Symptom Levels in Care-Seeking Bangladeshi and Nepalese Adults With Advanced Cancer

abstract

Purpose Three-fourths of patients with advanced cancer are reported to suffer from pain. A primary barrier to provision of adequate symptom treatment is failure to appreciate the intensity of the symptoms patients are experiencing. Because data on Bangladeshi and Nepalese patients' perceptions of their symptomatic status are limited, we sought such information using a cell phone questionnaire.

Methods At tertiary care centers in Dhaka and Kathmandu, we recruited 640 and 383 adult patients, respectively, with incurable malignancy presenting for outpatient visits and instructed them for that single visit on one-time completion of a cell phone platform 15-item survey of questions about common cancer-associated symptoms and their magnitudes using Likert scales of 0 to 10. The questions were taken from the Edmonton Symptom Assessment System and the Brief Pain Inventory instruments.

Results All but two Bangladeshi patients recruited agreed to study participation. Two-thirds of Bangladeshi patients reported usual pain levels ≥ 5, and 50% of Nepalese patients reported usual pain levels ≥ 4 (population differences significant at $P < .001$).

Conclusion Bangladeshi and Nepalese adults with advanced cancer are comfortable with cell phone questionnaires about their symptoms and report high levels of pain. Greater attention to the suffering of these patients is warranted.

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Richard Reed Love

Tahmina Ferdousy

Bishnu D. Paudel

Shamsun Nahar

Rumana Dowla

Mohammad Adibuzzaman

Golam Mushih Tanimul Ahsan

Miftah Uddin

Reza Salim

Sheikh Iqbal Ahamed

Author affiliations appear at the end of this article.

Corresponding author: Richard Reed Love, MD, Amader Gram Cancer Care and Research Center, 11/8 Iqbal Rd, First Floor, Dhaka 1207, Bangladesh; e-mail: richardibcrf@gmail.com.

INTRODUCTION

Three-fourths of patients with advanced cancer are reported to suffer from pain,[1] and "85% of patients with pain can be well palliated with the use of simple, inexpensive, 'low technology' oral analgesics."[2(p715)] A primary barrier to provision of adequate treatment of symptoms is failure to appreciate the intensity of the symptoms patients are experiencing.[2] To provide optimal care for patients with cancer, accurate, complete, and timely information about symptoms—daily information if possible—is necessary. In particular, failure to use (repeatedly) validated symptom assessment tools prevents communication between patients and health care providers to bring attention to symptom issues.[3] The usual way such information is obtained is through direct questioning or information provided by patients in paper questionnaires during patients' office visits with medical practitioners. Such visits can rarely be daily. For patients with cancer, the most widely used questionnaire for this task is the Edmonton Symptom Assessment Survey.[4] This is a 10-question instrument that is usually answered by patients on paper.

Because pain is the most common distressing symptom for patients with cancer, a second instrument with more detailed questions about pain (worst [highest] level, best [lowest] level, and usual level in the last 24 hours)—the Brief Pain Inventory—is often used.[5] Common practice is to have patients provide answers on paper to these instruments when they are seen in doctors' offices. A more abbreviated symptom assessment strategy in doctor-patient encounters is simply to have patients verbally report their current level of pain using a visual analog scale of 0 to 10. However, this is a one-time and one-item assessment strategy. In an ideal situation, to monitor patients more completely, know how patients feel every day, and then make adjustments in treatments (such as types, amounts, and timing of pain medicines), it would be good to have data from such questionnaires every day. One even more practical way to make obtaining such detailed symptom information possible and usable by physicians is to put the questionnaires on a cell phone software platform, which the patient or his/her attendant could then complete at home and send by phone each day to a doctor's records and/or office.

Data on narcotic medication consumption in Bangladesh and Nepal show low consumption levels, which would suggest that pain control among patients with advanced cancer in these countries is likely to be poor. This conclusion characterized the recent Economist Intelligence Unit Quality of Death Index evaluation, in which Bangladesh was ranked 79th out of 80 countries (Nepal was not ranked).[6,7] Although long- and short-acting morphine are available in Bangladesh, access is limited to few pharmacies, and few physicians are comfortable using these drugs. In Nepal, opioids are available but accessible only in major cities, and again, only a minority of physicians are comfortable with their use. There are, however, limited published data about the symptomatic status of such patients. In these overall contexts, then, as part of a study evaluating the feasibility of using a cell phone platform questionnaire to obtain symptom status information, we have obtained such data from > 1,000 Bangladeshi and Nepalese outpatients with advanced cancer.

METHODS

We have taken items from the open source Edmonton Symptom Assessment Survey (nine of 10 items: nausea, tiredness, depression, anxiety, drowsiness, appetite, well-being, shortness of breath, and current pain; the "other problem" item was omitted) and Brief Pain Inventory (three items: worst, least, and usual levels of pain in last 24 hours) validated questionnaires, added three items (constipation, quantity of sleep, and quality of sleep) because these are standard questions that palliative care physicians ask of patients, and put these 15 questions on a cell phone platform in Bangla (the native language of Bengal/ Bangladesh) and Nepali. In < 3 minutes, patients can answer the questions by moving a cursor along visual analog scale bars (0 to 10) to indicate intensities of their symptoms. The cell phone program has the questions in both written and audio form, so that patients who cannot read or with impaired vision or poor visual acuity can also answer the questions. We have piloted this application with several patients and made adjustments to make sure the instrument presented in this form is easy to understand and use.

After obtaining appropriate scientific and ethical review board approvals in Bangladesh, Nepal, and the United States, at two tertiary care clinical sites in Bangladesh, and at three sites in Nepal, at the time of presentation for outpatient visits, we recruited adult patients with advanced incurable cancer who had normal mental status; performance status 0, 1, 2, or 3 on the Eastern Cooperative Oncology Group scale; ability to understand and cooperate with the study protocol, including cell phone operation; and willingness to participate and provide written informed consent. At the time of one single visit, each participant privately completed the instrument using a smart phone with the application provided by—and after training by—a research assistant. The research assistant did not look at or share individual patients' data. The data collected by the cell phone application were sent via a secure connection to a cloud server database. They were then accessed for analysis over a secure connection by a team at Marquette University. Occasionally there were network delays or power outages that prevented immediate transmission of the questionnaire data to the cloud, but otherwise all data transmission was successfully accomplished. The data were collected with some interruptions between April 2013 and August 2014.

RESULTS

Two patients of 642 individuals approached in Bangladesh and no patients of 383 patients in Nepal refused study participation. The distributions of the most common primary cancer types among the 286 Bangladeshi men (45%) and 354 Bangladeshi women (55%) and the 182 Nepalese men (47%) and 205 Nepalese women (53%) are shown in Table 1. Compared with the estimated major cancer incidences and causes of death in Bangladesh, colorectal cancer in men is modestly over-represented, breast cancer in women is over-represented, and cervical cancer in women is under-represented. Similar comparisons for Nepalese suggest that colorectal cancer and prostate cancer are slightly over-represented in men, and breast and colorectal cancers are slightly over-represented in women. Thirty-eight percent of Bangladeshi patients were ≤ 40 years old, and 19% of the Nepalese patients were in this age group.

Data for the four pain scores—average, maximal, minimum, and current—showed the following. Average/usual pain scores for Bangladeshis were ≥ 5 in 64%; in Nepalese they were ≥ 5 in 27% and < 4 in 50%. Maximal pain scores for Bangladeshis were ≥ 5 in 67%; in Nepalese they were ≥ 5 in 60%. There were no maximal pain scores of 9 or 10 in Bangladeshis. Minimum pain scores for Bangladeshis were ≥ 5 in 20%; in Nepalese they were ≥ 5 in 7%. Current pain scores in Bangladeshis were ≥ 5 in 74%; in Nepalese they were ≥ 5 in 52%. For the Bangladesh data, if we assume the population mean pain

Table 1. Major Primary Cancer Types Among Bangladeshi and Nepalese Patients Questioned About Their Symptoms

Bangladeshis		Nepalese	
Men (n = 286)	**Women (n = 354)**	**Men (n = 182)**	**Women (n = 205)**
Lung, 53 (19)	Breast, 99 (28)	Lung, 48 (26)	Breast, 52 (25)
Lymphomas, 47 (16)	Lung, 34 (10)	Head and neck, 46 (25)	Cervix, 32 (16)
Colorectal, 41 (14)	Ovary, 27 (8)	Stomach, 19 (10)	Lung, 22 (11)
Stomach, 21 (7)	Colorectal, 26 (7)	Lymphomas, 15 (8)	Ovary, 18 (9)
Head and neck, 21 (7)	Cervical, 19 (5)	Colorectal, 13 (7)	Colorectal, 14 (7)
Liver, 19 (7)	Lymphomas, 19 (5)	Prostate, 9 (5)	Stomach, 12 (12)

NOTE. Data presented as No. (%).

level is 5, then the T score = 2.125, with degrees of freedom (DOF) = 639 and P value = .0339. For the Nepal data, if we assume the population mean pain level is 5, then the T score = −3.2596, with DOF = 382 and P value = .0012. Testing then for differences in pain values of the two populations together, the T score = −3.8568, with DOF = 1,021 and P value < .001, suggesting that the two populations are significantly different in the levels of current pain. An analysis for usual or average pain showed similar results.

Average or usual pain score levels seemed to provide the highest correlations with other pain scores in both Bangladeshi and Nepalese populations. For Bangladeshis, scores for nausea, anxiety, loss of appetite, and sleep quality each showed correlations ≥ 0.74 with current pain levels. Scores in both country populations for men and women for all items were similar, and scores for the most common cancer types—lung in men and breast in women—were no different from those for all other cancers combined.

DISCUSSION

The first striking observation from our study is that in both countries essentially all patients were willing to and could provide data about their symptoms using a cell phone platform and did this successfully. This suggests that longitudinal repeated assessment using this cell phone application in these settings may be possible and that acceptance of such technology is high. In the settings of Bangladesh and Nepal, where there are no hospice services, the potential for use of such cell phone reporting to allow remote management is real and worthy of exploration.

In interpreting and attaching significance to specific data in this study, certain limitations should first be noted. We have recruited convenience samples; our data are from patients able to present to tertiary care facilities by dint of economic resources, location, and their nonterminal performance status. It is reasonable to suggest that our study subjects might, if anything, be better off (less symptomatic) than those in population-based samples in both countries. Demographically, our Bangladeshi patients were younger than the Nepalese patients and less representative of a normal population of patients with cancer, which would be expected to be older. How much the skewed percentages of types of cancer from those expected in the population generally might have affected the broad characteristics of the symptom data is uncertain but would seem to be small.

These limitations noted, our data suggest first that, as expected, Bangladeshi and Nepalese patients with advanced cancer are generally significantly affected with pain. Maximal and current pain scores were ≥ 5 in the majority of patients from both countries. As in other countries, these specific data are consistent with the low levels of narcotic drug consumption and now should justify greater attention to symptom and pain management in such patients.[6] Second, of possible clinical interest is that although higher Bangladeshi than Nepalese patient scores for pain may of course reflect the composition of the populations studied, it is possible that there are significant cultural differences in how these populations perceive their discomfort. In this study we did not share individual patients' data with their treating physicians, because in the circumstances in which the data were obtained this was not practical or, possibly, appropriate. Consequently, we could have no data on possible impact of this information on immediate patient care.

In conclusion, Bangladeshi and Nepalese adults with advanced cancer able to seek outpatient care are comfortable with cell phone questionnaires and report high levels of pain. Greater attention to the suffering of these patients is warranted, and the use of a cell phone application offers a

mechanism for real-time, daily or more frequent, monitoring of levels of symptoms.

AUTHOR CONTRIBUTIONS

Conception and design: Richard Reed Love, Rumana Dowla, Sheikh Iqbal Ahamed

Administrative support: Tahmina Ferdousy, Bishnu D. Paudel, Reza Salim, Sheikh Iqbal Ahamed

Provision of study materials or patients: Bishnu D. Paudel, Shamsun Nahar, Rumana Dowla

Collection and assembly of data: All authors

Data analysis and interpretation: Richard Reed Love, Rumana Dowla, Mohammad Adibuzzaman, Golam Mushih Tanimul Ahsan, Miftah Uddin, Sheikh Iqbal Ahamed

Manuscript writing: All authors

Final approval of manuscript: All authors

Accountable for all aspects of the work: All authors

Affiliations

Richard Reed Love, **Tahmina Ferdousy**, and **Reza Salim**, Amader Gram Cancer Care and Research Center, Khulna and Rampal; **Shamsun Nahar**, Bangabandhu Sheikh Mujib Medical University; **Rumana Dowla**, Bangladesh Palliative and Supportive Care Foundation, Dhaka, Bangladesh; **Bishnu D. Paudel**, National Academy of Medical Sciences, Kathmandu, Nepal; and **Mohammad Adibuzzaman**, **Golam Mushih Tanimul Ahsan**, **Miftah Uddin**, and **Sheikh Iqbal Ahamed**, Marquette University, Milwaukee, WI.

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