj/article/view/398/483> (Accessed 14 September 2020).

Thurman, T., Lockett, B., Taylor, T., Nice, J., Carnay, M. and Spyrelis, A. 2017. Best Practices for evaluating Care and Support Programmes for HIV-affected Families. In: Henrickson, M., Toefy, Y. 2010. HIV/AIDS, Religion and Spirituality. In P, Rohleder., L. Swartz., S.C. Kalichman and L. Simbayi. *HIV/AIDS in South Africa 25 years on: Psychological perspective*. New York: Springer, pp235-251.

UNAIDS. 2015. *AIDS by the numbers: World AIDS Day 2015*.

UNAIDS, 2020. *Seizing the Moment: Tackling entrenched inequalities to end epidemics*. Global AIDS Update.

Utley, J.L., and Wachholtz, A.B. 2012. Spirituality in HIV+ Patient Care: *Psychiatry Information in Brief*. Volume 8, Issue 3. doi.org/10.7191/PIB.1047.

Van Deventer, C. and Wright, A. 2017. The psychosocial impact of caregiving on the family caregivers of chronically ill AIDS and/or HIV patients in home-based care: A qualitative study in Zimbabwe. *Southern African Journal of HIV Medicine*. Volume 18, Issue 1, pp1-7.

Van Dyk, A.C. 2010. Treatment adherence following national antiretroviral rollout in South Africa. *African Journal of AIDS Research*. Volume 9, Issue 3, pp. 235-247. 10.2989/16085906.2010.530177.

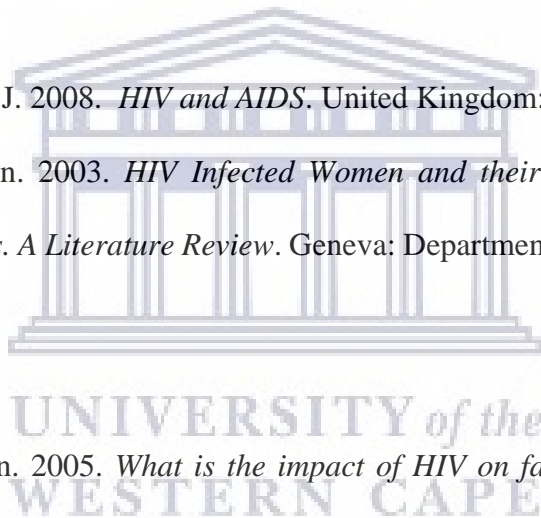
Van Dyk, A., Tlou, E. and van Dyk P. 2017. *HIV and AIDS Education, Care and Counselling: A Multicultural Approach*. Sixth Edition. South Africa: Pearson.

Walsh, F. 2012. *Normal Family Processes: Growing Diversity and Complexity*. 4th Edition. New York: Guilford Press.

Welbourne, A. and Hoare, J. 2008. *HIV and AIDS*. United Kingdom: Oxfam GB.

World Health Organisation. 2003. *HIV Infected Women and their Families: Psychosocial Support and Related Issues. A Literature Review*. Geneva: Department of Reproductive Health and Research.

World Health Organisation. 2005. *What is the impact of HIV on families?* Europe: Health Evidence Network.



APPENDIX 1: INTERVIEW GUIDE

Interview Guide

1. Tell me about yourself

Prompt: How would you describe yourself?

Prompt: How would you describe your family?

Prompt: What do you enjoy most about your family?

2. What was it like for you when the family first heard about one of its members HIV/AIDS positive status?

Prompt: What was your own reaction?

Prompt: What sense do you make of how you reacted to the situation?

3. How would you describe your family's reaction to the disclosure?

Prompt: What were the different reactions from different family members?

Prompt: What sense do you make of how your family experienced the disclosure?

4. How has the family adjustment process evolved over time?

Prompt: What are the influences that affect how the family processed the disclosure?

Prompt: How are the various relationships within the family impacted by the disclosure?

Prompt: How do you understand this?

5. What does it mean for you and for your family to be identified as HIV affected?

Prompt: Why do you say that?

Prompt: How does that make you feel?

6. If you could change any aspect of what happened in your family during this adjustment process, what would it be? What would you keep the same?

Prompt: Why do you regard this as important?

7. If you could offer any information or advice to other families adjusting to being affected family what would it be?

Prompt: Why do you say that?



APPENDIX 2: ETHICS LETTER



OFFICE OF THE DIRECTOR: RESEARCH
RESEARCH AND INNOVATION DIVISION

Private Bag X17, Bellville 7535
South Africa
T: +27 21 959 2988/2948
F: +27 21 959 3170
E: research-ethics@uwc.ac.za
www.uwc.ac.za

17 March 2017

Ms N Tshoto
Social Work
Faculty of Community and Health Sciences

Ethics Reference Number: BM17/2/10

Project Title: Lived experiences of family members adjusting to HIV/AIDS disclosure.

Approval Period: 10 March 2017 – 10 March 2018

I hereby certify that the Biomedical Science Research Ethics Committee of the University of the Western Cape approved the scientific methodology and ethics of the above mentioned research project.

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval. Please remember to submit a progress report in good time for annual renewal.

The Committee must be informed of any serious adverse event and/or termination of the study.

The permission from the health facility and/or health department must be submitted for record keeping to BMREC.

A handwritten signature in black ink that reads 'Josias'.

Ms Patricia Josias
Research Ethics Committee Officer
University of the Western Cape

PROVISIONAL REC NUMBER -130416-050

APPENDIX 3: CONSENT FORM



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 021 7635320 Fax: 27 21- 021 797 3356

E-mail: ncedisatshoto@gmail.com

CONSENT FORM

Title of Research Project:

Lived experiences of family members' adjusting to HIV/AIDS disclosure within the family



The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

Participant's name.....

Participant's signature.....

Date.....



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 021 7635320 Fax: 27 21- 021 797 3356

E-mail: ncedisatshoto@gmail.com

CONSENT FORM

Isihloko sophando:

Amava osapho nokutshintsha kwesimo emva kokuba ilungu losapho lunikeze inkcazelo ngokufuniswa sinentsholongwane kaGawulayo

Uphando lucacisiwe kum ngolwimi endiluvayo nendiluthethayo. Imibuzo ebendinayo ngoluphando iphendulekile. Ndiyaqonda ukuba ndizakuthatha inxaxheba ngokukhululekileyo nesigqibo sokuthatha inxaxheba ibisesam. Ndiyaqonda ukuba ubumna okanye igama lam lizokugcinwa liyimfihlo. Ndiyayazi uba ndinalo ilungelo lokuyeka ubayinxalenye yoliphando ngaphandle kokoyikiswa ngeziphumo ezibi okanye ukuphoswa ngamaqithi-qithi.

Participant's name.....

Participant's signature.....

Date.....

APPENDIX 4
INFORMATION SHEET



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 021 7635320 Fax: 27 21- 021 797 3356

E-mail: ncedisatshoto@gmail.com

INFORMATION SHEET

Project Title:

Lived experiences of family members' adjusting to HIV/AIDS disclosure within the family.

What is this study about?

This is a research project being conducted by Ncedisa Tshoto at the University of the Western Cape. We are inviting you to participate in this research project because of your experience as a family member affected by HIV/AIDS. The purpose of this research project is to understand how you as a family member experienced adjusting to having a member of the family who is HIV positive. This research study might bring insight on how families can be supported.

What will I be asked to do if I agree to participate?

You will be asked to answer questions relating to your and your family's reactions when you first heard the news and how you coped with it until now.

Would my participation in this study be kept confidential?

The researcher will keep your name and personal information confidential. To ensure your anonymity, you will be allocated a false name. To ensure your confidentiality, a file with a password will be created for electronic data and hard copies of data will be stored in a locked cabinet. If we write a report or article about this research project, your identity will be protected. All data and information will be destroyed after a period of 2 years.

What are the risks of this research?

All human interactions and talking about self or others carry some amount of risks. We will nevertheless minimise such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help the researcher learn more about lived experiences of families affected with HIV/AIDS. We hope that, in the future, other people might benefit from this study through improved understanding of how HIV/AIDS has affected families and how they can be supported.

Do I have to be in this research and may I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized.

What if I have questions?

This research is being conducted by Ncedisa Tshoto at the University of the Western Cape. If you have any questions about the research study itself, please contact Ncedisa Tshoto at 072 2150 968 or ncedisatshoto@gmail.com.

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Professor Nicky Roman
Head of Department: Child and Family studies
University of the Western Cape
Private Bag X17
Bellville 7535
nroman@uwc.ac.za

OR

Prof José Frantz
Dean of the Faculty of Community and Health Sciences
University of the Western Cape
Private Bag X17
Bellville 7535
chs-deansoffice@uwc.ac.za

This research has been approved by the University of the Western Cape's Biomedical

Research Ethics Committee_REFERENCE NUMBER:



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 021 7635320 Fax: 27 21- 021 797 3356

E-mail: ncedisatshoto@gmail.com

INFORMATION SHEET

Isihloko se Projekthi:

Amava osapho nokutshintsha kwesimo emva kokuba ilungu losapho lunikeze inkcazelo ngokufunyaniswa sinentsholongwane kaGawulayo

Singantoni esi sifundo?

Le yiprojekthi yophando olwenziwe ngu Ncedisa Tshoto, kwi Dyunivesithi ye Ntshona Koloni. Niyamenywa ukuba nithathe inxaxheba kule projekthi yophando. Sicinga ukuba amava enu okuhlala nomntu ochaphazeleke yintsholongwanwe kaGawulayo. Isizathu sale projekthi yoluphando kukuqonda nzulu ngamava ngosapho olunomtu ophila nentsholongwane kaGawulayo ukuba isimo sakhe sibachaphazele njani njengosapho. Oluphando lunganceda ukuthi xa kuthobozwa intsholongwanne kujongwe nendima enokudlalwa ngamalungu osapho, okwesibini ivula amanye amathuba ophando kwesisihloko

Kuza kubuzwa ntoni xa ndithatha inxaxheba?

Uzakucelwa uphendule imibuzo malunga namava wakho okuba yinxalenye yosapho oluchaphazeleke ngu Gawulayo eyakuthabatha imizuzu engamashumi amane anesihlanu ukuya kwiyure .

Ngaba ukuzibandakanya kolu phando luyakuba yimfihlo na?

Umphandi uzokwenza konke okusemandleni ukugcina ulwazi ngawe luyimfihlo. Akuzukusetyenziswa magama wakho okwenyani ukukhusela ubuwena. Ukuqinisekisa ngemfihlelo uphando luzakugcinwa kwikhompuyitha okwazi ukuzivula ngndlela eyodwa ekhuselekileyo. Ezibhaliweyo zona zizikugcinwa kwikhabhathi enesitixo apho wonke ubani engenakufikelela khona.

Bobuphi ubungozi koluphando?

Lonke unxulumano lwabantu luchaphazela ukuthetha ngabo nabanye oko kunabo ubungozi bokuba ubani athethe ngezinto zophando. Siyazama ukukhusela obu bungozi ngoba singenelele zisuka sikuncede ngoncedo lwengcaphephe zengqondo (psychological) okanye naluphina uncedo umthathi nxaxheba aludingayo ngethuba ethatha inxaxheba.

Yintoni inzuzo kolu phando?

Oluphando aludalelwangwa ukuba luncede uqobo lwakho kodwa iziphumo zalo zinganceda umphandi afunde lukhulu ngamava abantu abanamalungu osapho achaphazeleke sisifo sikaGawulayo nokuthi amalungu osapho angathatha eyiphi inxaxheba ekuthomalaliseni isifo sikaGawulayo

Ingaba kufuneka ndithathe inxaxheba koluphando /ndingayeka na xa ndifuna ?

Uba yinxalenye yoluphando ngokukhululekileyo. Kukuwe ukuba uyafuna ukuthatha inxaxheba okanye awufuni. Uba kuthi sekhuphakathi ufune ukuyeka,ungayeka nanini na awuzukohlwaywa. Ukuba uthe waziva udinga uncedo emva kemibuzo , uzokuthunyelwa apho unoncedakala khona

Xa unemibuzo

Oluphando luqhutywa ngu Ncedisa Tshoto kwiDyunivesithi yaseNtshona Koloni. Ukuba uthe wanemibuzo qhagqamshelana no Ncedisa Tshoto kulenombolo yomnxeba 072 2150 968 okanye umbhalele kwiemail ncedisatshoto@gmail.com

Ukuba uthethe wanengxaki ngophando okanye amalungelo akho njengomthathi
nxaxheba qhagamshelana naba babhalwe ezantsi

Professor Nicky Roman
Head of Department: Child and Family studies
University of the Western Cape
Private Bag X17
Bellville 7535
nroman@uwc.ac.za

OR

Prof José Frantz
Dean of the Faculty of Community and Health Sciences
University of the Western Cape
Private Bag X17
Bellville 7535
chs-deansoffice@uwc.ac.za

Oluphando luphunyezwe yi University of the Western Cape Humanities and Social
Science Research Committee.

