CHAPTER 5

RESULTS AND DISCUSSION

5.1. INTRODUCTION

This chapter presents the results, in accordance with the research aims and questions of the study. Using the qualitative technique of content analysis, several relevant themes and sub-themes have been identified within the data and are presented here. Direct quotes from the transcribed data have also been presented in order to substantiate and represent the themes and general findings that emerged from the analysis of the data. The identified themes are based on information conveyed by participants from both sites of the Tapologo HIV/AIDS programme, namely Boitekong and Phokeng. Included also are some frequencies pertaining to the emergent themes. Finally, a discussion of the results has also been provided, linking the results to relevant literature and theory within the field of study.

5.2. HOME-BASED CAREGIVERS' GENERAL WORKING CONDITIONS

For the purpose of this study, the thematic unit 'Home-Based Caregivers' General Working Conditions' has been conceptually defined to incorporate some of the circumstances and conditions that the home-based caregivers are facing within their current work environment. This broad thematic unit has been conveniently divided into five sub-themes in order to highlight and encompass some of the more specific and pertinent conditions experienced and reflected within the data. These sub-themes include: 'The Art of Volunteering', 'An Incentive for Work Done', 'The Working Hours', and 'Taking a Break: Annual Leave'.

5.2.1. The Art of Volunteering

All the participants indicated that they work for the Tapologo HIV/ AIDS programme on a purely voluntary basis. It was also suggested from the data that working in this capacity serves to formulate and conceptualize much of their identity and self-image. This is captured in the following statements:

"We are not hired, we are volunteers"

"I like to be a volunteer, hence I volunteered from the beginning"
"We are volunteers and I love this work"

In a study conducted by Thompson, Barnes, Hussey, Mostache and Conn (2003, p. 8) volunteerism is described as being part of a volunteers "personality" and "self-image", and serves to formulate much of the way in which volunteers view themselves i.e. it forms part of self-concept -"who I am". Integral to this, Thompson, Barnes, Hussey, Mostache and Conn (2003 p. 8) also comment on volunteerism forming part of a "volunteer's life task" and part of what they perceive as an "obligation to make a difference", which in turn can perhaps be seen to provide them with a sense of meaning and identity.

Whilst it was evident that the act of volunteering serves to formulate much of the participants' identity and self-image, some participants expressed that they felt that the act of volunteering also serves to contribute to feelings of being unsupported and unheard by the governing NGO, both financially and emotionally. This was indicated from the following statements:

"I am a volunteer but they (NGO) somewhat hide information, which we need to know, from us and do not share it with us..."
"I cannot say I'm angry because I knew I'm volunteering but at least they should feel for us and give us support financially and emotionally".

These feelings of being unsupported by the governing NGO may be of concern in terms of ensuring the participant's emotional and psychological well-being and sense of containment within the programme. According to Ross, Greenford & Bennett (1999) it is important for individuals to feel contained and heard in order to prevent anxiety, stress, and, or burnout.

5.2.2. An Incentive for Work Done

Despite the participants working on a voluntary basis, it was suggested from the data that the participants do receive a small incentive/ remuneration on a monthly basis. Discussion around this issue seemed particularly difficult for the participants to discuss, however, perhaps because of the personal and sensitive nature of this topic, and also because the majority of them feel that their incentives are too little in relation to their workloads and

personal commitments e.g, family commitments. They experience and find their low incentives difficult to manage, which appears to cause them much distress, stress, and frustration. It was also observed that whilst acknowledging and portraying their incentives as being minimal and difficult to cope with, some degree of justification for their feelings were evident (language of justification). This may have been related to participants not wanting to come across as being ungrateful or dissatisfied with their incentives and work, as well as being fearful of owning their complaints. It seemed important for them to portray themselves to the researcher in a positive light. These findings were suggested from the following comments:

"The incentive is too little because we have families and this makes me feel sad".
"The salary is too little whereas we work very hard and sometimes I feel like staying at home and is frustrating to me…It is stressful that".
"Its just an incentive and we get it once a month but because I told myself I want to help people so I try to cope with it".
"…it is too little but because we are volunteers and I love this work, I want to help".

These findings are similar to findings reported by Russel and Schneider (2000), in which the incentives received by home-based caregivers were identified to be insufficient, especially given the caseloads and workloads of home-based caregivers. This may prove to be problematic for Home Based Care programmes in general, especially given that home-based caregivers form a significant part of the working force behind home-based care. It is important that they stay invested and feel that their work is being acknowledged and rewarded on both a financial and emotional level (Russel & Schneider, 2000; Uys, 2003). Inadequate incentives and remuneration may also contribute to stress and burnout, as they are faced with not only having to deal with the difficult nature of their work, but also the stress of managing their finances and making ends meet within their personal lives (Ross, Greenford & Bennett, 1999).

5.2.3. The Working Hours

This sub-theme aims to capture and comment on the working hours required of the participants. According to various participants, the stipulated working hours within the Tapologo HIV/AIDS programme is 4 hours per week. However, several participants

suggested that in reality this is not necessarily realistic. On average the participants reported working 7 hours and 19 minutes per day. The introduction of Antiretrovirals (ARVs) seemed to be a central cause in the increase and variability in these hours.

"I cannot estimate the hours because it goes according to our patients' needs, sometimes we take the whole day but the stipulated hours was to work four hours a week with a patient but it does not always work that way. We work far more than that. On average we work from 07h30 until 15h00 or 16h00, which is more than 4hrs."
"We find ourselves having to work more hours because of these ARVs more especially when the patient is taking the medication for the first time. It becomes hard for us because we are required to work at night as well".

In addition to being requested to work for four hours per week, it was also stipulated or requested that the home-based caregivers work three days per week. However, according to several participants, clients[1] can arrive at their homes at any given time. Working on the weekends was also suggested to be common. These findings were suggested by the following statements:

"Most of the patients go to M (a community member) for advice and she takes them to where I stay that is why I have so many because I helped her... I ask them not to go to my house because my children get stressed, but some of them just go even then."
"We also counsel them on weekends for those who work"
"Sometimes relatives bring patients that are not well on my day-offs, like Saturday and Sunday, and I assist them."

Working directly in the community means that the participants were available to the community constantly, which appears to cause their stipulated working hours and days of work to be heightened. Similar findings were found by Russel and Schneider (2000), and Knott (2003) who found that because home-based caregivers work directly in the community, often they are never off duty. They are constantly being referred new clients, being requested to counsel clients and or advise clients and their families. Van Dyk (2001) urges that this can potentially be risky in terms of home-based caregivers becoming overwhelmed and or burning out. The workload in Home Based Care is often very demanding and home-based caregivers frequently experience stress, and the lack of privacy in their own homes (van Dyk, 2001).

---

[1] Please note that the term "client" has been used here instead of "patient" as the beneficiaries of the programme are preferably seen as clients rather than patients within the context of receiving services from the home-based caregivers, who are not medically trained.

5.2.4. Taking a Break: Annual Leave

The majority of participants (80%) reported taking annual leave, whilst a minority (20%) reported that they did not take annual leave. The stipulated number of days of leave was 21 days per annum. For those participants who reported that they did not take leave the following comments were made:

"I was supposed to take leave this year but Sister T who is in charge fell sick. She transports patients and so I had to take over.."
"We are supposed to take, but I never do. I don't have the time. My patients need me."

Reasons for not taking leave, therefore, appears to be related to time constraints and demanding work schedules, as well as filling in for people who are unavailable or absent i.e. a lack of resources. These findings seem to contradict the Department of Health (2002) and the World Health Organization's (2002) stipulation that mandatory leave fall under part of the protocol for alleviating and preventing emotional and psychological stress, perhaps indicating that some of the participants of this study may be at risk of stress, burnout, and, or secondary trauma (Franken, 1988; Knott, 2003; Uys, 2003; van Dyk, 2001).

5.3.   MOTIVATION

The thematic unit 'Motivation' aims to capture some of the driving forces that appear to motivate home-based caregivers volunteering their services at the Boitekong and Phokeng sites of the Tapologo HIV/AIDS programme. Various factors can be seen to contribute to their levels of motivation.

Several participants made reference to a desire and need to help those who are suffering or who are in need. Other participants expressed a need to help others as a result of experiencing their own personal difficulties and or facing their own personal experiences of illness and disease. Another strong motivating factor acknowledged included the desire and motivation to work for the benefit of the community. Several participants acknowledged, for example, that through the programme a greater number of people, who are "suffering" due to illness

and disease, could be reached. Others expressed a desire to "make a difference" within the community. These findings are suggested from the following statements:

"... I volunteered from the beginning to help the patients that need help because they cannot help themselves."
 "I like to work with people in need and want to offer them security
"...one of my sisters was a patient here so I want to help in caring for people."
"I had a friend who died of AIDs, I was not aware then that it was AIDs, and I was taking care of her and she has left me with her children."
"The reason why we've done this is because we felt we needed to reach out to people. There are people really in need of care and once the patients are discharged from the hospital to go home, there is nobody to take care of them in the community"
 "They started this volunteering campaign here and I joined because I know I will be doing some good to the people."
"...we felt we could make a difference."

Other more general motivating factors observed included: the desire to pass on and utilize one's knowledge; religion; and high unemployment rates. These points were indicated by the following comments:

"When I was at the hospital I used to work with the sick people and therefore wanted to help them further."
"...I could not just sit and watch them suffer and according to our church we must help. I am a minister, so I give them sacrament, listen to their problems even if it is not members of our church."
"It is because there is no work and if you stay at home doing nothing, you become bored and hence I felt that it is better to help people."

According to Franklen (1988), personal or altruistic factors in terms of motivating people to assist or help others is common. People find such work self-fulfilling (Thompson, Barnes, Hussey, Mostache and Conn, 2003). By working with people that they identify with, or by giving something back to society, their self-esteem and sense of belonging is heightened (Calvert & Evans, 1991; Toates, 1986). Calvert and Evans (1991) refer to these as direct and indirect personal motivating factors and compare them to more abstract motivational factors such as "I wanted to do something, which fitted with my moral code". Thompson, Barnes, Hussey, Mostache and Conn (2003, p. 8) suggest that the act of volunteering and the need to give to others is central to one's "self-image". Such individuals are "receptive to helping those less fortunate and are flexible in how they reach out to others" (Thompson, Barnes, Hussey, Mostache and Conn, 2003, p.8). They also suggest that the desire and motivation to

help those less fortunate than ones self is "rooted in childhood", forming part of a "tradition" rather than a "trend" (Thompson, Barnes, Hussey, Mostache and Conn, 2003, p. 9). Finally, the desire for employment and financial gain, no matter how minimal, can be seen to form the motivational basis for providing for one's physical needs such as eating, drinking, shelter and so forth, and the sustainability of life in general. This forms part of and ties in with Maslow's first identified need on his hierarchy of needs, namely "physiological needs" (Thompson, Barnes, Hussey, Mostache and Conn, 2003).

5.4.   CLIENTS

The thematic unit 'Clients' aims to encompass and discuss information and themes pertaining to the clients receiving care from the home-based caregivers at the Boitekong and Phokeng sites of the Tapologo HIV/AIDS Programme. This thematic unit has been divided in to three sub-themes in order to highlight some of the more specific and pertinent issues pertaining to the clients servicing the programme. The sub-themes include: 'The Main Beneficiaries', 'Workload: The Number of Clients Seen Per Home-Based Caregiver', and 'The Allocation of Clients to Home-Based Caregivers'.

5.4.1. The Main Beneficiaries

From the results of the present study, it is apparent that the majority of the home-based caregivers perceived the main beneficiaries of their work, to be HIV/AIDS clients. However, some participants also suggested that other beneficiaries included clients with diabetes, hypertension, and cancer, although these clients can be seen to occur less frequently. One participant expressed some concern about being identified as a programme which only offers services to HIV/AIDS clients, and stressed the fact that they offer services to a variety of chronically-ill clients. According to other participants, other beneficiaries of their work also included families, and the community in general. These findings were suggested from the following:

   "It is mainly the HIV positive patients although we cover all patients and do no reject any. We are doing this specifically for HIV positive patients."

"...the person who benefits the most really is the patients, especially the HIV positive patients...we are mainly targeting HIV/AIDs ones and are concentrating more on those"

"...others suffering from chronic diseases it adds up to 20. Chronic diseases include things like hypertension, diabetes, cancer etc."

"People used to take us as people who wanted to take care of HIV/AIDS patient...we... do not want to be stigmatized and thought to be caring for HIV/AIDS patients only, as was the case before"

"I think both the patients and their families benefit a lot from the programme although some of them reject us."

"I also benefit and so does my family and the community"

These results are in line with those beneficiaries identified and stipulated by the Department of Health (2001; 2003). According to the Department of Health (2001), the Home Based Care should aim to assist and benefit the following clients:

- At risk or frail older persons
- At risk people with moderate to severe functional disabilities
- People recovering from illness, in need of assistance (for example post deliveries, post operation treatment and care)
- Terminally ill persons (e.g, cancer clients)
- Persons living with HIV/AIDS or other debilitating diseases/conditions (e.g, mental illness, substance abuse, cancer)
- Any other disadvantaged or vulnerable group/person in need of support and care, especially children and women or people in crisis
- Family and Friends

Finally, the participants' observations that HIV/AIDS clients are the primary beneficiaries of the programme is in keeping with much of the literature in the field of study (Department of Health, 2001, Uys, 2003, and Gwyther and Marston, 2003). The participants in the study did not comment on exactly why their workloads were predominantly HIV/AIDS cases, but such findings can perhaps be seen to be in accordance with the fact that HIV/AIDS has reached epidemic proportions within the South African context, and therefore it seems hardly surprising that HIV/AIDS clients are predominant.

5.4.2. Workload: The Number of Clients Seen Per Home-Based Caregiver

The average number of clients seen per home-based caregiver was reported to be 16 at any given time. The number of clients being seen ranged from 8 and 36 within a one-week period. Therefore, the caseload per home-based caregiver can be seen to vary, and be relatively unpredictable and uncertain. This finding may be influenced by the fact that the home-based caregivers are based and work directly in the community, and are thus required to take on clients as and when they present themselves (Knott, 2003; Russel & Schneider, 2000). Van Dyk (2001) suggests that working within the community with unpredictable and varying workloads can be very disconcerting and stressful for caregivers, especially those working with terminally-ill clients, who prove to be very time consuming and demanding. Furthermore, research done by Kalibala in Southern Africa (1995, as cited in Kaleeba, Kalibala, Kaseje & Ssebbanja, 1997, p. 15) suggests that caregivers often report that providing care for AIDS clients, in particular, is more "time-consuming and stressful than caring for clients with other diagnoses". The emotional and psychological toll that this has on home-based caregivers, may therefore be seen as somewhat alarming, potentially resulting in significant stress, burnout, and even varying degrees of secondary trauma (Gilliland & James, 1993; Hesse, 2002; Knott, 2003).

5.4.3. The Allocation of Clients to Home-Based Caregivers

From the data, it is suggested that clients are not allocated to home-based caregivers in a structured or formalized fashion. Instead home-based caregivers were seen to rely on the community itself to directly lead them to clients in need. Individuals in the community who may facilitate this process were indicated to include family members and neighbours. Home-based caregivers also suggested voluntarily seeking out clients within the community themselves. Referrals from local clinics were also suggested, and clients were also reported to seek the assistance of the home-based caregivers themselves. These findings were suggested from the following comments:

"Sometimes families come to us as they know that we are the homecare nurses. Otherwise we receive them from neighbours…"

"The community knows us and they come and tell us about some people who are not well and so do our patients and we then go there…"

"We do not allocate the patients, the carers go the village and go from house-to-house to find their patients

"...and the others (patients) come from Sr G (at the clinic) who refers them to us and we go and find them from the house numbers provided.

According to one participant in particular, it is also important that various contacts and relationships are maintained and established with certain key leaders, informants and authority figures within the communities so as to facilitate the process in which home-based caregivers are directly immersed within the community they are working for. This was indicated by the participant's following statements:

"When we started going to the communities we introducde ourselves to the head, even if it is a squatter camp. We tell them about us, that we are here and we are taking care of very sick people. That is how the counselor introduces us to the very people so that house members know that we are there to assist them with their sick people...In areas which are not squatter camps or where there are headmen, we introduce ourselves and also to the professional nurses at the local clinic... They then tell the community and they come. The headmen sometimes advises us to come to Lekgotla, a meeting always held in villages where people come together and that is also where things get discussed...That is how we get to be known..."

Thus, from the results it can suggested that the home-based caregivers rely heavily on the support of the community in order to identify and locate their prospective clients. Establishing and maintaining a good relationship with the community is seen as being important. These findings are in accordance with the World Health Organization (2003) and the Department of Health's (2002) perception of Home Based Care being an integral and integrated aspect of "Based care", in which the health consumer (beneficiary) can access care near to, or within their home. Furthermore, according to research conducted by Russel and Schneider (2000), this provides a means of working collaboratively, and providing a continuum of care to clients.

5.5. TRAINING RECEIVED BY HOME-BASED CAREGIVERS WITHIN THE TAPOLOGO HIV/AIDS PROGRAMME

The thematic unit 'Training Received by Home-Based Caregivers within the Tapologo HIV/AIDS Programme' aims to capture the essence and dynamics of the training received by the participants from the Boitekong and Phokeng regions of the Tapologo HIV/AIDS programme. The thematic unit has been divided up in to five sub-themes. These sub-themes

include: 'Selection Criteria of Home- Based Caregivers', 'Provision of Training: Type and Content', 'Training in Self-Care', 'Personal Views on Training Received in Psychological/Emotional Support (Counselling Skills) and Feelings of Competency', and 'Recommendations for Training'.

5.5.1. Selection Criteria of Home-Based Caregivers

It is suggested from the data that before prospective candidates are selected on to the programme and subsequently trained, several criteria are regarded as important and essential. For example, whether prospective candidates are able to display empathy and warmth; if they are willing to volunteer and are not' just looking to join the programme for financial gain; and finally, if candidates' are able to read and write, despite their level of education. These findings were suggested from the following comments:

"...The thing we do, which I think is the most important one that we really look at, we need to get somebody with a heart, who is really able to take care and is willing to give love to these patients. Because sometimes you find that, especially the HIV positive patients, what they really need is love and care and to make them feel that they are also being accepted as human beings."
"We also try to explain to them that this is really not being taken for the sake of getting money but one needs to volunteer to try and help and be supportive to those in need of help"
 "We also try to get people who can read and write. A person needs not have Grade 12 or Standard 10 for as long as the person is able to read and write."

Choosing appropriate candidates for Home Based Care is important. This is consistent with research conducted by Cameron (2003), which asserts that if home-based caregivers are not properly equipped and well suited to the programme, they will not be able to function as part of the multi-disciplinary health care team, and the Home Based Care programme is unlikely not succeed. From the data it is evident that various precautions and criteria have been set in place by the Tapologo HIV/AIDS programme, such as being able to read and write, and therefore it seems as though some consideration has been given to ensuring that the home-based caregivers are suitable and adequately equipped in order to cope with the needs and demands of the programme.

5.5.2. Provision of Training: Type and Content

The results of the present study indicate that the home-based caregivers receive various types of training. In general these include training in counselling, 'Directly Observed Therapy Short-Course (DOTS) for Tuberculosis (TB), first aid, home-based care (or home-care nursing/primary health care), and palliative care. Furthermore, it is evident that this training is offered from a variety of sources, including Hospice, Lifeline, professional nurses, and the local mines and so forth.

All of the participants acknowledged receiving some form of *initial* training before starting to work as a volunteer on the programme, and 15 of the participants reported receiving *on-going* training on a regular basis, whilst 1 said they had not. It was evident from the data that ongoing training is primarily received from Lifeline. However, some participants also commented on receiving other types of training on an ongoing basis, for example, training in home-based care, ARVs, as well as training from Hospice.

i) Lifeline

From the data, it was suggested that Lifeline can be seen to essentially offer the home-based caregivers training in basic counselling skills, for example, listening skills, and the ability to maintain and keep boundaries in terms of the work they do and what they are physically capable of.

ii) DOTS and First Aid

The data indicates that the Tapologo Outreach Programme assists the Department of Health with its Tuberculosis (TB) Treatment Programme via the DOTS mechanism, and training in First Aid. Training in First Aid appears to be provided either from various professional nurses, or from a location within the local mines (platinum mines). The following statements suggested these findings:

"DOTS helps us to challenge and help a patient that you suspect can be infected by TB"
"...then DOTS is training for TB."
"...after that I went to the mine for First Aid."

iii) Home-Based Care

The data suggests that the training in home-based care provides home-based caregivers at Phokeng and Boitekong basic with skills in nursing, nutrition, and self-care, and appears to be very practically orientated. An emphasis also appears to be placed on training the home-based caregivers with the skills to educate family members of clients (psycho-education), and to pass on some of their basic skills of care and nursing. This can be seen to be done at the local Hospice. These findings were indicated by the following:

"Home- Based Care involves how to nurse the patient, the nutrition, how to take care of one's self so as not to be infected.
"We also teach the family on how to take care of the sick, we build relationships between the family and sick i.e. practical skills and make sure that they accept the sick and understand their condition."
"...how to nurse the patient, the nutrition, how to take care of one's self so as not to be infected".

iv) Palliative Care

Training in palliative care at the Hospice was also suggested from the data. This training can essentially be seen to involve training in care for terminal clients, although not only for HIV/AIDS clients. This training includes medical care and training, but also attempts to equip and train home-based caregivers with the emotional and psychological strains of working with terminally-ill clients. Furthermore, it was suggested that not all of the home-based caregivers receive training in palliative care. There appears to be a selective process in terms of who is able to receive this training, for example, training seems to be mainly aimed at the professional nurses working within the programme.

According to the Cameron (2003) and van Dyk (2001), the identification and provision of psychological and emotional support for those who are terminally or chronically ill, their families, significant others, and the community in which they live, is vitally important. Managing the turmoil and emotion associated with the fear of death and dying, as well as with the fear of loosing someone seems particularly important in the face of the HIV/AIDS pandemic, where the experience of loss is frequent and common. Furthermore, it is important that home-based caregivers working with terminally-ill clients are trained to feel competent and equipped enough to deal with factors pertaining to death and dying, and be able to cope themselves with the atrocities they witness and face on a daily basis (Uys, 2003). Familiarity and knowledge of primary health care and basic nursing skills is also deemed as essential,

with home-based caregivers being required to educate family and friends were applicable (Department of Health, 2001).

It is, therefore, evident that the provision of training at the Tapologo HIV/AIDS programme is relatively holistic in nature, which is in accordance with Department of Health's (2002) curriculum for Home Based Care. Adopting a holistic approach with a high standard of care is crucial (Cameron, 2003).

5.5.3. Training in Self-Care

Seven of the participants indicated that they had received training in self-care, whilst 5 said they had not. Of those that said they had received training in self-care, various aspects of their training were discerned, for example training in how to set boundaries and limitations, relaxation techniques, and the importance of expressing one's emotions and not suppressing them. The following comments highlight these findings:

"She (one of the sisters) told us to keep cool or calm and know what to do when it comes to us as individuals. I now control myself and try to take care of myself by accepting that I'll help the person up to a certain extent and will not stress myself beyond that.
"Sometimes the social worker visits us and tells or explains to us how to deal with stress, e.g, Relaxing"
"...On arriving home one must be quite, but if one feels like crying, then they must cry because it is good to cry. If you do not you may become sick. If one feels like talking to someone then you must do so."
"They tell us to speak to other people and to do some exercises. I sometimes go to other carers and talk about what breaks my heart."

It was suggested from the results that the social worker primarily offered participants training in self-care, although some training in self-care was also evidently offered from various sisters as well as Lifeline. This was suggested from the following statements:

 "We were being helped by a social worker this year on how to cope with the situation and on further training."
 "It was one of our sisters who was coming to ask us about the problems that we were coming across and was telling us how to handle them and also how one can help one's self... Lifeline tells us to have limits in whatever we do and not to do more than we can afford to"

According to the literature, the provision of training in self-care is important in terms of preventing stress and, or eventual burnout (Montgomery, 1993; Muldary, 1983; Ross,

Greenford & Bennett, 1999; van Dyk, 2001). Home-based caregivers need to take care of their own physical and mental health in order to work effectively and productively (van Dyk, 2001). It of concern that 5 of the participants claim that they had never received training in self-care.

5.5.4. Personal Views on Training Received in Psychological/Emotional Support (Counselling Skills) and Feelings of Competency

Fifteen of the participants said that they perceived their training in a favourable and beneficial light, and indicated that they felt that it had adequately prepared them for the work that they do, whilst 1 of the participants indicated that they felt their training had not prepared them for their work adequately. These findings were suggested from the following comments:

"I think it (training) is sufficient because of this on-going training more so because we go to servicing after a month."

"Its very good because from the start we did not know anything about caring. We used to feel depressed and sad, but we are now able to deal with any condition the patient is in."

"No, because I do not know BP (Blood Pressure) and some things because they said that they will tell us, they never got a chance to teach us."

"I still need more training because I am not confident and comfortable enough…"

The provision of adequate training is vital to the success of Home Based Care programmes (Cameron, 2003). Furthermore, by equipping home-based caregivers with the necessary skills and knowledge, information can be generated amongst the community, thus empowering the community (van Dyk, 2001). This seems especially important given that the communities with which the Tapologo HIV/AIDS programme primarily work, are predominantly poverty stricken, and uneducated, requiring as much practical help and assistance as possible (Tapologo HIV/AIDS Management Team, 2004). Furthermore, by educating the communities, hopefully some awareness is also generated, ultimately facilitating disease prevention.

5.5.5. Recommendations for Training

Some of the participants indicated that they were happy with the quality and type of training received and indicated that no recommendations were necessary.

"I think in my opinion they touch on everything and I'm therefore happy with the way it is."

"I am happy with the training the way it is."

Other participants commented on several issues that they felt could be improved on, included, or elaborated on in their training. These included

1. The provision of more training in palliative care
2. The provision of more training in home-based care/ nursing and first aid (i.e. general medical issues)
3. The provision of more training in counselling
4. A need for training in the community itself
5. The provision of training related to working with children. Children are also affected and are suffering as a result of illness and disease, and bereavement-related issues.

5.6. IDENTIFIED NEEDS OF THE CLIENTS

This thematic unit attempts to capture some of the identified needs of the clients of the Tapologo HIV/AIDS programme, as discerned from the data. For the purpose of this study the identified needs of clients have been incorporated and included in to two sub-themes, these include 'Practical Needs: Physical and Biological Needs' and 'Psychological/ Emotional Needs'.

5.6.1. Practical Needs: Physical and Biological Needs

According to the data, several identified physical and biological needs of clients included very practical care for the needs of clients, such as: bathing, house-keeping chores, cooking (nutritional needs), education and assistance in terms of taking medication (Antiretrovirals) correctly, and financial needs and concerns.

Clients may not be well enough to care for their needs on their own, or have family members to assist them when reaching the terminal stages of their illness (van Dyk, 2001). Thus, the provision of practical needs, such as those listed above, is often beneficial to both the

terminally- ill client, and his or her family. In a report published by the Department of Health (2001), "National Guideline on Home-Based Care and Community-Based Care" several similar identified practical needs of clients were identified. These included "personal needs" such as physical/biological (medical) needs; "environmental needs" which incorporated factors such as the client's physical environment and social environment; "life style needs" which include factors such as nutrition, exercise and rest, personal habits and sexuality, recreation, household chores, and shopping (Department of Health, 2001, p. 30). It is evident from the results that at the Tapologo HIV/AIDS programme these practical needs are being met on a number of levels by the home-based caregivers.

5.6.2. Psychological/Emotional Needs

Several key psychological/ emotional needs were identified, which included:

1. The provision of emotional/psychological support and or spiritual support in order to help clients come to terms with their illness and, or loss (acceptance).
2. Assistance in educating (psycho-education) and facilitating acceptance within the family (i.e. overcoming stigmas affiliated with the client's condition).

According to the literature, being diagnosed with a chronic and, or terminal illness can be very taxing emotionally, psychologically, as well as socially, on both the client and the family members of the client (Gwyther & Marston, 2003; Knott, 2003). Clients affected by illness and disease may be emotional, anxious, and even depressed (Department of Social Development, 2003). High levels of psychosocial distress including denial, blame of others for the infection, and hopelessness regarding the future are also often associated with psychological symptoms (Kaleeba, Kalibala, Kaseje & Ssebbanja, 1997). From the data, it is apparent that *acceptance* appears to be a primary psychological and emotional need of both the client and his or her friends or family. According to Kübler-Ross's theory of death and dying, the first response of clients facing death and dying, is denial where the client or significant others finds it difficult to consciously deal with their "loss" (van Dyk, 2001; Poss, 1981). This is similar to Worden's tasks of mourning, in which the first tasks to be accomplished is the "acceptance of the reality of loss" (Worden, 1993, p. 22). Kübler-Ross urges that this is a temporary response and is a healthy initial reaction to an uncomfortable

and painful experience (Poss, 1981). Nevertheless, it is important that it is successfully worked through so that more healthy defenses emerge, allowing the client to confront the situation, instead of forcing them to avoid it (Worden, 1993).

Finally, whilst AIDS bereavement can, and often does, follow the stages or task of normal grief, there can be differentiating factors which can increase the possibility of complicated bereavement occurring, therefore resulting in the issues of acceptance being more difficult to master. Differentiating factors may include issues such as: the stigma associated with HIV/AIDS; homophobia and the isolation of these populations; multiple loss of friends and family members to HIV/AIDS; increased suicidal ideation statistics associated with HIV; and increased alcohol and substance abuse associated with HIV/AIDS-affected populations (Knott, 2003). The stigma associated with HIV/AIDS serves to complicate the grieving process dramatically, making it difficult for clients and loved ones to accept the disease, thereby often fixating them within the denial phase of loss and bereavement (Shaw, 1992).

5.7. THE TYPES OF SERVICES OFFERED BY THE HOME-BASED CAREGIVERS

The thematic unit 'the Types of Services Offered by the Home-Based Caregivers' aims to address and comment on some of the identified services that are provided by home-based caregivers working within the Tapologo HIV/AIDS Programme, at Boitekong and Phokeng. For convenience sake this thematic unit has been divided in to two sub-themes, 'A General Overview of Services Offered' and 'The Psychological/Emotional Services Offered'. The emphasis for the purposes of this study will be primarily on the latter, as this is the primary focus of the research.

5.7.1. A General Overview of Services Offered

From the data it is implied that most of the services provided by the home-based caregivers within the Phokeng and Boitekong site of the Tapologo HIV/AIDS programme, are offered within the context of the client's home environment and community setting. Home-based caregivers therefore are required to make home-visits, where home-based nursing is provided, and if they cannot cope with or manage the client they bring the client to a local

community clinic. Furthermore, within their capacity as homecare nurses, it was suggested from the data that they may also be required to offer services to clients' families, for example, teaching them about how they can assist and care for their relatives basic hygiene, medical needs and emotional needs and so forth. Teaching client's families was also seen to help alleviate some of the Home-Based Caregiver's workload. These findings were evident from the following statements:

"We see and care for them (the patients) in their homes".

"We take them (the patients) to the local clinic."

"…things I teach to the family and the children with which they stay because I cannot be able to go there everyday. It is necessary for them to take care of the patients' health and the love is as important. It makes them feel better."

"We also teach the family on how to take care of the sick, we build relationships between the family and sick i.e. practical skills and make sure that they accept the sick and understand their condition."

Home-based caregivers can also be seen to play a fundamental role in assisting with the provision of medical services, which may not necessarily be administered within the home but at the Boitekong or Phokeng sites/clinics themselves. These services may include the administration of blood tests, taking client's blood pressure, the provision of medical treatment, and ensuring that client's receive regular check-ups with the local General Practitioner. Home-based caregivers also appear to provide clients with assistance with managing their homes, such as cooking and cleaning, and social support and guidance, for example assistance with grants, funeral arrangements and so on. These findings were suggested from the following:

"Tuesday is doctors' day and on Thursday the pricks (i.e. those who come for (blood) testing.)"

"(we) ring them to the doctor, check if they take their medication (ARVs etc.)."

"…If there is no food we try and buy some and if the food is there but not cooked we cook it and try to make the patient eat and drink, then bath and dress the patient, do some washing, clean the room in which they are sleeping and wash the dishes…"

"…explain to them where to collect grants"

"We also get hold of the burial society and ask the family to give their contact details so that should something bad happen to the patient, they know who to contact and who will assist the patient's children"

These results seem to be in line with the policies stipulated by the Department of Health (2001), which suggests that Home Based Care needs to essentially aim to empower individuals and communities, by ensuring them access to comprehensive services and support. By offering clients and loved ones practical, medical and social support within their home, and by directing them to local clinics or initiatives when necessary, it can be argued that the home-based caregivers working within the Tapologo HIV/AIDS programme at Boitekong and Phokeng are empowering both their clients and community, and that their objectives are in keeping with the policies stipulated by the Department of Health (2001). The role of home-based caregivers is essentially deemed to provide preventative care; basic care (primary health care); rehabilitation; hygiene and safety; health promotion; emergency care; education; and referrals (Department of Health, 2001; Russel & Schneider, 2000), and the home-based caregivers at Boitekong and Phokeng can be seen to be providing these services.

5.7.2. Psychological/ Emotional Services Offered

All of the participants (100%) reported that they provide some sort of psychological and emotional support to their clients. From the data, it was evident that the types of emotional and psychological support provided include: being supportive; using basic listening skills; establishing trust and rapport; ensuring confidentiality; and being empathic. It was also observed that home-based caregivers attempt to provide psychological and emotional services utilizing a 'step-by-step' approach, respecting their clients' needs and feelings, and if they are unable to deal with a particular client, for whatever reason, they refer them out usually to the social worker. These findings was suggested from the following statements:

"We then counsel them because as a carer one should have counselling skills. We let them speak out their feelings and we then deal with their feelings. For example, by talking about and sharing their feelings-it helps them to accept."

"They need love, someone who can help them to be fair and honest with all those things- openness and listen to them."

"If the patient is hurt, I talk to them until I see that they have overcome the anger."

"I counsel them more especially when they loose hope, I tell them that this disease is not so terminal- they will still live longer."

"This cannot be dealt with in one day, you kind of divide the days and counsel the patients about the feelings they have and then the following week you take another step meaning that it is a step-by-step process until one wins them."

 "Usually we divide our work and give to social worker the cases we are unable to resolve."

Invested within their counselling skills it was also evident that the majority of the home-based caregivers utilize a strong spiritual component. Perhaps this is because their investment in the programme is primarily run under the auspices of the Catholic Church.

"Sometimes we read through the bible and we discuss it and they talk and tell me about their feelings"

 "If they are emotionally down we give them something spiritually uplifting to make them "feel better. There is no cure for AIDs but you tell the patient about God, that he is helpful and that Jesus is there for us. When Jesus was on the cross, like him we also hope that someday we will go there, we will not live forever."

Some indication for pre-and post-test counselling was also evident, as was the therapeutic technique of psycho-education. This may involve answering clients' questions and responding to their fears in an educational and factual manner in terms of their condition (psycho-educational).

"…you start with counselling them and they agree (for) you take them for a test and continue counselling them. They are then put on treatment, and after that counselled again."

"Before we can take blood from the patients, we counsel them and seek their permission"

"Sometimes they ask us where the HIV/AIDS disease comes from and how they got infected and we have to explain that it is contaminated in many ways, through needles, injection, if one has a scratch and another person gets close to them and they are positive. They also want to know what is going to happen when they die."

In terms of the manner in which these services are offered it is evident that psychological and emotional support is offered to clients by the home-based caregivers on both an individual and group basis. However, despite both individual and group support being offered, it is evident that the provision of psychological and emotional support was offered primarily on an individual basis. Nine of the participants reported only offering individually-based support, none offered group support work only, and seven said that they used a combination of both. This may be because of confidentiality, as suggested by one participant.

"I encourage them to go for the support group which we have every Tuesdays and where we give them spiritual support."

"To both individuals and the groups. We talk about the ARVs , the treatment and how they must help each other. Support groups are run for an hour on average."

"There are those things you cannot, however, discuss in a group setting and you then take the patient aside."

From the results it is suggested that the home-based caregivers have been equipped with basic counselling skills, such as the provision of empathy, active listening skills, establishing confidentiality, and establishing boundaries (Brems, 2001). The provision of basic counselling skills and psycho-education can be seen to be in keeping with the general aims of HIV counselling, in which the primary aims are to promote the prevention of HIV transmission, and to support those affected directly and indirectly by HIV (Sims & Moss, 1991). The provision of pre and post-test counselling is also beneficial, especially in a context such as South Africa in which there are limited resources, and thus, the provision of counselling services and support programmes are often required to be brief, rather than long-term (Knott, 2003). Finally, it was also suggested from the results that the issue of "acceptance" is prevalent. The provision of emotional and psychological support can therefore be argued to largely centre on getting clients to accept and acknowledge their illness, utilizing various counselling skills and, or spiritual support.

5.8. THE PROVISION OF PSYCHOLOGICAL AND EMOTIONAL SUPPORT TO THE HOME-BASED CAREGIVERS

Fifteen of the participants interviewed acknowledged that they found their work within the Tapologo HIV/AIDS programme emotionally draining, whilst 1 reported that they did not. The thematic unit 'Provision of Psychological and Emotional Support to the Home-Based Caregivers' has therefore been conceptually defined to incorporate and identify some of the coping styles, skills, and support that are employed and utilized by the home-based caregivers, in order to deal with their work. The results of the present study indicate that the home-based caregivers utilize and rely on support from both within and outside programme. For this reason, this thematic unit has been sub-divided in to two sub-themes; 'Provision of Support From Within the Programme', and 'Provision of Support External to the Programme'.

5.8.1. The Provision of Support Within the Programme

This sub-theme aims to encompass and identify some of the support mechanisms utilized by the Tapologo HIV/AIDS programme in order to help and assist the home-based caregivers cope with the stressful and draining nature of their work. Identified key providers of support within the programme included; the social worker/s, the counsellor/s from Lifeline, the sister/s in charge, the church, supervisor, and colleagues. Some participants also commented on the lack of or absence of support all together. Table 5 gives some indication as to how the internal services provided by the programme are being used, for example eight out of 16 participants acknowledged relying on and using the social worker/s for support.

Table 4: Internal Types of Support

Type of Internal Support	Frequency
Social Worker	8
Sister in Charge	5
Church	4
Counsellor at Lifeline	3
Supervisor	3
Support From Colleagues	3
No Internal Support	2
Total	28

(The total exceeds 16 because of the possibility of multiple responses being given by each participant).

From this table, it is evident that the majority home-based caregivers rely on social workers for support, then the sister in charge, and next the church. The utilization of the counsellor at Lifeline, supervisor and support from colleagues at work all appear to be utilized equally.

i) Support from the Social Worker(s)
Although several participants identified the social worker(s) as being their predominant means of support within the programme, it was also evident from the data, however, that

support provided by the social worker(s) was not necessarily provided on a continuous and consistent basis, and was offered on a group basis rather than on an individual basis. One participant identified that the social worker provides "emotional support", another participant acknowledged that the social worker(s) provides debriefing. The provision of some degree of psycho-education and the passing of knowledge from the social worker(s) was also indicated. These findings were suggested from the following statements:

"...and go to the social worker and talk and also to get support."
"It's only that some days a social worker comes and talks to us and we feel better."
"If one's problem is critical then they talk to them individually but she usually speaks to us as a group because we are many."
"The social worker is giving us emotional support to deal with the patients' needs."
"We speak to the social worker who also gives us some debriefing."
"She (the social worker) also gives us pamphlets to read on our own."

ii) Support from Lifeline

The provision of support from counsellors at Lifeline was also indicated in the data. According to one participant, one particular sister mainly provides counselling to home-based caregivers at Lifeline. It was also indicated that an opportunity is provided at Lifeline for home-based caregivers to ask questions and receive supportive advise on various issues pertaining to their work, for example, counselling issues. This support can perhaps be seen to be more psycho-educational. These findings were indicated by the following statements:

"Through counselling from Lifeline…"
"...and when we go to this on-going training (at Lifeline) we pose the questions to the lecturer(s) and listen to what they advise us to do."

iii) Support from the Sister(s) in Charge and Programme Supervisor

Emotional support and debriefing sessions can also be seen to be received from the sister/s in charge as well as the programme supervisor. The supervisor's role was to oversee that the home-based caregivers receive emotional and psychological support and that their needs are met in this regard. Supervision and debriefing was also observed to be provided to the home-based caregivers by their supervisor. These findings were indicated by the following statements:

"We also get debriefing from Sister...."

"If I feel a situation is worse for me, I call my supervisor to deal with it because sometimes the patients are not the same, others are difficult, stubborn and unmanageable and it really sometimes becomes hard... you ask for assistance and support from the supervisor."

iv) Support from the Church

The role of the church and spirituality also could be seen to serve as means of support within the programme. Several participants commented directly on utilizing their spirituality in order to help them cope, and emotional support offered by the priest from the Catholic Church was also indicated.

"We get healed through our spirituality and religion."

"...and once every three months we meet at Phokeng...they know how to help us so as to be able to help ourselves."

v) Support from Colleagues

Support from colleagues also seemed to be a pertinent theme. This was suggested from the following statements:

"So we talk to other Home-Based Caregivers and not to people outside."

"...talk to other carers and feel better thereafter."

vi) A Lack of Support

Finally, of the participants interviewed 4 claimed that they did not receive support within the programme. One participant argued that the internal support was insufficient and had declined in recent times. Another participant commented that more debriefing was required, especially given that the debriefing appeared to be offered on a group basis rather than on an individual basis. However, it was also simultaneously acknowledged that offering individual debriefing session was difficult due to time constraints. This was indicated by the following statement:

"Not much, we used to get from A, who was our counsellor, and Sr N who was our teacher but we do not get it these days, I don't know whether they are busy at the Hospice."

"...people do come to us, sometimes every month or every alternative month, but I still think we need more debriefing."

"The debriefing is not offered on an individual basis but is to a group and that is why I say we need more."

"Even if there is one particular homecare nurse that is struggling a lot, they would not be able to talk to her alone because of time constraints."

The provision of adequate support to home-based caregivers within Home Based Care programmes is not only vital to the home-based caregivers themselves, in terms of preventing stress, burnout and or secondary trauma, but it is also important to the sustainability and success of the programmes (Montgomery, 1993; Muldary, 1983; Maslach, 1982; Ross, Greenford & Bennett, 1999; UNAIDS, 2002a; van Dyk, 2001). Support needs to be provided on both a personal and organizational level (van Dyk, 2001). Liaison with supervisors, colleagues and so forth are all important. Working within a multi-disciplinary team and supporting one another is an effective way of preventing stress and burnout. More formalized methods such as debriefing and supervision sessions are also important at an organizational level, if home-based caregivers are not to be at risk of burning out. The Tapologo HIV/AIDS programme appears to offering a number of services in terms of providing their home-based caregivers with support. However, there does seem to be some areas for improvement. For example, the social worker(s) could perhaps offer their services on a more consistent and continuous basis, and more debriefing sessions could be useful on either a individual or group basis.

5.8.2. Provision of Support External to the Programme

This sub-theme aims to encompass and identify some of the types and methods of support utilized by the home-based caregivers outside of the Tapologo HIV/AIDS programme. Table 6 depicts how participants' utilize various types of external support systems are utilized, for example 6 out of 16 participants commented on utilizing and relying on support from friends.

Table 5: External Types of Support

Type of External Support	Frequency
Support from Friends	6
Support from Family	8
No External Support	7
Total	21

(The total exceeds 16 because of the possibility of multiple responses being given by each participant).

From this table, it is evident the participants primarily utilize and rely on support from their family members, then on no external support at all, and finally on their friends. A major contributing factor to participants not seeking any external support seems to be related primarily to the issue of confidentiality. Participants even commented on relying on themselves for support because of this issue. The following statements indicated these findings:

"Nothing, it's confidential. I don't like to trouble others with my work."
"We do talk to friends but one has to be very careful because these are confidential issues.
"...I also counsel myself"

It is interesting to note that participants from Boitekong were inclined not to seek external support outside of the programme compared to their colleagues at Phokeng, who were willing to seek support outside of the programme. Perhaps this is related to different supervising methods, and a different emphasis being placed on whom one is able to rely on for support and whom one is not. Participants at Boitekong seemed to be especially concerned about confidentiality issues in terms of seeking support external to the programme, and perhaps their understanding and training on the meaning of confidentiality has been different to those participants at the Phokeng site.

According to van Dyk (2001) personal support systems outside of work are just as important as support at an organizational level. Sharing experiences can be seen as cathartic in nature,

relieving stress, burnout and or secondary trauma (Knott, 2003). The fact that some participants at Phokeng and Boitekong are not seeking support outside of their work, can therefore be seen to be relatively problematic, increasing their risk of stress, burnout and or secondary trauma.

5.9. IDENTIFIED ISSUES OF CONCERN WITHIN THE PROGRAMME

This thematic unit aims to incorporate some of the weaknesses and or issues of concern within the programme as identified by the participants of the study. Identified issues of concern included:

1. Unmanageable workloads. A recent general increase was recorded in the data because of the added task of home-based caregivers managing patients ARVs.
2. Finances and incentives. Participants complained of being unable to sustain themselves on the incentives received.
3. Transport. Several participants commented on having to visit patients on foot.
4. Poor communication between the participants and management/ NGO.
5. A general lack of resources.

According to the theory on stress and burnout, often it is these very issues which are regarded as contributing to stress and burnout (Gilliland & James, 1993; Montgomery, 1993; Muldary, 1983; Maslach, 1982; Ross, Greenford & Bennett, 1999; UNAIDS, 2000a; van Dyk, 2001; WHO, 2002). Workloads in this field are often very demanding, and home-based caregivers frequently experience stress due to the lack of space and privacy in their work especially given that they are located within the community (van Dyk, 2001). Furthermore, home-based caregivers themselves are most often faced with issues of poverty, volunteering their time for a minimal incentive (Knott, 2003; van Dyk, 2001). The result is that home-based caregivers bare an enormous financial burden, which subsequently may result in stress and or burnout. Poor communication between different organizational levels such as the home-based caregivers and the management of the NGO, may also result in home-based caregivers feeling frustrated, stressed and or burnt out (van Dyk, 2001). A general lack of resources in general can be seen as overbearing and tiresome, in circumstances that are already taxing and difficult.

5.10. IDENTIFIED STRENGTHS WITHIN THE PROGRAMME

This thematic unit aims to incorporate some of the strengths of the programme as identified by the participants. Several participants acknowledged a strength of the programme being its capacity and ability to reach and service a greater number of people within the community than might otherwise be possible. One participant commented on this factor providing patients with a sense of dignity and worth, and the fact that home-based caregivers working within the community are able to facilitate family cohesion. They are able to help the family to deal with their ill family member better, and also look after them. These findings were suggested from the following:

"I saw many patients suffering outside with no support from their families and wanted to help. They could not go to the clinic -no see the nurses as they are far away from them. I therefore felt sorry for them and decided to volunteer."

"We are able to give help to people who have been neglected...because we have been discharging people to homes and we never made any follow-ups. So I would say for us to be doing this home-based care has been a blessing to the patients because we are able to make follow-ups in peoples' homes."

"Our people now die with dignity. They also feel that even if they are sick, they are still needed, we still consider them as part of us."

"...I would say that is good because sometimes the person does not want to open up to the family member, they have more trust on the carer. Sometimes you find that there are family disorganszations, and then as Home-Based Caregivers we are able to hold some family meetings in order to unite the family. I've seen that to be very good because some patients are sick not because of the illness alone but from the treatment at home, so it really has a huge impact."

Finally, another identified strength of the programme is that it offers some means of employment to those who are unemployed. This was indicated by the following:

"It is because there is no work and ...felt that it is better to help people."

These strengths can be seen to tie in with the general objective of Home Based Care programmes, which is to empower communities and to ensure access to comprehensive services and support in the presence of limited resources (Department of Health, 2001). It is also interesting to note that the desire for employment outweighs the issues of concern around the minimal incentives. This feature highlights the high unemployment rates in South Africa, and the desperation perhaps of people to earn some form of income in order to survive.

5.11. CONCLUSION

This chapter presented the results and discussion of the study in terms of the home-based caregivers' general working conditions, motivating factors, patients, training received, identified needs of the patients, type of services offered by the home-based caregivers, provision of psychological and emotional support to the home-based caregivers, identified issues of concern within the programme, and identified strengths within the programme.