Participatory Approach to Assess Patient Experience of Care and its Impact on Quality of Care
Divya Sarma, Sanghamitra Iyengar, Prabhu N Katti, Kamalakshi Kammar, Paramesh Gorkhal and K Sulekha

Background
Palliative care in the context of HIV involves multiple dimensions. Different needs of the patient – physical, psychosocial and spiritual-needs to be constantly assessed and addressed. An understanding of the patient’s experience of care and their assessment of care on multiple domains can give valuable feedback to improve the quality of care.

Samraksha is running Asha Jyoti, a 15 bedded palliative care centre for people living with HIV, in Koppal, North Karnataka. Recently a systematic process of seeking feedback from patients was initiated. This approach was developed in a staff led participatory way.

Methods

Tool Development
A consultation with the staff helped in identifying what they perceived as the critical domains of care which was provided at the centre. After multiple iterations, a list of 11 critical domains of care were finalized.

A feedback form was developed based on these 11 domains, where the patients had to assess their experience of care, on a five point Likert Scale.

<table>
<thead>
<tr>
<th>SL No</th>
<th>Domain</th>
<th>Excellent</th>
<th>Very Good</th>
<th>Good</th>
<th>Average</th>
<th>Poor</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Peace</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Courage</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Belief</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Information</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Acceptance</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Nutritious Food</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Emotional Support</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Pain Relief</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Symptom Relief</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Anxiety reduction</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Support for Family members</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Any Specific Suggestions or Complaints

Feedback Form for Seeking Inputs from Patients

Data Collection
Data is collected from every patient at the time of discharge by the counselors. Family members are also included in the process if they want to be. The counselor reads out each of the domains and asks the patient to rate their experience of care on that domain. If patients seek explanations to understand what constitutes a domain, this is given.

Specific suggestions to improve the services at the centre are also sought from the patients and family members.

Discussion of Data from Patient Feedback

Data Consolidation and Analysis
The patient assessment of services is consolidated on a quarterly basis and shared with the staff. Scores on each domain are discussed and ways of improving these are identified. Ways of incorporating the suggestions of patients and addressing the problems they complain about are also discussed.

Use of Feedback from Patient Assessments to Improve the Quality of Services
Patient assessment of services gave valuable inputs into how the services were received by the patients. It helps staff identify gaps and come up with ways to improve this.

Motivation for Improvement among the Staff
Since the feedback process is continuous, staff understand how certain improvements or good practices is contributing to better quality and see this reflected in the scores. This helps them assess if their practices really contributed to addressing an issue. It also motivates them to continue improvements.

The discussions also allows new staff to understand and appreciate the importance of different practices adopted in the care centre, and motivates them to start adopting them immediately.

Illustration: Improvement in the Domain of Symptom Reduction
The percentage of patients rating the service as Excellent or Very Good on symptom reduction has increased steadily over the quarters. There was a sudden drop in one quarter, caused due to acute shortage of staff and its impact on the service.

During the staff meetings, the centre’s protocol for regular and systematic assessment of each symptom was discussed and the importance of following this protocol was emphasized.

Following this, the care team adhered to the protocol and used this systematic assessment to make more effective treatment planning.

Conclusion
Participatory approach to quality of care which involves the staff in developing the assessment framework, collecting and analysing data has a positive impact on quality of care.

It gives feedback to staff on the quality of care and points to gaps. As staff make efforts to improve the continuous feedback system demonstrates the impact of these improvements.

Since the processes are completely managed by the staff themselves, there is an additional motivation to change, improve and sustain good practices.

Illustration: Improvements on the Domain of Decreasing Anxiety and Fear
The percentage of patients who felt that the service was average or poor when it came to reducing fear and anxiety has been steadily decreasing over the quarters.

An important improvement which was made to was that there was daily assessment of psychosocial concerns using a concern checklist. This helped to understand emerging concerns and address them promptly. It also helped in better planning of the counseling sessions.

Regular case discussions with counseling supervisor also helped counselors in reflection and ensuring that they stayed true to the principles and values of counseling.

Implementing Suggestions made by the Patients
Patients also have the option of making specific suggestions for improving the service at the centre, or sharing some problems which they face. These suggestions are once again consolidated and shared at the quarterly staff meetings. The staff then come up with ways to address the problem or incorporate a suggestion.

Patient feedback helped in making the following changes at the care centre.

Improving the Service
Patient feedback helped in modifying the doctor’s hours at the centre, to allow patients and family members optimum time to consult with them. Feedback also helped in the mobilizing of the support from a local doctor, who volunteered to be available on call for night time emergencies. A counselor was also made available on call.

Changing Practices
Patient suggestions were incorporated to charge the menu at the centre. The care centre was providing wheat rotas as part of the meal. But many patients expressed a preference for the rotis made from locally available millets. This is the food consumed in most houses in the area.

After consultation with the kitchen staff, the weekly menu was changed to incorporate these preferences. Care was taken to ensure that the food is prepared in ways which suited the patients' preferences and also was suitable for the patient to eat in their health conditions (where health problems like oral candida are a constant concern).

Helping staff identify shortcomings in Facilities
Patient complaints/suggestions brought certain shortcomings in facilities to the notice of the staff. The Staff then evaluate the reasons for these shortcomings and make appropriate changes in the centre’s systems and processes to address this.

Samraksha Registered Office
No. 17, 1 Cross, 3 Main, SBM Colony, Anand Nagar, Bangalore 560024.
Ph 080 23534563
Website: www.samraksha.org
E Mail: samraksha@samraksha.org

Samraksha
Asha Jyoti Palliative Care Centre
Old District Hospital
Koppal 583231