

Using a Concerns Checklist to explore dimensions of distress in People Living with HIV admitted at a Palliative Care Centre

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The Issue

A multi-disciplinary approach which focuses on physical, emotional, social and spiritual issues is essential for managing Total Pain of People Living with HIV. But often some of the concerns of people living with HIV are missed, and this can lead to gaps in care.

Assessment of concerns, therefore, needs to be done in a systematic manner.

Samraksha's Response

Samraksha has been running Palliative Care Services for people Living with HIV in Karnataka since 1997. Our experience over the years in trying to address Total Pain has shown us that we need to explore the concerns of the patients in multiple dimensions, and a checklist is a useful tool to do this.

Of the different concern checklists that we have used, we found the checklist provided by the National Cancer Survivor Initiative (UK) to be the most helpful. It led to a comprehensive assessment of the patients' concerns which in turn led to more systematic care planning and management.

The Checklist

The original checklist was developed by Macmillian Cancer Support, Department of Health and the National Health Service UK. It has 56 items on six broad dimensions.

This checklist was modified and translated to suit the local context. Modifications included dropping certain items which were not relevant to the local context and adding certain other significant concerns derived from counselling situations. Certain items were split into two or more items, for better clarity.

Samraksha's modified checklist has 67 items which explore concerns on the same six different dimensions. These are explored with the patient at the time of admission by the counselor.

Physical Concerns :	25 Items
Concerns regarding daily living:	15 items
Concerns regarding family:	7 items
Emotional Concerns :	10 items
Spiritual or Religious Concerns:	3 items
Information needs/ lifestyle changes :	7 items

Benefits from Using the Checklist

- It helps in more comprehensive assessment of the patients' concerns and how these were contributing to their distress.
- It helps in prioritization of concerns and planning of care.
- It helps the care team to make linkages between different concerns and how these were contributing to the patients' pain and distress.
- It contributes significantly to the management of Total Pain.



Asha Jyoti Care Centre for People living with HIV, Koppal



Most common concerns identified by a sample of 30 patients at the care centre, during a one month period

Concern	Percentage of patients identifying it (n=30)
Physical Concerns	
Extreme Tiredness	76.6%
Lack of appetite	70%
Dyspnoea	63.3%
Diarrhoea	63.3%
Concerns regarding Daily Living	
Concern about caring responsibility	86.6%
Ability to work	50%
Concerns regarding family	
Concern regarding children	86.7%
Emotional Concerns	
Worry, fear and anxiety	66.6%
Inability to plan for the future	66.6%
Inability to express emotions	60%
Spiritual Concerns	
Not being at peace and regrets about the past	76.6%
Information Needs regarding lifestyle	
Diet and Nutrition	16.7%

Case Story : Understanding Barriers to Treatment

Shivamma, a middle aged women had been diagnosed with HIV seven years ago, but had not been monitoring her CD 4 count at all. She came to the centre with the support of a local volunteer and since her CD 4 was very low, she was immediately started on ART. She had multiple physical symptoms including lack of appetite, problems in sleeping, extreme tiredness and swelling in legs.

Shivamma was worried about how she would take care of herself and also how she would continue her housework. She expressed great motivation to be regular on ART and revealed that she was very concerned about her children's future and wanted to remain healthy and support them. But she also had some concerns regarding her husband, who was not allowing her to take ART. He feared that if both of them were seen taking medicines regularly, his HIV status would get revealed in the community. Despite her many attempts, he refused to let her go and get herself registered and refused to even give her money for travel. She had finally sought the help of a volunteer and come to the centre. She also reported feeling worried and anxious about how she would continue to take ART.

After this major issue was identified, the counselor helped Shivamma come up with alternate support systems who could help her to continue with ART. She identified her natal family, specially her mother and sister as potential supports and resolved to take their help to ensure adherence and regular monitoring. The counselor also helped her come up with strategies for dealing with her husband, should he object to her coming out for her treatment.

Case Story : Understanding Concerns Holistically

Ramappa, a 46 year old man was admitted to the centre with high fever, tiredness and diarrhoea. He was barely able to walk and had to be carried by his family members. Family members also shared that he was prone to extreme fits of anger, where he would fight with his family members.

Ramappa had been recently diagnosed with HIV. His wife was negative. He had two children, a daughter who had got recently married and a son.

After a thorough examination of his physical condition, he was started on ART and the counselor motivated him to follow positive living practices. Sputum test was also positive, and hence he also had to start ATT. These treatment regimens scared him a lot and he was confused about how to follow them and what impact they would have on him. The counselor addressed his confusions and helped him understand the treatment regimen and the need for adherence. The counselor also helped him identify people who could support him in treatment.

Using the checklist, his concerns regarding family were explored. He was worried about the welfare of his wife and children. They had walked away from the joint family after he found out about his status. He felt he would leave them without making adequate provisions to support them. He also revealed that though he and his son were living together, they were not even on talking terms after they had a fight five years ago. Now he was scared that his son will not forgive him and will not look after him when he was sick. Emotionally he reported an inability to plan for anything and a feeling of depression. When his spiritual concerns were explored, he reported that he was not at peace with himself and had many regrets in life. He had a feeling of shame for being diagnosed as HIV positive at a time when his children were grown up and his daughter was married.

After some family counseling sessions, Ramappa was reassured that his son will definitely care for him when he needed it. His son stayed with him at the centre for a few days to reassure him. He was later discharged.

All Names Changed to protect identity of the patient.



Conclusion

Palliative care in the context of HIV needs to involve a comprehensive assessment of multiple issues which are troubling the client. Use of tools like the concerns checklist can help in comprehensive assessment and understanding of hidden concerns. It also helps in prioritization of different issues and more systematic care planning.