

By deliberately setting up a safe space for the telling of a life story, parents and children can be engaged in using memory work as a communication tool (German, 2006:45). In practice the caregivers do not have time to do this and the help of volunteers could be called upon to assist with this valuable project of memory work. They do encourage their patients to have memory boxes and get their wills and documentation in order. They also encourage members of the community to go for voluntary STD, TB and HIV and AIDS testing, as well as to stick to their ARV programmes. They encourage their patients to go to the clinics on a regular basis for CD-4 count blood tests.

Coordinator

Caregiving efforts need to be coordinated or strengthen communication lines within families, to decrease anxiety and to improve problem solving. Hospice TLC caregivers play a vital role as coordinators. By building a relationship marked by trust, support and coordination of services, the affected family's increased stress levels and sense of disorder could be minimised.

With the TLC caregivers' involvement over the last two years, it is evident that the needs of terminally ill patients and their families have been efficiently addressed. Rendering support on an ongoing basis decreases the patient's and affected family's sense of bewilderment as a result of the trauma of the diagnosis. The caregivers form a valuable link between other resources and members of the multidisciplinary team (Jerant *et al.*, 2004:56).

Mediator

As a mediator, the Hospice TLC caregiver also plays an important role. The HIV and AIDS patients might initially only confide in the caregiver, lacking the courage to disclose to their family, neighbours or the community (Wood *et al.*, 2006:1924).

The mediator helps by facilitating anticipatory mourning, by assisting family members to maintain a sense of mastery, integrity, cohesiveness, identity and open communication lines (Danielson *et al.*, 2007:171).

Communicator

As communicators, the Hospice TLC caregivers play a vital role. Through research it was found that teenagers prefer to be told the truth about the sickness of their parents. In African cultures children are simply told that a person who died "went away". Death is considered an inappropriate topic for discussion with children. Through contact with the affected families they are able to communicate their needs to the appropriate individuals and resources within the community.

Because of the stigmatisation, AIDS-related death is often considered to be a "bad death". People tend to link it in their minds to shameful, unacceptable sex, as well as to moral dangers and the political transitions of modern life.

Within the African context children display a tendency to show signs of internalising grief by falling into a state of depression, withdrawal and failure to thrive. The opposite also happens when children start with acting-out types behaviour by becoming angry, rebellious and disruptive (Wood *et al.*, 2006:1924-1925).

Through their training, Hospice TLC caregivers are equipped to deal with these cultural issues in which certain topics such as death are taboo, as well as to encourage family members to have open communication lines. They are able to identify possible warning signs of children being neglected, abused or made vulnerable because of the impact of the sickness.

The Hospice TLC caregivers have a great sense of loyalty and commitment to the patients and families they deal with. They fulfil the role of collaborator by working together with their patients and families. According to them, it takes an average of 16-18 months to build a strong relationship of trust. All of the caregivers have experienced loss in their own lives, which enables them to show empathy to the people they deal with. They have persevered over the last two years and are presently experiencing a great sense of fulfilment and job satisfaction. They are working as volunteers for an NPO and their main aim is not to work for monetary reward, but to help people in their own communities who are in need. The patients and their families confide in them regarding their fears, doubts and worries. The children bond with them and are glad to see them. They support the primary caregivers. Often a granny is not only caring for the patient, but also for the rest of the family.

To offer realistic hope and relief from anxiety, caregivers need to understand what the sickness means to the family. Ongoing training is necessary in order to increase their knowledge of the needs of the infected and affected people they deal with. They should encourage the family to mobilise their social support network to help relieve strain and stress (Danielson *et al.*, 1993:172-173). The caregivers themselves need support to prevent burnout and compassion fatigue. They experienced the loss of one TLC caregiver during 2007 as a result of HIV and AIDS, which was very traumatic.

The researcher pointed out to them during the focus group sessions that they cannot bear all the responsibilities of support themselves. They need to refer the patients with their affected families to relevant individuals and resources within the community, as suggested by Danielson *et al.* (1993:66).

Living with hope is more positive than constantly thinking of dying of HIV and AIDS. This is the attitude the Hospice TLC caregivers are installing in the people they deal with.

To live with hope means:

- Most people infected with HIV are well and could live a good life some years after being infected;
- During this period adults and children with HIV can live active productive lives;
- They need support, advice and counselling to be able to look forward to several years of normal life;
- The surrounding community should be a source of love, care and support;
- Communities need to be encouraged to realise their potential (Halkett, 2005:81).

Discussion

After the diagnosis of HIV infection, people need help in coping with psychological distress. To live with the condition, receive treatment and deal with the social stigma they need support (Kagee, 2008:249). HIV and AIDS are regarded as stressors. The affected family needs to adapt to the new situation in which they also need support (Danielson *et al.*, 1993:66).

The role of the caregivers working for Hospice TLC would be to give the needed support. This happens through the caregivers gaining entry to the affected families by taking care of the infected patient (Smit, 2007:2). Through palliative care the needs of the patient are addressed (Corr *et al.*, 1999:186). With the *circles of support* (Smart, 2003:43) in mind, the caregivers enable the infected patients together with their affected families to make use of resources

within the community to address their needs and to increase community support for families infected with, or affected by, HIV and AIDS.

CONCLUSIONS

- Through their training, the Hospice TLC caregivers are equipped to render support and care to patients and families infected with, or affected by, HIV and AIDS. This also gives them an appreciation of the research process, resulting in good cooperation between the researcher and the caregivers.
- They act as a valuable link between professional medical staff and the patients and their families. They are able to communicate information at an understandable level. They are also aware of the cultural context in which the patients and families are functioning, enabling them to “come alongside” the patients and their affected families in a meaningful, supportive manner.
- As teachers/educators they can help to clarify misconceptions about HIV and AIDS, and can help to minimise stigmatisation.
- In addressing material needs, they provide regular food parcels, assist with families obtaining relevant grants and educate families with regard to good nutrition and living healthy lifestyles.
- They manage to link up needy families with relevant resources within the community and educate them on the availability of resources.
- They motivate the patients to adhere to the ARV treatment programme.
- They assist with planned orphan care by helping the patients to get all the relevant documentation in order and referring them to the appropriate facilities in the community.
- Memory work does not receive the necessary attention because of the caregivers’ very busy working schedules. Volunteers could be co-opted to assist with doing memory books and preparing memory boxes.
- No support groups are in operation. This should receive attention in future. They could also be run by volunteers.
- Caring for the carers needs special attention to assist them with debriefing and bereavement counselling. They could easily suffer from burnout or compassion fatigue.
- The caregivers have been in the field for approximately two years. They experience a deep sense of loyalty and commitment towards the patients and families they deal with.
- As volunteers they do not work for big monetary rewards. They receive a stipend if it is available. Care needs to be taken that good incentives are in place to keep them motivated to remain in the service of Hospice TLC, Kokstad, e.g. to improve their qualifications, or arranging a function in appreciation of their jobs well done.
- In motivating people for voluntary counselling and testing, it was found that they would rather go for tuberculosis (TB) testing as there are fewer stigmas associated with TB than with HIV and AIDS.
- The caregivers experience that churches are still very judgmental towards people infected with HIV and AIDS.
- After persevering in their jobs for two years as caregivers, they are now experiencing job satisfaction and fulfilment.

RECOMMENDATIONS

Through their training the caregivers have an appreciation of the research project and were thus cooperative. Further training on a regular basis is recommended within the community for them to be able to meet the needs of the families they deal with.

- Material needs are the most prominent and it is recommended that regular food parcels be made available for distribution among needy families.
- As educators, they should continue to help minimise misconceptions and eliminate the stigma within the community, and encourage adherence to the ARV programme.
- Children at risk of being orphaned should be referred to relevant resources and be part of planned orphan care.
- Volunteers could be trained to assist with memory work and support groups.
- Special attention and support should be given to the caregivers to prevent burnout or compassion fatigue.
- From this research it is clear that the Hospice TLC caregivers fulfil a vital role in meeting the psychosocial needs of families infected with, or affected by, HIV and AIDS in the Kokstad area and they should be assisted by being referred to the relevant resources. Therefore it is recommended that the following aspects receive attention through further research:
 - The identification of the bio-psychosocial needs of these infected or affected families;
 - The improvement of service rendering to these families by utilising their circles of support.

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