

Community Readiness to Support Palliative Care Services : An Exploration in Raichur

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Background:

The experience of Kerala has demonstrated the importance of community in establishing a support system for people living with chronic illness and their families. Karnataka's new palliative care policy also stresses on this and as the first round of implementation is about to begin, it is important to understand community's attitudes and understanding regarding chronic illness and their readiness to support affected people and families. This will help in developing appropriate community engagement strategies.

Study Objectives :

This study seeks to assess community readiness to support palliative care through an exploration of the ways in which community members were currently supporting people living with life limiting conditions and their family members,.

The study was undertaken in Raichur district which has been chosen for the first round of implementation of the palliative care policy by Samraksha, an organization with over two decades of experience in community work and HIV care and support.

Findings :

Communities understand the multiple kinds of distress which are faced by those with chronic illness and their families – Physical, Psychosocial and Economic

In all villages, community showed an understanding of how chronic illness affects the patient and family- not just the physical pain and distress but also the emotional distress and also the economic vulnerability of the family following the onset of chronic illness.

Communities are willing to support people with chronic illness and their families

In all villages and across different groups, community members affirmed their willingness to support people with chronic illness and their families. They also shared about instances of having supported people in the past. However, there was not yet a systematic mechanism which ensured support for such people and families, and communities need capacity building and mentoring support in order to be able to develop such systems .

Patients with life limiting conditions and their carers have benefited from the support extended by community

60% of the patient interviewed reported having benefited from different forms of support from the community. 20% of the patients said they received emotional support from community members, 20% said they received support during crises and emergency, and 20% said they received some support in care. 42% of the carers also reported having benefited from community support.

Methodology	
Sample Size	Five Villages in Raichur District
Sampling Method	Purposive Sampling. There was an equal representation of villages near the taluka centre and villages in remote location and one village with a predominantly tribal population.
Data Collection Methods	
Focus Group Discussion	12 discussions across five villages involving 117 participants with separate discussions with men and women in each village.
Interviews with people living with Chronic Illness	24
Interviews with carers of people living with chronic illness	21
Interview Respondent Profile : People living with Chronic Illness	
Men	14
Women	11
Carers of People with Chronic Illness	
Men	3
Women	18
Conditions of the Respondent	
Paralytic Stroke	4
Orthopedic Problem	7
Cancer	4
Coronary Problem	3
Renal Problems	5
Hypertension	1

Instances of Community Support : Emotional Support and help in seeking services

My friends and neighbors have been very supportive. When I was very sick, they helped take me to the doctor. They keep asking about me and encouraging me to take treatment. I go regularly to Bangalore for treatment.....Venkatesh, 49 year old man suffering from heart problem



Instances of Community Support : Economic Support

People have given us loans whenever needed. In fact, once they made a collection in the village and gave the money to my brother and me for my sister in laws treatment. But we said no need and managed it ourselves. Mariyamma, caring for her sister in law with renal problem.

Instances of Community Support : Caring in the absence of care giver

When I am not at home, then neighbors come and look after my sister in law. They call me if she suddenly is feeling unwell.... Mariyamma, who is caring for her sister in law with kidney problem.

There is a man who has stroke near our centre. His child is coming to our Anganwadi centre. In the afternoon, when his wife is out for work one of us go him and gives him food and whatever he needs..... Sunita, Anganwadi teacher in Gandhinagar

Instances of Support : Supporting the Carer

Earlier, he used to manage his daily work independently, but of late, he is not able to do that. So I have to bathe him and clean him. I find it difficult to lift him up, so the neighbors come and help me. Daily, we ensure that he is clean. Yankamma, 54 year old woman, caring for her husband with cancer

Ever since he got stroke, someone has to look after him. My son has also started living separately now so its only me. I stopped working in the fields and work in a house nearby. My neighbors help when I am out working.... Ramjanbi, 51 year old woman caring for her husband with stroke

Conclusion

This study shows that community based support systems for people with chronic illness is feasible in other areas with widely different development context compared to Kerala. But communities need capacity building and mentorship in order to develop ongoing systems of support. Recognizing and building on these community based systems of support has to be a critical part of the implementation of the palliative care policy.