

Assessment of Psychosocial Distress among the Palliative Care Patients in Wardha District of Maharashtra

Nikhil Dhande, Sunil Kumar¹, Ashwini Bolane²

Departments of Community Medicine and ¹General Medicine, Jawaharlal Nehru Medical College, Datta Meghe Institute of Medical Sciences (Deemed to Be University), ²Department of Kaumarbhrtya, Mahatma Gandhi Ayurved College, Datta Meghe Institute of Medical Sciences (Deemed to Be University), Wardha, Maharashtra, India

Abstract

Aim: Palliative Care Outcome Scale (POS) is one of the various tools, available for the evaluation of the effectiveness of palliative services, having 10item multidimensional questionnaire, designed to assess the physical, psychosocial, spiritual, and practical aspects of patients with various sufferings. In this study, we had assessed psychosocial distress among the patients of a palliative care clinic of a rural teaching hospital at Wardha district. **Methods:** In this cross-sectional study, a total of 118 patients attending the palliative care clinic under the medicine department were enrolled between July 2018 and March 2019. POS has 10 questions in Likert type of scale with a scoring of 0–4, 0 for no effect to 4 for overwhelming effect. Each question provides the information regarding how the patient feels in the past 3 days. **Results:** In the first assessment for anxiety about illness or treatment, 32% of the participants reply that they occasionally feel the anxiety, whereas the same reply has been given in follow-up assessment by 34% of the participants, with an average mean score of 1.59 and 1.31, respectively. Approximately 48% of the participants feel that their family or friends were occasionally anxious and worried for them in the first assessment of POS compared to follow-up assessment where the feeling has been changed with approximately 46% for not at all anxious or worried followed by 39% occasionally. **Conclusion:** Participants were satisfied and accepted the palliative care treatment provided by the team with frequent visits, and also, the level of improvement fastens.

Keywords: Distress, palliative care, psychosocial, rural center

What is already known about the topic?

Most of the states in India, especially in rural areas, lack palliative care and also palliative care providers in the form of physicians and nurses.

What this paper adds

The anxiety and fear related to critical illness releases as soon as they get more information and explanations from palliative care clinical team members, as psychosocial distress was assessed in the form of pain, feelings affected by other symptoms, anxiety about illness, family or friends anxious or worried, information given to patient, sharing feelings with friends or family, depression, and feeling good about themselves.

Implications for practice, theory, or policy

- Evidence are needed for guidance and better decisions regarding symptom management, decision-making

approaches about treatment options, different health-care models, and communication on sensitive topics such as death and support for caregivers, especially closed family members

- The studies help to modify the future treatment and management approach for the effective implementation of palliative care services, as this improves the quality of life of patients through prevention and relief of all forms of suffering, including psychological distress, by means of early identification, assessment, and treatment.

Address for correspondence: Dr. Sunil Kumar,
Department of Medicine, Jawaharlal Nehru Medical College, Datta
Meghe Institute of Medical Sciences (Deemed to Be University), Wardha,
Maharashtra, India.
E-mail: sunilkumarmed@gmail.com

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INTRODUCTION

Palliative care works in four domains starting from physical, emotional, spiritual, and psychosocial which improves the emotional to physical suffering, strengthening of doctor–patient communication, an assurance of continuous coordinated care through hospital wards, indoor patient department, outdoor patient department, and home care services so as to maintain the well-being of person living in that critical life-limiting condition.^[1,2] Concept of palliative care has been introduced in India in the mid 1980s, and from then the palliative care services started developing in the form of hospitals, palliative care clinics, hospice through deep, hard and non-profitable efforts of committed peoples from different parts of society such as health professionals and national international organizations. A multimethod review identified 138 hospice and palliative care services in 16 states and union territories.^[2]

The quality of life of patients in palliative care improves with time, emotional support, good communication, and an essential treatment to get relief from sufferings, pain, and other problems and strengthening of family relationships. Chemotherapy, radiation therapy, and different investigations help in the management of distressing sufferings in a better way.^[2,3] Evaluation of psychological problems in palliative care is challenging. Physical symptoms such as fatigue, pain, gastrointestinal symptoms, changes in sleep and appetite, concentration, and energy are common in palliative care and are also used to diagnose traditional categories, such as depression.

Various tools are available for the evaluation of the effectiveness of palliative care services. Palliative Care Outcome Scale (POS) is one of them, having 10-item multidimensional questionnaire, designed to assess the physical, psychosocial, spiritual, and practical aspects of patients with various sufferings.^[3,4] In this score, 10 items are divided to assess the psychosocial distress in the form of pain, feelings affected by other symptoms, anxiety about illness, family or friends anxious or worried, information given to patient, sharing feelings with friends or family, depression, feeling good about themselves, time wasted on health-care appointments, and practical issues addressed. Normalizing of distress by patients and a lack of awareness and skill by clinicians in identifying and differentiating distress from appropriate sadness, along with limited management options, contribute to this under detection. With this aim, the study has been conducted for assessment of psychosocial distress among the patients of a palliative care clinic of a rural teaching hospital at Wardha district.

METHODS

In this cross-sectional study, a total of 118 patients attending the palliative care clinic under the medicine department were enrolled between July 2018 and March 2019.

Data collection process

Patients approached through routine hospital and field visit. All palliative care patients enrolled under the palliative care clinic of Acharya Vinoba Bhave Rural Hospital, Wardha. Critically ill patients, those with hearing and speech defects, those aged <18 years, and those who are not ready or not willing to participate in the study were excluded from the study.

Study tools

It consists of POS, a predesigned questionnaire which was translated in local Marathi language (with the help of translation-retranslation method). Scoring was done by a blind observer, usually workers who had knowledge about palliative care. It was done at least two times, as at the first time some patients were not able to understand the questions.

A predesigned questionnaire was given. They were first explained about the objective of the study and its probable benefits in local language and terminology and encouraged to give a reply and interviewed using a closed-ended questionnaire POS. POS has 10 questions in Likert type of scale with a scoring of 0–4, 0 for no effect to 4 for overwhelming effect. Each question provides the information regarding how the patient feels in the past 3 days. Each participant with a score from 0 or 1 requires less clinical attention than items that score 3 or 4. After explaining the purpose of the study, written information consent was obtained. Data obtained were kept confidential. Ethical approval was obtained from the Institutional Ethics Committee of the university.

Statistical analysis

Descriptive statistics was used for analyzing the data. The data are expressed in terms of frequency, measures of central tendency using mean with standard deviation, or median with range depending on the distribution of data. The significance level was set at $P < 0.05$. All tests were done using International Business Machines Corporation Statistical Package for the Social Sciences, Chicago (USA) statistical software version 19.

RESULTS

All the 10 items representing the finding of POS are addressed in Table 1. Out of 118 patients enrolled in this study, majority had pain with a mean score of 2.95 in the first assessment of POS and in the follow-up visit had 1.19. Normalizing of distress by patients and a lack of awareness and skill by clinicians in identifying and differentiating distress from appropriate sadness, along with limited management options, contribute to this under detection.^[5] In the first assessment for anxiety about illness or treatment, 32% of the participants reply that they occasionally feel the anxiety, whereas the same reply has been given in follow-up assessment by 34% of the participants, with an average mean score of 1.59 and 1.31, respectively. Approximately 48% of the participants feel that their family or friends were occasionally anxious and worried for them in the first assessment of POS compared to follow-up assessment where the feeling has been changed with approximately 46% for not at all anxious or worried

Table 1: Descriptive statistics showing various psychosocial distress subscales of the Palliative Care Outcome Scale

POS items	Variables	First assessment (n=118)		Follow-up assessment	
		n (%)	Mean score	n (%)	Mean score
Pain	0. No, not at all	2 (1.7)	2.95	67 (56.8)	1.19
	1. Slightly	7 (5.9)		13 (11)	
	2. Moderately	17 (14.4)		6 (5.1)	
	3. Severely	61 (51.7)		13 (11)	
	4. Overwhelmingly	31 (26.3)		19 (16.1)	
Affected by other physical symptoms	0. No, not at all	55 (46.6)	1.08	50 (42.4)	1.15
	1. Slightly	28 (23.7)		31 (26.3)	
	2. Moderately	11 (9.3)		17 (14.4)	
	3. Severely	18 (15.3)		9 (7.6)	
	4. Overwhelmingly	6 (5.1)		11 (9.3)	
Anxiety about illness or treatment	0. No, not at all	32 (27.1)	1.59	37 (31.4)	1.31
	1. Occasionally	37 (31.4)		40 (33.9)	
	2. Sometimes	15 (12.7)		20 (16.9)	
	3. Most of the time	15 (12.7)		9 (7.6)	
	4. Can't think of anything else	19 (16.1)		12 (10.2)	
Family or friends anxious or worried	0. No, not at all	39 (33.1)	0.98	54 (45.8)	0.81
	1. Occasionally	57 (48.3)		46 (39)	
	2. Sometimes	12 (10.2)		9 (7.6)	
	3. Most of the time	5 (4.2)		4 (3.4)	
	4. Always	5 (4.2)		5 (4.2)	
Information given	0. Full information	68 (57.6)	0.75	86 (72.9)	0.37
	1. Given but hard to understand	28 (23.7)		20 (16.9)	
	2. Given on request	12 (10.2)		12 (10.2)	
	3. Very little given	4 (3.4)		0 (0)	
	4. None at all	6 (5.1)		0 (0)	
Sharing feelings with family/friends	0. Yes	23 (19.5)	1.67	34 (28.8)	1.17
	1. Most of the time	28 (23.7)		46 (39)	
	2. Sometimes	36 (30.5)		26 (22)	
	3. Occasionally	27 (22.9)		8 (6.8)	
	4. No, not at all	4 (3.4)		4 (3.4)	
Life worth living/depressed	0. No, not at all	12 (10.2)	1.99	20 (16.9)	1.62
	1. Occasionally	12 (10.2)		20 (16.9)	
	2. Sometimes	73 (61.9)		69 (58.5)	
	3. Most of the time	7 (5.9)		3 (2.5)	
	4. Always	14 (11.9)		6 (5.1)	
Felt good about themselves	0. Yes, all the time	10 (8.5)	2.25	31 (26.3)	1.47
	1. Most of the time	25 (21.2)		39 (33.1)	
	2. Sometimes	40 (33.9)		25 (21.2)	
	3. Occasionally	12 (10.2)		8 (6.8)	
	4. No, not at all	31 (26.3)		15 (12.7)	
Time wasted on health care	0. None at all	95 (80.5)	0.59	89 (75.4)	0.52
	2. Up to half a day wasted	11 (9.3)		22 (18.6)	
	4. More than half a day wasted	12 (10.2)		7 (5.9)	
	4. Not addressed	33 (28)		25 (21.2)	
Practical concerns addressed	0. Addressed/no practical problems	41 (34.7)	1.86	71 (60.2)	1.22
	2. In process	44 (37.3)		22 (18.6)	
	4. Not addressed	33 (28)		25 (21.2)	

POS: Palliative Care Outcome Scale

followed by 39% occasionally. The mean score in the first assessment is 0.98, whereas the follow-up assessment having mean score is 0.81. Only 58% think that they have been given full information about their illness and any other related in the first assessment, which was increased to 73% in the follow-up assessment. When asking for the feelings to be shared with

family or friends, approximately 31% of the participants marked sometimes in the first assessment, whereas in the follow-up assessment, 39% marked most of the time they shared the feelings. Majority of people sometimes feel that they are having life worth living with such illness, followed by always feeling and occasionally feeling. Approximately

34% sometimes felt good about themselves, whereas 21% most of the time felt good about themselves. In follow-up assessment, 33% of the participants most of the time felt well about them and 26% always felt good about themselves. Most of the participants feel that they not at all wasted time in health care but few of them that up to half a day has been wasted for the health-care appointments and attached things always. Thirty-seven percent of the participants noticed that their problems were addressed appropriately, whereas 34% said no problems or all problems had been addressed. While in followup assessment, 60% noticed no practical problems or all problems were addressed and 21% thought of not being addressed.

DISCUSSION

In this study, it has been observed that the intensity of pain was lowered in the subsequent visits, but in some cases who reply not changed, it may be due to the advanced stages of disease and mental unsatisfaction. Majority of people in the question about pain in the first assessment of POS replied as severely affected (52%), and in the follow-up visit, the majority are for no pain at all. Similar results were observed in other studies where the POS was introduced to check the difference of care providers and patients.^[6,7] Palliative care patients are mostly at the critical stages of their illness; hence, the expectation of improvements may not be as typically found compared to other patients. The feeling of anxiety and not worth living between patients and the family and friends lowers as the palliative team helps to understand the severity and intensity of disease and its effective treatment. In this study, 58% of the patients think that they have been given full information about their illness and any other related in the first assessment, which was increased to 73% in the follow-up assessment. Similar results were also observed in the previous study.^[7,8] When asking for the feelings to be shared with family or friends, approximately 31% of the participants marked sometimes in the first assessment, whereas in the follow-up assessment, 39% marked most of the time they shared the feelings. Most of the patients share their feelings with family members as compared to the friends and other members, as they are more favorable in patients' social comfort zone. With advanced stages of illness or unsatisfactory cure, the patients reject the treatment by thinking that it is the wastage of time to wait for the hospital appointments and health-care provision. They may be expecting an early and complete cure to live the life as their people in the surrounding environment lives.

Chaturvedi *et al.* observed that the decision and preferences of patient many time influenced by the family members and the ethical dilemma made the professional and caregivers confused, whether ethical decisions based action would work.^[8] Koh *et al.* suggested that there must be adequate training to be conducted of the palliative care team with respect to the

mental state and emotional counseling of the palliative care patients to improve their bonding and efficacy of treatment.^[6]

Limitation

As a single institution-based study, possible institutional bias cannot be ruled out. Mostly, the family and social supporters hide the critical information from the severely affected patients; it may be due to fear of losing the affected member.

CONCLUSION

There is a scope to modify the future treatment and management approach for the effective implementation of palliative care services, as in this study participants were satisfied and accepted the palliative care treatment provided by the team with frequent visits, and also, the level of improvement fastens. A measure such as wide use of holistic palliative care and social support can reduce the patients' distress thereby quality of life and social functioning may be improved.

Future directions

Evidence are needed for guidance and better decisions regarding symptom management, decision-making approaches about treatment options, different health-care models, and communication on sensitive topics such as death and support for caregivers, especially closed family members.

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Conflicts of interest

There are no conflicts of interest.

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