

Awareness of Palliative Medicine among Pakistani Doctors: a Survey

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Abstract

Objective: To establish the awareness of palliative medicine in Pakistani doctors through a questionnaire.

Methods: A questionnaire was developed after consultation with the professionals working in palliative medicine. It was distributed, by hand, to a convenience sample of doctors who worked at various teaching hospitals in Pakistan. The distribution and collection of questionnaires was carried out within six months.

Results: The results suggested that 74% doctors felt that cancer was the commonest reason for the palliative care teams to be involved. Forty five percent mentioned tht pain control was their prime job; 54% said that they had some experience of palliative medicine; 64% wanted to be involved in palliative medicine; 60% thought that they broke bad news properly to the patients; 59% were satisfied with their own performance while dealing with an incurable patient (57% said that they had heard about a hospice). There was a wide range of drugs for the cancer pain.

Conclusion: Amongst Pakistani doctors, there is a lack of training in palliative medicine. A significant number of doctors are interested and they are willing to have more training in pain control, breaking bad news, communication skills and terminal care (JPMA 54:195;2004).

Introduction

Palliative Medicine is one of the developing medical specialities. It has been recognised by World Health Organisation (WHO) and defined as an approach which improves quality of life of patients and their families facing life-threatening illness through prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems as physical, psychosocial and spiritual.¹

In United Kingdom, General Medical Council has held doctors guilty of serious professional misconduct because they had been unable to provide Palliative Medicine or refer for specialist Palliative Medicine.² The concept of Palliative Medicine is not new. In 460 BC, Hippocrates became the father of Medicine by providing

simple symptom relief. In the modern world, many developed countries do not consider Cancer services provision appropriate until the services have the back up of Palliative Medicine teams.³ Many developing countries, including some Muslim countries, also recognise the need for Palliative Medicine. India is running well-designed teaching programmes with the establishment of Indian Association of Palliative care⁴, whereas Saudi Arabia has also taken important steps in this context.⁵ This article reports on the results of a survey undertaken to investigate the views of doctors working in teaching hospitals in Pakistan on their understanding of Palliative Medicine in general.

Methods

The questionnaires (Table 1) were distributed to a convenience sample of 110 doctors working in different

teaching hospitals in Pakistan. The questionnaire approach was used to reach a wider number of responses in a relatively short time and at lower cost. No reminders were sent.

The questionnaire was evolved by the authors after discussion with the professionals working in specialist Palliative care services in United Kingdom and India. Responses were returned from the doctors of varying experience, working in 10 different medical colleges in Pakistan.

Results

Of 110 questionnaires sent, 70 (63.6%) were returned. Highest numbers of questionnaires returned from a single institution were from Hamdard College of Medicine and Dentistry, Karachi (Table 2). The respondents

Table 1. Questionnaire distributed.

1.	Demographic details (post, speciality, affiliation, experience)
2.	What are the reasons for the involvement of Palliative Medicine <ol style="list-style-type: none"> Diseases What are the aims of Palliative Medicine?
3.	What has been your experience in Palliative Medicine? <ol style="list-style-type: none"> Have you been involved? Do you want to be involved? Do you think the failure of curative treatment is explained properly?
4.	What is the analgesia of choice for terminal cancer pain? Parenteral and orally?
5.	Any other treatment (other than allopathic)?
6.	What are the responses expected? <ol style="list-style-type: none"> What is the response of the Staff after death of a patient? What is the response of the families after being told the failure of the curative treatment?
7.	About a hospice:- <ul style="list-style-type: none"> - Worked - Heard about - Seen
8.	Where should patient be in the last days of life? <ul style="list-style-type: none"> - Home - Hospital - Hospice

Table 2. Doctors surveyed.

Institution	No. of questionnaires returned	Percentage
Hamdard Medical College, Karachi	20	28.5
Dow Medical College and Civil Hospital, Karachi	15	21.4
Muhammad Medical College Hospital, Mirpurkhas	12	17.1
Jinnah Postgraduate Medical Centre	11	15.7
Baqai Medical College, Karachi	5	7.1
Quaid-e-Azam Medical College Hospital, Bahawalpur	2	2.8
King Edward Medical College Hospital, Lahore	2	2.8
Combined Military Hospital, Rawalpindi	1	1.4
Punjab Medical College, Faisalabad	1	1.4
Pakistan Institute of Medical Sciences, Islamabad	1	1.4
Total	70	100

had a background of a variety of specialities, with 30/70 (42.8%) doctors working in General Medicine, whereas 22/70 (31.4%) worked in Surgical and allied fields. Thirty three (47.1%) doctors were working at assistant Professor or higher level. Most doctors were experienced with 34 (48.5%) having over 10 years experience, 25 (35.7%) having 5-10 years experience and 11 (15.7%) having less than 5 years experience.

After the demographic details, they were asked questions about:

- The reasons for providing Palliative Medicine (diseases and aims)
- Their experience of Palliative Medicine
- Pain control
- Issues around terminal care

The diseases, for which doctors felt Palliative Medicine was important, ranged enormously. In total, they named 17 diseases as first priority, 28 as second priority and 33 as third priority. The most frequently mentioned diseases requiring Palliative Medicine, in any priority order, to be mentioned were cancer (52 - 74.2%), old age (22 - 31.4%), stroke (20 - 28.5%), Arthritis (18 - 25.7%) and Hepatitis (9-12.8%).

Thirty two doctors (45.7%) mentioned pain control as the primary aim for Palliative care management, 21 (30%) rehabilitation whereas 13 doctors stated counselling

(18.5%). Rest did not answer this question. When they were asked whether they have any experience in Palliative Medicine, 36 doctors (54.2%) stated that they had been involved whereas 34 (48.8%) said that they were never involved in Palliative Medicine. Among those doctors who had no experience of Palliative Medicine, 22 (64.7%) wished to be involved in the future.

When asked whether they felt the bad news of the disease being incurable, was conveyed appropriately, 42 (60%) agreed to it. Twenty eight doctors (40%) felt it was not done properly. Among the 42 doctors who felt it was done properly, 11 (26.1%) stated that they conveyed the news to the families and not directly to the patients.

When asked about the reaction of the staff after death of a patient, 28/47 (59.5%) stated that they felt satisfied with their performance, whereas 12/47 (25.5%) felt disappointed, 7/47 doctors (14.8%) felt emotionally disturbed. When asked about the reaction of the families/patients on realising the incurable nature of the disease, 50 doctors (71.4%) felt that the families were disappointed and 44 doctors (62.8%) mentioned that the families/patients sought a second opinion. Nineteen doctors (27.1%) responded that the explanation to the families/patients was sufficient to be accepted.

the opinion that it is left to the patient's/family's discretion.

Lastly, the doctors' knowledge about the hospices were questioned. Forty doctors (57.1%) stated that they had heard about a hospice, although only 19 doctors (27.1%) had seen one. Only one doctor (1.4%) wrote that he had worked in a hospice. When asked about the preferred place of providing terminal care, 49 doctors (70%) mentioned home, 16 doctors (22.8%) hospital and 2 doctors (2.8%) chose hospice.

Statistical tests on the data were not performed as the questions asked were open ended with answers given on individual discretion.

Discussion

Palliative medicine is now perceived as an integral part of medical care rather than 'elite medicine'. Like any other sub-speciality, Palliative Medicine training is an essential part of general internal medicine. As the methods to relieve intractable symptoms and patients' distress are increasing day by day, it will be inappropriate to expect all the doctors to be able to provide Specialist Palliative Medicine services. However, it remains a generalist's, either primary care doctor or General Physician/Surgeon, responsibility to start Palliative management.

Table 3. Analgesia of choice in terminal cancer pain.

Oral medication	Number of answers	Percentage	Parenteral medication	Number of answers	Percentage
Morphine	4	5.7	Morphine	19	27.1
Tramadol	11	15.7	Tramadol	15	21.4
NSAID's	13	18.5	NSAIDs	16	22.8
'Opiate'	3	4.2	Pethidine	8	11.4
Buprenorphine	2	2.8	Phenazocine	5	7.1
Paracetamol	1	1.4	Nalbuphine	1	1.4
Nefopam	1	1.4	No answer	6	8.5
No answer	35	50			

When asked about the choice of the analgesia, used orally or parenteral, in terminal cancer pain, a range of drugs was mentioned. The results are shown in Table 3.

The doctors were also asked whether they felt comfortable with any other form of treatment other than allopathic. Forty seven (67.1%) doctors (67.1%) stated that they had no objection whereas 23 (32.8%) felt uneasy about it. The treatment mentioned by the doctors were spiritual (n=23, 32.8%), homeopathy (n=14, 20%), herbal/hikmat (n=16, 22.8%), acupuncture (n=6, 8.5%), whereas 11 doctors (15.7%) did not mention any treatment or were of

In first part of the questionnaire, the doctors were asked about their perception of Palliative Medicine and its uses. World Health Organisation defined Palliative Medicine for the first time in 1990, as 'a facet of oncology, concerned with the control of symptoms rather than with the control of the disease'.⁶ The approach now, as designed by WHO, is to consider all the incurable, life-threatening diseases, but cancer remains the top reason for the referrals. Other diseases mentioned by the sample doctors like Arthritis or old age are certainly not the cases for specialist Palliative Medicine. Other diseases for referral to specialist

Palliative Medicine teams are incurable neurological diseases e.g., multiple sclerosis, motor neurone disease and incurable infective diseases e.g., AIDS, multi-drug resistant tuberculosis etc. The findings of this survey indicate that doctors in Pakistan need to be more aware of the disease trajectory of palliative medicine.

In the questionnaires, although a guide was written to identify the aims of Palliative Medicine team, a slot was left to write what doctors felt was the main aim. The doctors mentioned pain control, counselling and rehabilitation as the main aims. A study in UK had indicated that these are the same aims identified by the general population in UK.⁷ Interestingly, the aim identified by the doctors themselves has been 'Quality of life as 'Primary focus of Palliative Medicine'. It is worth stressing that the quality of life should be subjective and multidimensional, dynamic, time-specific and is not defined by functional ability, performance status or cognition.⁸ The findings of the survey indicate that the doctors in Pakistan are aware of the remit of Palliative Medicine.

The results of the answers about the experience of Palliative Medicine and breaking bad news were interesting. Sixty percent doctors felt that they convey the bad news appropriately, 26% conveyed the news to the families and not to the patients and only 27% felt that the patients accepted the diagnosis. Studies have shown that 49% consultants have no formal training in breaking bad news and generally 70% of consultants felt that breaking bad news was inadequately done in the hospitals across UK.⁹ Furthermore, there are no formal studies of any protocol to suggest any one way is better than the other.¹⁰

According to our questionnaire, 26% doctors mentioned that not infrequently, they relay the bad news to the families and not to the patients. It is a well-established concept that a mentally competent patient has the right to knowledge. It is an ethical and legal requirement in many countries.¹¹ One can argue that in western world, where individualistic attitudes are common, this principle is valid whereas in countries like Pakistan, families are entitled to share information. It is a perfectly reasonable argument and should be followed in good practice. However, the doctors should not deprive patients of the truth. There is considerable evidence that patients who are aware of their conditions accept the treatment and consequences better and also have improved quality of life.¹² There is sometimes the fear that the patients would 'give up' after they are told about the diagnosis of a terminal illness. But studies suggest that usually these fears are unfounded and can cause more damage than harm. Also that there are models which can help provide quality of life after being told of terminal nature of disease.¹³ This is very much consistent with Hazrat Ali's saying, 'The truth known achieves three things:

Trust, Love and Respect.'¹⁴ The findings of the survey indicate that the Pakistani doctors are confident about their understanding of breaking bad news. Further data is required to explore their techniques and patients' experiences of doctors' expertise.

Regarding the pain control in cancer patients, World Health Organisation guidelines for managing cancer pain refer to a ladder pattern. At first step, it advises to administer non-opioids (e.g., Paracetamol), if necessary in addition of an adjuvant drug (e.g., NSAID). Second step asks for adding moderate opioids (e.g., Codeine, Tramadol etc.) and third step advises to administer strong opioids (e.g., Morphine - Gold standard).¹⁵ In Pakistan, where morphine is usually difficult to obtain, there are different other strong opioids e.g., Buprenorphine, Pentazocine, Fentanyl etc. A similar problem exists in India but lateral thinking has helped to overcome it.¹⁶ Lack of knowledge about the cancer pain is sometimes due to more stress on curative treatment and failure to accept the terminal nature of the illness.¹⁶ Also direct lack of education has been attributed as the most prevalent cause of inadequacy of cancer pain control.^{17,18} Although, in our survey doctors identified various appropriate drugs, none of them referred to the WHO ladder, which implies that there is a need to explain this most important protocol. This approach has been tested and proven valuable in many studies. In one of the studies, out of 156 patients, 87% ultimately became pain free using this ladder analgesic pattern.¹⁹

There was a fair amount of thought in our survey about the complementary medicine. There is no evidence that any complementary medicine can help curative treatment, but techniques like aromatherapy, music therapy, acupuncture, relaxation therapy etc. have been helpful in managing patients' suffering and mental distress.²⁰ In eastern world in general, and in Muslim countries especially, the religious coping mechanisms are well-established source of strength and well being.²¹ This mechanism is also supported in the bereavement phase. In the west, the bereavement support is provided by trained counsellors but in east, extended families play an important role. The findings of this survey indicate that majority of the doctors respect the patients' right to complementary medicine.

About 60% of the doctors felt satisfied with their performance whereas 27% said that the families/patients were accepting the explanations. This small sample, shows a big discrepancy. It has been identified by healthcare professionals around the world and governing bodies like WHO, that families should be recognised as experts in gathering information about specific behaviours that helps in patients' care (e.g., patients' like and dislikes, fears, concerns and beliefs etc.).²² Also it is recognised that by

sharing the information, doctors can create a good relationship with patients and families, which leads to smooth transition of events of continuing and terminal care. It must also be said that although more than 27% doctors felt disturbed or disappointed, it must be realised that death is the only sure event in our lives. Dying is not a failure. It is dying with loss of dignity and in distressing symptoms, which is deemed unacceptable.²³

Although more than 85% of doctors had heard about/seen/worked in a hospice, only 2.8% mentioned that hospice would be their patients' preferred place for dying. In fact, 22% mentioned that they would prefer hospitals. This figure is very much culturally dependant. In Belgium, which is a Western European country, with lot of emphasis on individualism, data suggests that only 16% of the patients die at home, whereas 76% die in hospital/nursing home.²⁴ In contrast to that, data from Italy, which is a Mediterranean country with strong family values, shows that 86% of patients die at home and only 14% in hospital and nursing homes.²⁵ Wide availability of Palliative Medicine services should enable the patients to die at home, with their loved ones. Hospitals have been felt too intrusive or busy at times to deal with the dying patients. The findings of this survey indicate that doctors are conscious of patients' needs while making decisions about the venue of the patients' last days.

References

1. World Health Organization. Cancer pain relief and palliative care. Geneva: WHO, 2002.
2. Riley J. The General Medical Council and the right to specialist palliative care. *Palliative Med* 1997;11:317-18.
3. Manual of Cancer Services Standard. London: National Health Services, 2000.
4. Sureshkumar K, Rajgopal M. Palliative care in Kerala. *Palliat Med* 1996;10: 293-8.
5. Brown S, Black F. Palliative care in the Kingdom of Saudi Arabia. *Eur J Palliative Care* 2001;8:196-8.
6. Saunders C. Appropriate treatment, appropriate death: the management of terminal malignant disease. London: Edward Arnold, 1984.
7. Jarrett N, Payne S, Turner P, et al. Someone to talk to and pain control. What people expect from a specialist palliative care team. *Palliat Med* 1999;13:139-44.
8. Waldron D, O'Boyle CA, Kearney M, et al. Quality of life measurement in advanced cancer: assessing the individual. *J Clin Oncol* 1999;17:3603-11.
9. Barnett M. Lecture at 8th Congress of European Association of Palliative care. The Hague. Netherlands, 3rd April 2003..
10. Waitzkin H, Stoeckle JD. The communication of information about illness. *Adv Psychosomatic Med* 1987;8:180-215.
11. Buckman R. Communication in palliative care: a practical guide. Oxford Textbook of Palliative Medicine. 2nd Ed. London: Oxford University Press, 1999.
12. Weisman A. Coping with cancer. New York: McGraw-Hill, 1979.
13. Penson J. A hope is not a promise: fostering hope within palliative care. *Int J Palliat Nurs* 2000;6:94.
14. Usool-kafi. Vol. 1, Page 460. Qum, Iran.
15. World Health Organisation. Cancer pain relief. Geneva: WHO, 1986.
16. Dwyer L. Palliative medicine in India. *Palliat Med* 1997;11:487-8.
17. Larue F, Colleau SM, Fontaine A, et al. Oncologists and primary care physicians' attitudes towards pain control and morphine prescribing in France. *Cancer* 1995; 76:2375-82.
18. Zenz M, Zenz T, Tryba M, et al. Severe undertreatment of cancer pain: a 3 year survey of the German situation. *J Pain Symptom Manage* 1995;10:187-91.
19. Takeda F. Results if filed-testing in Japan of the WHO draft interim guidelines on the relief of cancer pain. *Pain Clin* 1986;1:83.
20. Fishman B. The treatment of suffering in patients with cancer pain: In Foley K, Bonica J, Ventafridda V. eds. *Advances in pain research and therapy*, vol 16. New York: Raven Press, 1990, pp. 301-16.
21. Spilka B, Spangler JD, Nelson CB. Spiritual support in life-threatening illness. *J Relig Health* 1983;22:98-104.
22. Wilson-Barnett J, Richardson A. *Nursing research*. London: Oxford University Press, 1999, pp. 98-104.
23. Sykes NP, Pearson SE, Chell S. Quality of care of the terminally ill: the carers' perspective. *Palliative* 1992;6:227-36.
24. Schrijvers D, Joosens E, Middelheim AZ, et al. The place of death of cancer patients in Antwerp. *Palliat Med* 1998;12:133-4.
25. De Conno F, Caraceni A, Groff L, et al. Effect of home care on the place of death of advanced cancer patients. *Euro J Cancer* 1996; 32A:1142-7.