

# Emotional Distress and Secondary Trauma in HIV positive Professional Caregivers : Coping Strategies

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## The Issue :

Professional caregivers in a palliative care centre have to regularly deal with death and dying. There is a lot of secondary trauma which can cause emotional distress. This distress can be particularly acute if the experiences of the patient are similar to the professional care givers own life experiences.

## Samraksha's Experience:

Samraksha is running palliative care services for people living with HIV since 1997 in Karnataka. In Koppal , in North Karnataka, we have been running a 15 bedded palliative care centre since 2001. In this centre, 1/6 of the staff are themselves living with HIV and about 1/3 of them are affected by HIV. These staff hold various positions- counselor, nurse, other support staff.

In Samraksha's experience, there is a definite benefit in this practice since there is greater empathy between the patient and the caregiver. The caregiver is also able to relate to the life experiences of the patient. But this degree of empathy and identification also causes emotional distress to the caregivers. It is important to acknowledge and address this distress for the sake of well-being of both the patient and the caregiver.

## Reasons for Emotional Distress:

The caregiver may find it difficult to deal with a certain group of patients because it causes him/her emotional distress. This is especially so, if there is a high level of identification with the patient's life and experiences. This identification can trigger anticipatory anxiety about their own health or future.

Patient histories sometimes act as painful reminders of their own experiences and trigger emotional distress.

*Despite many years of working in this field, I still find it very difficult to break news of the death or dying of a parent to a child. - Counsellor at Care Centre*

*I am able to work with most patients, but if the patient is a woman of about my age and I have to tell her family that she is dying, I find it very difficult. When her parents cry for her, I think that this is how my own parents will mourn for me, and I become very emotional. - Nurse at the Care Centre.*

*Sometimes, when I see a patient's wife caring for him, I am reminded of how I cared for my own husband. But we were not able to save him. - Nurse at the Care Centre.*

## Impact of the Emotional Distress :

Emotional distress affects the professional care-giver's capacity for care and in turn, the quality of care for the patient.

It causes a high level of work related stress for the professional care giver which contributes to his/her burnout.

Staff may, at times, consciously or unconsciously avoid or hesitate to interact with patients whom they feel may trigger emotional distress. If this avoidance is not acknowledged, it could lead to gaps in the care process.

*When I started working as a counselor, I would get so disturbed if I saw a patient with a child as a carer. I always thought of how my children would have to care for me. I hesitated to even approach these patients, because I could not control my own emotions. Now, I am more aware of myself. I try to help patients as well as their children, but if at some point, I get overwhelmed by emotions, I hand over the patient to someone else and withdraw to deal with my own distress. - Counselor at the care centre.*

*Even now, when I see some family member grieving, I just can't control my own emotions. I grieve with them. I am trying to be supportive, but sometimes, my own grief overwhelms me and the tears just keep flowing from my eyes. - Nurse at the care centre*

*It is important to identify, acknowledge and support the staff when they are dealing with emotional distress. Otherwise, both the patient's well-being and the staff's own well-being is compromised. - Programme Director of the Care Centre*

## Strategies Adopted by Samraksha to Handle this Issue :

### Supportive Supervision

Supportive supervision is a form of supervision which tries to ensure the well being of **three critical stakeholders – the staff, the patients and families as well as the organization.**

In a care environment, supportive supervision tries to ensure the **optimum quality of care** to the patient, tries to create a **supportive work environment** for the staff and addresses issues which may be causing them distress, and also ensures that the **values of the organization** are upheld and the ethical and **medico-legal responsibilities discharged.**

To help professional care givers deal with secondary trauma and emotional distress, supportive supervision can be provided through the following activities.

### One to one Support

This includes aspects of clinical supervision. It is a space where the care givers can reflect on whether they are being true to the ethics of caregiving, identify and address issues like over-identification or entanglement with patients and making judgments on patients' lifestyle or choices based on ones own life situation. It is also an opportunity to discuss challenges faced with specific patients and alternate strategies for dealing with them.

*"At times, specially if the care givers are themselves affected by HIV, they do link their own life to that of the patient and even make judgements on the patients' life or choices. They may become more directive of the patient and family members. It is perfectly understandable why they do it, but it is important to get them to reflect and recognize when they are slipping into this mode. Otherwise, they cannot stay true to the values of acceptance, non-judgmental attitude and client self-determination." Programme Director at the Care Centre.*

### Encouraging care givers to identify and be aware of their feelings

Activities like journaling where care givers can express their feelings in specific situations either through writing or drawing, can help in being aware of emotional over-involvement, drawing boundaries and keeping the self separate from the patient.

*"I am now coping with my distress in different ways, when I have to deal with a child carer. Rather than think of how my own children will feel after I pass away and get overwhelmed with my feelings, I take that time to tell myself that I have to keep myself healthy. I have to make sure I live till my children grow up, so that they don't face this situation." Counsellor at the care centre*



Journaling

### Case Discussion

Weekly case presentations and discussions are where a multi-disciplinary team discusses the issues – physical and psychosocial- which are affecting the patient and the steps take to address them at the centre. This also becomes another space for the care-givers to evaluate if their own feelings towards the patient or their situation is in any way affecting the care. It helps care givers cope with difficult situations with patients and also facilitates care planning.

*"Having case discussions helps us clarify what kind of feelings and expectations we are having from the patient or family members and how this is affecting care. Earlier, I looked at family members only in terms of what kind of support they were giving the client. Now I have learnt to understand the stress they are themselves going through and look at them also as recipients of care." Counsellor at the care centre.*



Case Discussion

### Grief Meeting

Grief and bereavement meetings after every death at the care centre help the staff in coping. It is a space to express their emotions regarding the patient and the family.

It also gives the staff an opportunity to review the care given to the client and the attempts which were made to ensure the patients' or family members comfort. It becomes a reflective exercise vent their feelings, and also thoroughly review the care, check if there were any gaps, identify reasons for this and develop systems and processes which can address this gap for other patients in the future.

*"It is important to have grief meetings, because when there is a death at the centre, care givers face a lot of stress, frustration and even regrets about what they may see as gaps in the caring process. It is good to express all this, so that they can reconcile with this, else quality of care to other patients will be affected..... Programme Director at the Care Centre*



Grief Meeting

### Conclusion :

It is important to recognize secondary trauma among professional care givers and its impact on the quality of care. Therefore, systems and processes which can help care givers deal with this issue is critical in a palliative care centre.