QUESTIONNAIRES

Questionnaire 1: Preintervention form

Impact of health awareness campaign in improving the perception of the community about palliative care: A pre- and post-intervention study in rural Tamil Nadu

Form no. ____________________________ Date- ________________

Section A- sociodemographic details

1. Address (house no., street name, village)- __________________________
2. Nearest health facility- ____________________________
3. Mobile no./tel no.- ____________________________
4. Type of family-nuclear/joint ____________________________
5. Name of the respondent- ____________________________
6. Details of family members-

<table>
<thead>
<tr>
<th>Serial number</th>
<th>Name</th>
<th>Age</th>
<th>Sex</th>
<th>Relationship with head</th>
<th>Education</th>
<th>Occupation</th>
<th>Monthly income</th>
<th>Answer to Q12</th>
</tr>
</thead>
<tbody>
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</tbody>
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7. Any other source of income - ________________
8. Annual income – ________________
9. Per capita income- ____________________________
10. Socioeconomic status – __________________

Section B- Need of palliative care in the family and community

B.I Family
11. Presently,
   a) Is any member of the family bedridden?
   b) Is any member in the family unable to go for work for the last 3 months because of an illness?
   c) Does the patient have problems with daily living activities?
12. If yes to any of the above 3 questions then, Is it because he/she is suffering from any of the following illnesses for more than 3 months in last 1 year? If no, then skip to Q.24

<table>
<thead>
<tr>
<th>Heart disease</th>
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<tbody>
<tr>
<td>Lung disease</td>
<td></td>
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<tr>
<td>Cancer</td>
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<tr>
<td>Kidney disease</td>
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<td>Neurological/brain disease</td>
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<td>Arthritis</td>
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<td>Diabetes</td>
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<td>Hypertension</td>
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<td>Congenital disease</td>
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<tr>
<td>Others, specify</td>
<td></td>
</tr>
<tr>
<td>(paralysis/old age-related disease)</td>
<td></td>
</tr>
</tbody>
</table>

13. What medical services are the person receiving now and from where?
14. Are you satisfied with the health services provided?
15. Is the person experiencing unresolved physical symptoms (including problems with pain, breathlessness, sleeping, appetite, bowel, fatigue, nausea, edema, or cough)?
16. How do they manage these symptoms?
17. Does the person have psychological symptoms that are interfering with well-being or relationships?
18. Does the person have concerns about how to manage his/her medication and treatment regimens?
19. Does the person have concerns about spiritual or existential issues?
20. Are you aware that the person has financial or legal concerns that are causing distress or require assistance?
21. Are there health beliefs, cultural, or social factors involving the patient or family that are making care more complex?
22. Do the person/their families get any counseling? If yes, then at what interval?
23. Do you think that patient’s caregiver (family/nonfamily) need to be counseled and to be taught about how to provide better care for the patient?

B. II Community
24. Are you aware of any person in your village who is presently? If no, then skip to Q.29
   a) Bedridden, or
   b) Unable to go for work because of a physical illness or
   c) Not well and needs help in looking after his/her daily living activities? Yes/No
25. If yes, how many such people are there in your village? __________
26. Are they receiving any medical services?
27. Are their families satisfied with the services?
28. Do the persons/their families get any counseling? If yes, then at what interval?

Section C - Awareness regarding palliative care
29. Have you heard about the term palliative care/end of life care/home care for bedridden people/community-based care?
30. If yes, what is the source of the information? If no, then skip to Q.40
31. What are the conditions requiring such care as in Q.29?
32. Who can provide such care as in Q.29?
33. What is the benefit of such care as in Q.29?
   a. Prolongs life
   b. Improves quality of life
Chandra, et al.: Impact of palliative care campaign

c. Reduces financial burden on the family
d. Reduces the stress and burden of care givers
e. Others, specify______________________________

34. Does palliative care helps in solving physical, psychological, social, and spiritual problems?
35. Can palliative care work alongside or could be integrated into existing programs/treatment?
36. What time during the course of such illness as in Q.31, is palliative care needed?
   - At diagnosis/terminal stage/generally available/cannot say
37. In your opinion who can provide such care to these people in your village?
38. Do you think community volunteers can
   a. provide such care
   b. facilitate such care
   c. both
39. Where can these services be provided best?
   - at home/hospitals/community/clinics/don't know
40. Do you think that as a community you can help each other in providing financial/psychological/social support to the needy members of the society?
41. In your opinion who can such compassionate communities exist?
42. If palliative care/end of life care/home care for bedridden people/community-based care services are provided in your village, do you think the people will utilize the services?
43. Are you interested in knowing more about palliative care/end of life care/home care for bedridden people/community-based care?
44. Would you like to be a volunteer for such services in your community?

Questionnaire 2: Postintervention form

Impact of health awareness campaign in improving the perception of the community about palliative care: A pre- and post-intervention study in rural Tamil Nadu

Form no. ____________________________ Date - ___________________

Name of the respondent-

Address-

1. Did you or your any family member attend the health awareness campaign conducted recently in your village about palliative care?
   If No, then give reason-
2. Have you heard about the term palliative care/end of life care/home care for bedridden people/community-based care?
3. If yes, what is the source of the information? If no, then skip to Q.13
4. What are the conditions requiring such care as in Q.2?
5. Who can provide such care as in Q.2?
6. What is the benefit of such care as in Q.2?
   - f. Prolongs life
   - g. Improves quality of life
   - h. Reduces financial burden on the family
   - i. Reduces the stress and burden of caregivers
   - j. Others, specify______________________________
7. Does palliative care helps in solving physical, psychological, social, and spiritual problems?
8. Can palliative care work alongside and could be integrated into existing programs/treatment?
9. What time during the course of such illness as in Q.4, is palliative care needed?
10. In your opinion who can provide such care to these people in your village?
11. Do you think community volunteers can
   a. provide such care
   b. facilitate such care
   c. both
12. Where can these services are provided best?
   a. at home/hospitals/community/clinics/don't know
13. Do you think that as a community you can help each other in providing financial/psychological/social support to the needy members of the society?
14. In your opinion can such compassionate communities exist?
15. If palliative care/end of life care/home care for bedridden people/community-based care services are provided in your village, do you think the people will utilize the services?
16. Are you interested in knowing more about palliative care/end of life care/home care for bedridden people/community-based care?
17. Would you like to be a volunteer for such services in your community?

Prompt sheet: Issues to consider during interview

Physical symptoms

Does the patient present with unresolved physical symptoms such as drowsiness, fatigue, dyspnea, vomiting/nausea, persistent cough, pain, edema, constipation, diarrhea, sleep problems, or loss of appetite?

Activities of daily living
   • Is the patient having difficulty with toileting, showering, bathing, or food preparation?
   • Is there a caregiver to assist the patient?

Psychological
   • Is the patient experiencing sustained lowering of mood, tearfulness, guilt or irritability, loss of pleasure, or interest in usual activities?
   • Is the patient experiencing feelings of apprehension, tension, anger, fearfulness or nervousness, hopelessness, or a sense of isolation?
   • Is the patient requesting a hastened death?

Spiritual/existential
   • Is the patient feeling isolated or hopeless?
   • Does the patient feel that life has no meaning or that his/her life has been wasted?
   • Does the patient require assistance in finding appropriate spiritual resources or services?

Financial/legal
   • Are there financial concerns relating to loss of income or costs of treatment, travel expenses, or equipment?
   • Is the family socioeconomically disadvantaged?
   • Are there conflicting opinions between patient and family relating to legal issues such as end-of-life care options and advance care plans?
   • Is the patient or family aware of the various financial schemes available and do they need assistance in accessing these?

Health beliefs, social and cultural
   • Does the patient or family have beliefs or attitudes that make health care provision difficult?
   • Are there any language difficulties? Does the patient or family require a translator?
   • Is the family preventing information about prognosis from being disclosed to the patient?
   • Is the patient or family feeling socially isolated?
   • Does the family live more than 50 km from the primary service provider?