

CHAPTER 6

CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

6.1. SUMMARY

The primary aim of the study was to determine the type of, and level of emotional and psychological support offered by home-based caregivers within a Home Based Care programme, and to explore the type of issues that home-based caregivers are dealing with on a day-to-day basis. The secondary aim of this study was to evaluate and determine the level of emotional and psychological support that is being offered and received by home-based caregivers themselves within a Home Based Care programme, as well as the type of training that they receive. This study used 16 participants, which was comprised of 9 home-based caregivers from the Boitekong site of the Tapologo HIV/AIDS Programme, 6 home-based caregivers from the Phokeng site of the Tapologo HIV/AIDS Programme, and the programme supervisor (key informant) for the entire Tapologo HIV/AIDS Programme. The semi-structured interview method was the main method of data collection. A qualitative approach to the study was adopted. Thematic content analysis was used to qualitatively analyze and interpret the data, and to elicit and explore as many salient themes and issues as possible.

Several main findings can be reported from this study, and will be discussed in terms of the research questions and aims of the study. The general types of emotional and psychological services offered by the participating home-based caregivers to the beneficiaries/clients of the Tapologo HIV/AIDS Programme included providing emotional support, using basic listening skills, establishing trust and rapport, ensuring confidentiality; and being empathic. Evidence for pre-and post-test counselling and psycho-education was also suggested, as well as a strong spiritual supportive component. Such emotional and psychological support appears to be offered predominantly on an individual basis, although evidence for group support being used in combination with individual support was also indicated.

Issues that the participating home-based caregivers are having to deal with on a day-to-day basis included addressing both the physical and emotional needs of clients, and helping

patients to accept their illness and disease as well as dealing with the subsequent loss/losses. These services and issues are suggested to be predominantly offered within the homes and or communities of clients. The participating home-based caregivers also indicated that they are having to offer such services using limited resources. The main beneficiaries of the programme were suggested to be HIV/AIDS clients.

The type of emotional and psychological support received by the participating home-based caregivers themselves was indicated to be provided from both within and outside of the programme. The provision of support provided from within the programme was suggested to be provided by the social worker(s), the sister(s) in-charge, the church, counsellors at Lifeline, supervisors, and colleagues. The majority of support was suggested to be provided by the social worker(s), then the sister in charge, followed by the church. The utilization of support from the counsellor at Lifeline, the supervisors and colleagues were all suggested to be used equally. Types of emotional and psychological support received by these service providers included general counselling and emotional support, debriefing, supervision, psycho-education, and spiritual support. Emotional support provided outside of the programme included support from family members and friends.

Finally, a holistic approach to training was indicated from the data and included training in counselling, “Directly Observed Therapy Short-Course (DOTS) for Tuberculosis (TB), first aid, home-based care, and palliative care. The types of emotional and psychological training received included the provision of basic counselling skill, psycho-educational skills, and training in self-care. This training was provided by Hospice, Lifeline, and professional nurses.

6.2. CONCLUSIONS

The type of, and level of emotional and psychological support offered by the participating home-based caregivers appears to be appropriate and adequate in relation to the emotional and psychological needs of the clients benefiting from the Tapologo HIV/AIDS programme. For example, through the provision of services such as the provision of emotional support, actively listening to client’s experiences and needs, being empathic, psycho-education, establishing trust and rapport, and ensuring confidentiality, the primary needs of clients such

as assisting them in coming to terms with their loss and acceptance is facilitated. In terms of providing for clients physical needs such as cooking meals for them, it could also be argued that indirectly the participating home-based caregivers are facilitating the process of providing adequate emotional and psychological care for their clients. If a client is hungry or malnourished, for example, s/he may not be receptive to any of psycho-education or counselling services provided.

The provision of emotional and psychological care within the community can be argued to be highly beneficial. Not only does it assist in alleviating the strain on institutional and hospital care, but it also means that a greater number of people are assisted and reached within the community. This is especially important in South Africa where the HIV/AIDS rates have reached epidemic proportions, and where more and more individuals are requiring medical, psychological and or spiritual assistance as a direct consequence.

The type of emotional and psychological support received by the participating home-based caregivers themselves can also be seen to be adequate and appropriate. Evidence for emotional support, debriefing, supervision, psycho-education and spiritual support were all evident, although some participants did suggest that it would be beneficial to receive more debriefing and supervision sessions with such session even possibly being provided on an individual basis rather than on a group basis.

The holistic nature and approach to the training programme for home-based caregivers at the Tapologo HIV/AIDS programme seems highly beneficial. By adopting a holistic approach to training the home-based caregivers at the programme are offered the opportunity to be trained in a diverse range of skills, equipping them for a variety of experiences and or problems. The training in counselling skills in particular also seemed adequate and appropriate. Evidence for training in skills which participating home-based caregivers could use with their clients was evident (e.g, basic counselling skills and psycho-education) as were skills which the participating home-based caregivers could apply to themselves (e.g, self-care). Fourteen of the participants suggested that they perceived their training to be favourable and beneficial, and felt that it adequately prepared them for the work that they do.

6.3. LIMITATIONS OF THE STUDY

Various methodical limitations should be taken into consideration when analyzing this study. Firstly, the sample used was limited by the fact that they reflect the views and opinions of the specific participants involved at the Tapologo HIV/AIDS Programme only, and thus the findings cannot be generalized to all Home Based Care Programmes. This limits the generalizability of the result obtained.

In addition, subjects participated in the study on a voluntary basis meaning that they were not obligated to participate in the study. This may have in turn meant that the voluntary participants provided information that was socially desirable (Rosnow & Rosenthal, 1991). It is therefore possible that the information presented by the participants is biased and not completely reflective of the home-based caregivers at the Tapologo HIV/AIDS Programme, or home-based caregivers in general. It is also possible that participants produced certain responses that were not in accordance with their true experiences as a result of the knowledge that they were part of a study (Hawthorne Effect) (Neuman, 1997; Rosnow & Rosenthal, 1991).

Another limitation is that some of the participants that were interviewed were not fluent in English. It is therefore possible that some of the meaning and essence of the questions asked and the messages conveyed were not conveyed or relayed in their original form, resulting in the loss of meaning. Also, in some cases the researcher had to prompt or even re-word certain questions so that participants could understand what was being asked of them. This may have affected the internal validity of some of the questions, and may also have resulted in the responses not being a true reflection of the participant's experiences.

Despite these limitations, it must be asserted and added that this study generally yielded valuable data pertaining to Home Based Care Programmes within South Africa, and several of the issues that home-based caregivers are currently facing.

6.4. RECOMMENDATIONS

6.4.1. General Recommendations for the Tapologo HIV/AIDS Programme

Several general recommendations were identified by the participating home-based caregivers of the Tapologo HIV/AIDS Programme themselves, and could perhaps be taken in to consideration by the governing body or board, or NGO for future 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.

Perhaps a greater emphasis on the importance of psycho-education should also be stressed. Psycho-education can potentially be used as a measure through which to educate communities about various illnesses and diseases. In the face of the HIV/AIDS epidemic in South Africa psycho-education acts as a vitally important tool in terms of disease preventions and management.

A request for more emotional and psychological support, in terms of debriefing and supervision was also made by the participating home-based caregivers. However, it was simultaneously acknowledged that this task seems difficult to accomplish given the limited resources available. The programme may, therefore, benefit from trying to incorporate other professionals in addition to the social worker(s), such as a psychologist(s), assisting with the debriefing and supervisory needs, and even training.

6.4.2. Recommendations for Future Research

Based on the results of the study, it may useful and beneficial to conduct future research in terms of focusing on the perceptions of the clients of Home Based Care programmes.

Particular emphasis could be placed on client's emotional and psychological needs when faced with a terminal illness or disease, or on family members and significant others needs when having to cope with a loved one facing death and dying. This could potentially be helpful in terms of clarifying the specific needs and perceptions of the clients of these programmes from an emotional and psychological perspective, which in turn could be used to refine the aims and objectives of the training received by home-based caregivers, as well as the emotional and psychological support offered by both the home-based caregivers. It may also assist in refining what emotional and psychological support home-based caregivers require themselves, as it would assist with clarifying what home-based caregivers are having to face and deal with emotionally and psychologically specifically on a day-to-day basis.

Another more general recommendation for future research might include researching whether different models of Home Based Care adopt different emotional and psychological approaches. This could be looked at specifically in terms of the types of emotional and psychological training provided as well as the emotional and psychological services offered to both clients and home-based caregivers themselves. Minimal research has been done in to this field of study in general, and comparing different approaches across the five models of Home Based Care may be useful in terms of determining what is proving to be effective in practice and what is not.