

## Short Reports

### End-of-life care of terminally ill geriatric cancer patients in northern India

VIVEK GUPTA, SANDEEP KUMAR, ABHISHEK SHUKLA, SHAILENDRA KUMAR, SURENDER KUMAR

#### ABSTRACT

**Background.** The geriatric population in India is increasing, and so is the prevalence of cancer. We aimed to study the knowledge, attitude and practices of end-of-life care issues of terminally ill geriatric cancer patients in our region.

**Methods.** A pilot cross-sectional qualitative study using case studies, focus group discussions on providers and recipients of palliative care, an open-ended, interviewer administered questionnaire on specialist doctors and practitioners (50), geriatric cancer patients (20) and healthy family members of patients (30), was done in Lucknow, the capital of Uttar Pradesh, India.

**Results.** Only 14 physicians (28%) could enumerate more than 3 important technical elements of end-of-life care. Two physicians (4%) utilized palliative care services but none had received training themselves. The explanations and counselling provided by physicians were mostly inadequate, incomplete and did not fully satisfy the patients and their relatives. Of the cancer patients, 19 (95%) desired to use special services but were unaware of such facilities. There was only one charitable organization for needy geriatric cancer patients in Lucknow. No specific health scheme existed in the programme of the Government of Uttar Pradesh.

**Conclusion.** The knowledge and practices of physicians and specialists were not up to the expectations and requirements of terminally ill cancer patients. Curriculum-based learning or organized teaching of end-of-life care issues was non-existent. Western countries have well-organized subspecialty facilities for end-of-life needs; such facilities are lacking in India. Capacity building for the care of terminally ill geriatric cancer patients is urgently required in north India.

Natl Med J India 2007;20:74-7

#### INTRODUCTION

India is in a state of demographic transition. The increase in life expectancy has led to an absolute and relative increase in the population of the elderly.<sup>1</sup> Projections by WHO reveal that the burden of cancer in the developing world is increasing. While western countries have organized subspecialty care for the geriatric

population, India lacks even basic awareness among healthcare providers. Every year an estimated 1 million people in developing countries die from cancer, but little is known about their end-of-life care.<sup>2</sup> Palliative care is currently available only in rich nations, with little or no such care in about half the countries in the world.<sup>3</sup> Although globally two-thirds of all cancer patients live in developing countries, <10% of cancer care resources are available to them.<sup>4</sup>

Our study was designed to focus on the needs and current status of palliative care available to terminally ill geriatric cancer patients in the city of Lucknow using open-ended interviews, case studies and focus group discussions.

#### METHODS

This study was conducted from January 2005 to January 2006 using cross-sectional data collected both qualitatively and quantitatively. Questionnaires were developed on 'End-of-life care in terminally ill geriatric cancer patients' after generating tea room discussions and focus group interviews of providers of cancer-related treatment, terminally ill geriatric cancer patients and their attendants. The questions on issues of end-of-life care were placed in two categories:

1. Physician awareness
2. Patient awareness

These 2 questionnaires aimed to evaluate the cognitive knowledge of physicians and patients, burden, needs and current facilities available for geriatric cancer patients including palliative care and bereavement services. Non-threatening, simple questions were framed to obtain responses on sensitive issues without upsetting participants with advanced illness. Thus, a semi-structured, flexible schedule was administered after obtaining verbal as well as written consent. Views of patients and relatives regarding their experiences during illness, and communication with their consultant physician and specialists were noted in an open-ended manner. An enquiry was made to identify common concerns or issues important from the healthcare provider's perspective by using the participant-observer method while working in the departments of surgery, oncology and radiotherapy. Both focus group discussions and semi-structured interview schedule techniques were used. Responses were noted in a narrative form, summarized to the participants and the conclusions from their versions were approved by all the authors. The questionnaire was peer reviewed for face validity. This being an open-ended study using a qualitative research methodology, no attempt was made to formally validate the questionnaires or determine a sample size.

The physician awareness questionnaire was administered to physicians ( $n=50$ ) who routinely dealt with cancer patients. This sample included specialists (10), general practitioners (20), and third-year resident doctors in the departments of surgery, oncology and radiotherapy (20). Two consultant psychiatrists were also interviewed. The patient awareness questionnaire was administered to 20 cancer patients and senior members (30) of the public (>60 years of age) who were either friends or relatives of the patients. Patients were between 50 and 84 years of age (mean [SD] 63.4 [8.61] years) and all were aware of their diagnosis of an incurable cancer (cancer gallbladder 4, pancreas 2, oral cavity 6, breast 4, rectum 3 and soft tissue sarcoma 1).

King George's Medical University, Lucknow 226003, Uttar Pradesh, India  
VIVEK GUPTA, SANDEEP KUMAR, SHAILENDRA KUMAR,  
SURENDER KUMAR Department of General Surgery

'Aastha' Geriatric Care Centre, Mahanagar, Lucknow, Uttar Pradesh, India  
ABHISHEK SHUKLA

Correspondence to SANDEEP KUMAR; [k\\_sandeep@hotmail.com](mailto:k_sandeep@hotmail.com)

## RESULTS

Only 14 physicians (28%) were aware of more than 3 important components from the listed 10 hospice and end-of-life-care issues (pain, anorexia and cachexia, constipation, dyspnoea, anxiety/depression and stress management, domiciliary or outreach care, grieving and abnormal grief in survivors, financial concerns, bereavement and managing death). An equal number of physicians (14 [28%]) had never heard the term hospice though they claimed to be routinely working with cancer patients. Only 8 respondents (16%) were aware of the existing services in the city and 2 (4%) had utilized these services.

Fourteen respondents (28%) were aware of the special protocol for counselling terminally ill patients. None of the physicians interviewed had received special training during their undergraduate or postgraduate years. Most of the physicians—23 (46%)—sent their terminally ill patients home in the care of the local general practitioner and admitted only those suffering from complications. The local physicians never had a dialogue with the referring specialist and felt inadequate in advising the patient and relatives on terminal care and palliation. A majority of respondents—48 (96%)—were supportive of the idea of creating hospices and providing special services, 48 (96%) were not satisfied with the current practice of palliative care and 6 (12%) wanted euthanasia to be legalized. Thirty-three physicians (66%) felt that they were comfortable in dealing with end-of-life care issues but were handicapped on account of poor infrastructure and felt the need for some training. Forty-one physicians (82%) preferred to counsel relatives rather than patients (Table I).

Of the 30 attendants and relatives of geriatric cancer patients who were also care providers, 23 (76%) felt that the diagnosis of incurable cancer should not be disclosed to the patient. Most attendants—25 (83%)—wanted these patients to be admitted to a hospital for proper symptomatic care. Twenty-nine respondents (97%) were unaware of the existence of a hospice and would have liked to utilize its services. Twenty-six respondents (87%) were ready for a surgical procedure or chemotherapy in the hospital, if affordable and with no major side-effects, even if it extended life by only 2 months.

Of the 20 cancer patients interviewed, 16 (80%) wanted to be aware of their diagnosis early and all of them wanted their doctor to inform them. Fourteen patients (70%) preferred to be alone with their doctors at the time of being informed. The next best person to share the news was the spouse or the head of the family (Table II). Forty-one physicians (82%) did not disclose the diagnosis of cancer directly to the patient and informed the relatives instead. The 2 psychiatrists interviewed said that the truth should be disclosed to the patient unless the person was mentally unsound. Some of the comments made in the open-ended study or narrated informally and found to be important are given in Table III.

Eighteen patients (90%) wanted to be admitted to a hospital. They were not aware of special services for advanced cancer care but would have liked to avail of them. For 18 patients (90%) any method of treatment that extended their lives by even 2 months was welcome. Their most important concern was the care of their families and financial limitations followed by the fear of pain and death. In a participant-observer study, during ward rounds, we perceived a lack of sensitivity on the part of healthcare personnel in informing elderly patients with incurable cancer.

## DISCUSSION

A PubMed Medline search for indexed articles using the keyword 'hospice' and 'palliative' returned 2151 articles. The same search

TABLE I. Physician awareness questionnaire (n=50)

Question/Response	n (%)
Are you aware of the concept of end-of-life care or hospice?	
Never heard of it	14 (28)
Only heard of it	17 (34)
Know a little bit about it	12 (24)
Know quite a bit about it	4 (8)
Can teach the subject	2 (4)
Can you enumerate some basic elements or things one provides in hospice care?	
Enumerated >3	14 (28)
Enumerated <3	36 (72)
Your views on dealing with an incurable cancer	
Patient should be sent home in care of local general practitioner	23 (46)
Patient should be kept in general hospitals	20 (40)
Special services such as hospices should be created/utilized	42 (84)
Curative treatment should never be stopped	3 (6)
Euthanasia should be practised and legalized	6 (12)
Any other suggestions	Narrative
Are you aware of any specialized services meant for geriatric people with advanced cancer in your area or town?	
Yes	8 (16)
No	42 (84)
Have you or people known to you ever utilized any service especially meant for geriatric people with advanced cancer?	
Yes	2 (4)
No	48 (96)
Are you aware of any counselling protocol for geriatric oncology cases?	
Yes	14 (28)
No	36 (72)
When you as an attending physician come across geriatric patients with terminal cancer, do you routinely counsel them or their relatives regarding end-of-life issues?	
Never	1 (2)
Sometimes but not always	4 (8)
Always	30 (60)
Want to but do not know what to say	15 (30)
Will you feel comfortable dealing or discussing with a patient with terminal cancer?	
Yes	33 (66)
No	17 (34)
Will you prefer discussing this subject with the relatives rather than addressing the patient directly?	
Yes	41 (82)
No	9 (18)
Have you received any training or read this subject yourself?	
Yes	0 (0)
No	50 (100)
Are you satisfied with the current system for dealing with these cases?	
Yes	2 (4)
No	48 (96)
Your views regarding end-of-life care issues in elderly cancer patients	Narrative

using the keywords 'hospice', 'palliative' and 'India' returned 10 articles with 2 papers from India in the past 5 years.<sup>5,6</sup> Three popular undergraduate textbooks of social and preventive medicine in India made no mention of hospice, palliative care and had no chapter on care of the dying patient. When we scanned the

TABLE II. Patient awareness questionnaire (n=20)

Question/Response	n (%)
If you were diagnosed to have cancer, who should tell you?	
The physician or your relatives	16 (80)
Would not like to be told at all	4 (20)
At the time of breaking bad news would you	
Like to be alone	14 (70)
Like to be with relatives	6 (30)*
Who disclosed the news of the current problem to you?	
Senior doctor/Specialist	4 (20)
Resident doctors	6 (30)
Relatives	6 (30)
No one told me, I found out	2 (10)
If you were diagnosed with cancer that is probably incurable, what would be your	
<i>Fears and worries</i>	
Pain	16 (80)
Death	2 (10)
Financial	16 (80)
<i>Expectations from yourself, relatives, doctors, society and government</i>	Narrative
If no cure is possible, where would you like to continue living (a brief description of a hospice was provided)	
At the hospital	18 (90)
At hospice	19 (96)
At home in the care of a local doctor	2 (10)
Are you aware of any special services for cancer patients of your age?	
Yes	1 (5)
No	19 (95)
If no cure is possible, would you like to undergo a procedure that could increase life expectancy by a maximum of 2 months?	
Yes	18 (90)
No	2 (10)

\*Head of family 2; Spouse 4

entire lecture series of 3 state-run medical colleges we found that no formal lecture on these subjects had ever been taken.

In a study reported from Delhi,<sup>5</sup> 100 resident doctors were interviewed on awareness and training in palliative care. The authors compared oncology and non-oncology residents on these issues and reported lack of training and knowledge, and confidence in managing advanced cancer patients. Hospice was identified as an important modality though the cost of care was considered high without any economic calculations being done. The study did not focus on patients' views and those of family members, general practitioners and specialist physicians. Views on 'breaking the news of incurable cancer' were also not taken.<sup>5</sup>

Our study was done to document a local perspective of palliative care using an open-ended qualitative research method, which can form the basis of quantitative research on quality-of-life issues in elderly patients with advanced cancer. An economic analysis of hospice care considering cost perspectives and quality-of-life issues would be the next step. A study on the cost of providing end-of-life care in inmate and outreach modes has already been initiated by us.

Our study confirms that there is a lack of infrastructural facilities for patients with incurable cancer and awareness of end-of-life issues. Less than one-third (28%) of the physicians interviewed had a reasonably accurate knowledge of hospice and end-of-life care and their components. Less than one-third were aware about the special protocol for counselling terminally ill patients.

TABLE III. Comments on breaking news about cancer

<i>Physicians</i>
Difficult to inform patients as it lowers their morale
Routinely inform the relatives rather than patient
If the patient is intelligent and demands to know (s)he can be informed
Like to inform my patient at an appropriate time
<i>Psychiatrists</i>
Patients should be informed irrespective of socioeconomic and literacy status
Psychiatric patients are exceptions
If relatives do not agree they should be counseled
<i>Patients</i>
Was informed by a junior doctor that nothing could be done
Just guessed as my relatives were using the word cancer

Only a few had utilized these services. These data suggest need for educating physicians in palliative care medicine. An end-of-life care module should be routinely taught to all medical students and postgraduates. Protocols such as the 'Education for Physicians on End-of-life Care' (EPEC) started by the American Medical Association provides an iterative decision-making algorithm and was intended to help physicians take care of their responsibility to provide good end-of-life care.<sup>7</sup> Apart from the EPEC project, a number of other programmes in various countries have worked towards improving end-of-life care.<sup>8-11</sup>

Most of our patients wished to know about their disease and the prognosis at the earliest. However, many physicians did not inform the patient about the diagnosis of advanced cancer. This added to the anxiety and helplessness of the patients and their relatives. Those who did inform patients, often did so in an insensitive manner resulting in harm to the patient. Many patients with cancer recalled how they found out about their disease in an indirect manner. None of the clinical units that we observed during the study had a protocol for end-of-life issues and bereavement. This was an important regional cultural influence that we noted. These regional differences are important as in some cultures physicians or families, or both, deem full disclosure unnecessary and prejudicial to the patient.<sup>12</sup> To plan services properly, the cultural milieu that may affect communication needs to be respected.<sup>13</sup> Our study shows that patients wished to know about their disease directly from the treating physician and early in the course of treatment.

Most patients wanted to continue in the hospital and were unaware of any special services that they could avail of. They welcomed any procedure that could increase their life by even 2 months if it was free from major side-effects. This suggested that elderly patients with cancer wish to live longer if good palliation could be achieved. Despair and a desire to die early were expressed by those who were in pain or depressed. This was in contrast to the common belief that elderly patients with incurable cancer were resigned to death whereas good palliation in terminally ill patients creates a desire to live an extra few days. Important concerns were care of the families and finances, followed by the fear of pain. Most patients preferred dying in hospital as they were unsure of the medical aid at home. In contrast, some studies found that half or more of terminally ill patients expressed a preference to remain at home until death.<sup>14-16</sup> In developed and developing countries there are differences not only in the resources available for patients dying from cancer but also in their experience of illness.<sup>1</sup> Murray *et al.* conducted 67 interviews in Scotland and 46 in Kenya. The emotional pain of facing death was the prime concern of Scottish patients and their carers, while

physical pain and financial worries dominated the lives of Kenyan patients and their carers. In Scotland, free health and social services were available, but sometimes underused. In Kenya, analgesia, essential equipment, suitable food and assistance for care were often inaccessible and unaffordable, resulting in considerable unmet physical needs. The patients' desire to die in a hospital in our study may be a representation of the latter.<sup>17</sup>

Special services comprising a dedicated team should be created as a priority; these should be attached to all tertiary care centres. Health policy-makers in India have so far not addressed quality of end-of-life care. Improving end-of-life care will require an attitudinal change and other interventions, both formal and informal. Managed and outreach care should evolve through public-private partnership. Educational programmes for health workers, social workers and for the people in households will need to be evolved. Financial issues will need to be addressed by local governments, philanthropic organizations, corporate donors, international funding agencies and charitable bodies. Advocacy of palliative care with decision-makers, provision of training programmes for health professionals, and making medications available and affordable are important challenges.<sup>18</sup> Quality end-of-life care is a public health issue that needs to be integrated into national government strategies in India

#### REFERENCES

- 1 UNDP. *Human Development Report 2003. Millennium Development Goals: A compact among nations to end human poverty.* Available at <http://undp.org/reports/global/2003/>.
- 2 Singer PA, Bowman KW. Quality care at the end of life. *BMJ* 2002;**324**:1291-2.
- 3 Olweny CL. Ethics of palliative care medicine: Palliative care for the rich nations only! *J Palliat Care* 1994;**10**:17-22.
- 4 Cancer pain relief and palliative care. Report of a WHO Expert Committee. *World Health Organ Tech Rep Ser* 1990;**804**:11.
- 5 Mohanti BK, Bansal M, Gairola M, Sharma D. Palliative care education and training during residency: A survey among residents at a tertiary care hospital. *Natl Med J India* 2001;**14**:102-4.
- 6 Simha SN. Issues faced by a hospice. *Indian J Med Ethics* 2005;**2**:85.
- 7 Education for Physicians on End-of-life Care (EPEC). American Medical Association, October 2000. Available at [www.epec.net](http://www.epec.net).
- 8 Ian Anderson Continuing Education Program in End-of-Life Care. November 16, 2001. Available at [www.pubmedcentral.gov](http://www.pubmedcentral.gov) and [www.cme.utoronto.ca/endoflife](http://www.cme.utoronto.ca/endoflife).
- 9 National Council for Hospice and Specialist Palliative Care Service. Available at <http://www.pubmedcentral.gov> and [www.hospice-spc-council.org.uk](http://www.hospice-spc-council.org.uk) (accessed October 2006).
- 10 European Association for Palliative Care. Istituto Nazionale dei Tumori, Milano, Italy., Oct 2001. Available at [www.pubmedcentral.gov](http://www.pubmedcentral.gov) and [www.eapcnet.org](http://www.eapcnet.org).
- 11 International Association for Hospice and Palliative Care. Oct 2000. Available at <http://www.pubmedcentral.gov/> and <http://www.hospicecare.com/>.
- 12 Bruera E, Neumann CM, Mazzocato C, Stiefel F, Sala R. Attitudes and beliefs of palliative care physicians regarding communication with terminally ill cancer patients. *Palliat Med* 2000;**14**:287-98.
- 13 Crawley LM, Marshall PA, Lo B, Koenig BA. End-of-life care consensus panel. Strategies for culturally effective end-of-life care. *Ann Intern Med* 2002;**136**:673-9.
- 14 Dunlop RJ, Davies RJ, Hockley JM. Preferred versus actual place of death: A hospital palliative care support team experience. *Palliat Med* 1989;**3**:197-201.
- 15 Townsend J, Frank AO, Fermont D, Dyer S, Karran O, Walgrove A, *et al.* Terminal cancer care and patients' preference for place of death: A prospective study. *BMJ* 1990;**301**:415-17.
- 16 Hinton J. Which patients with terminal cancer are admitted from home care? *Palliat Med* 1994;**8**:197-210.
- 17 Murray SA, Grant E, Grant A, Kendall M. Dying from cancer in developed and developing countries: Lessons from two qualitative interview studies of patients and their carers. *BMJ* 2003;**326**:368.
- 18 Dingle S, Anne M, Agnes B. Palliative care in Africa and the Caribbean. *PLoS Med* 1(1): e5 doi:10.1371/journal.pmed.0010005.