Introduction

Young doctors in South Asia are increasingly being exposed to principles of patient-centered communication in their training. Family doctors are often required to inform patients of a cancer diagnosis and be involved in their terminal care. However, there is little evidence on which South Asian family doctors can base their decisions with regard to how much information should be given to their patients. Most literature on communication preferences in medical consultations comes from western studies, which show that not all patients want or expect the same kind of communication. Several studies now confirm that the pattern of patients’ differing expectations can vary greatly between different cultural settings, including that of Nepal.[1-4]

In western countries there is usually a presumption that patients will be told their diagnosis if they are suffering from a serious disease. Some of the factors contributing to this practice include the rise of consumer rights, an emphasis on patient autonomy, and increasing medical litigation.[5,6]

The literature shows great diversity when comparing attitudes between different groups. It is also noted that there is great diversity within many of those ethnic groups.[6] In non-western settings, full disclosure of the cancer diagnosis to patients is often not expected or practiced. There are diverse attitudes found in African, Japanese, Chinese, Hispanic, Pakistani, and other Asian research.[7-16] As recently as 1984, oncologists in both western and non-western countries said that their usual practice was to tell the family rather than the patient.[17]

The reasons for non-disclosure to patients are diverse and are usually linked to cultural beliefs. The principle of
‘self-determination’ is central to western concepts of autonomy and promotes the idea of the independence of the individual. East Asian ethics refer to autonomy in a way that assumes ‘family determination,’ as an integral part of decision-making. The ideas of ‘harmonious independence’ and an ‘objective’ concept of good are part of this concept.\cite{19} Independence must be tempered by the need to maintain harmonious relationships. Many western doctors assume that a patient who defers to the advice of their family is acting under undue pressure. However, in many cultures family involvement is an integral part of a patient’s decision-making process.\cite{19}

Some cultures place the patient in a passive ‘sick role,’ in which they are to be protected from potentially harmful information or other stresses. It may be thought of as cruel to give too much information. One comprehensive literature review places the reasons for non-disclosure of a serious diagnosis into four main groups, as listed below.\cite{8}

1. It can be thought of as destroying hope for the patient
2. It may provoke depression in the patient
3. It may make a condition more real by verbalizing its existence, therefore, leading to a quicker death
4. It may be considered as rude or impolite to the patient

These concerns are reflected by an Iranian study that suggested that patients who did not know their diagnosis had better physical, emotional, and social quality of life.\cite{20} The widespread and varied nature of beliefs about disclosure are seen in international studies, which report rates of disclosure of terminal diagnoses from 17 (Japan) to 80% (USA).\cite{12} There is also a big variation in expectations of what doctors should provide, ranging from very technical details to broader emotional support.\cite{8,14}

There are several studies that have examined the question of disclosure in Nepal. A study done by Hospice Nepal showed that people in the Kathmandu valley favored being told about a serious cancer diagnosis. Eighty percent of the people surveyed said that they wanted to be told even if the cancer was incurable. This contrasted with the level of knowledge that cancer sufferers reported in a concurrent in-patient survey. Sixty-three percent of the patients reported that they had no knowledge of their cancer diagnosis.\cite{21} A study at Patan Hospital, Nepal, showed that people were generally keen to know about their own diagnosis, but were less keen to inform close relatives. This study found that 63% of the people would want to be informed if they had a cancer diagnosis. Thirty-four percent of the people reported that they would want a close relative informed in the same circumstances.\cite{22}

This diversity of attitudes and beliefs meant that each culture had to be studied separately to know what type of communication strategy was most appropriate. A prescriptive set of guidelines was not appropriate.\cite{23} The current study was undertaken to further explore the preferences and beliefs of Nepalese people, with regard to information-giving and information-receiving in cancer diagnoses. This information was important in guiding the communication training of medical students and junior doctors.

**Material and Methods**

A cross-sectional, hospital-based survey was carried out at the BP Koirala Institute of Health Sciences (BP KIHS) in Nepal. The objective of the study was to explore and compare the attitudes of medical students and patients, with regard to the disclosure of a cancer diagnosis. Ethical approval was obtained from the Ethics Committee at BP KIHS. The study instrument was a survey that was developed and piloted by the researchers, based on a survey instrument previously used in Kathmandu, Nepal.\cite{21} The subjects were first and fourth year medical students and the patients were those attending the General Outpatient Department (GOPD) at the study hospital. The survey first asked the subjects about their attitudes toward giving and receiving a cancer diagnosis. The subjects were then asked to rate their agreement, on a six-point Likert scale, to seven statements, about giving a cancer diagnosis. Four statements, taken from the literature, were about possible reasons for not telling the patients their diagnosis.\cite{10} Two statements were about the decision-making responsibilities of the family and patients. Finally, there was a general statement about telling patients the diagnosis. This was added to confirm the responses in the first section.

In the first phase of the study, the survey was given to 126 first year and fourth year MBBS students at BP KIHS, in 2009. It was self-administered in English, after giving consent for participation. All students were invited to participate and two declined. In the second phase, the survey was given to patients attending the GOPD at BP KIHS, in May–June 2010. The survey was translated into Nepali and back-translated, until a satisfactory version was reached. It was then piloted in GOPD and did not require modification. All patients attending the GOPD, for any reason, were eligible for inclusion, after giving consent. If the patient was under 16 years of age their main caregiver was approached for inclusion. The survey was administered as a structured interview, due to the low level of literacy in the population. This was done by one of the researchers, a doctor working in the GOPD. A convenience sample was taken, consisting of all the patients who saw that doctor during his rostered hours. The survey period was one month. The results were recorded in Excel and analyzed using the SPSS 17.0 software.

**Results**

There were 126 students surveyed in this study, 93 male (73.8%) and 33 female (26.2%). All students were aged between 18 and 25. There were 61 students from the first year and 65 from the fourth year MBBS, analyzed together and separately. One hundred patients were surveyed and the demographics are shown below (Table 1).

The responses to the first three questions — about giving and receiving a cancer diagnosis — are shown below. There were no
significant differences between the first and fourth year students’ responses. Question 1 was only given to students and the results were for the whole student group.

Question 1. If you were the treating doctor of a patient with cancer, would you tell them of their diagnosis?
A. Yes, only if the disease is curable. (6%)
B. Yes, even if the disease is not curable. (54%)
C. No, I would tell the patient’s party / family. (40%)
D. No, I would not inform the patient or their party. (0%)

Question 2. If a close relative was diagnosed with cancer would you like them to be informed of the diagnosis? [Figure 1].

Question 3. If you were diagnosed with cancer would you like to be informed of your diagnosis? [Figure 2].

The responses to the seven statements about giving a cancer diagnosis are shown below [Table 2]. Similar items were grouped for comparison, whereas, they were in a mixed order in the survey. The Likert scale was scored from ‘1’ — ‘strongly disagree’ to ‘6’ — ‘strongly agree’, 3.5 being the numerical mid-point. The mean scores and standard deviations were reported. A two-tailed t-test was performed and the P value given.

| Table 2: Student and patient responses to statements: Mean (SD) |
| --- | --- | --- | --- | --- | --- |
| Statement | Students | Patients | P value |
| You should not tell patients that they have cancer because it is polite | 3.66 (1.60) | 4.11 (1.68) | < 0.001 |
| You should not tell patients that they have cancer because it can make them depressed | 2.98 (1.53) | 4.28 (1.55) | < 0.001 |
| You should not tell patients that they have cancer because it will take away their hope of getting better | 2.54 (1.60) | 3.52 (1.77) | < 0.001 |
| It is the family’s responsibility to make decisions about the treatment of a patient with cancer | 3.52 (1.61) | 5.63 (0.80) | < 0.001 |
| It is the patients’ responsibility to make decisions about their own cancer treatment | 4.53 (1.55) | 4.73 (1.52) | 0.33 |
| It is best to tell the patients if they have a diagnosis of cancer | 4.56 (1.52) | 4.43 (1.82) | 0.57 |

The patients were significantly more likely to agree with all the possible reasons given for withholding a diagnosis. Ninety-six percent moderately or strongly agreed that it was the family’s responsibility to make decisions, whereas, students were divided on this. Students and patients generally agreed that the patient had some responsibility and that it was better if they were told. There were no significant differences found in patient responses between any demographic groups.

Two student sub-groups were analyzed according to their responses to Question 1 [Table 3]. If they had stated that they would only tell the patient’s party/family, regardless of the prognosis, they were classified as ‘non-tellers’. A two-tailed t-test was performed and the P value was given.

The responses to these statements indicated the most important factors influencing a student’s decision to tell a patient his/her diagnosis. Students as a whole were most likely to agree with the statement that causing a patient to become depressed was a reason for not disclosing the diagnosis. However, there were significant differences between sub-groups on all items. Among the ‘non-tellers’, the fear of making a patient lose hope was the most important factor. This item showed the greatest difference between the sub-groups. It was closely followed by the item on depression, but the difference was less. The item on fear of making the patient die more quickly was the other statement to show a large and significant difference between the sub-groups.

The attitudes of students toward the role of patient and family in decision-making were not associated with a different likelihood of telling and not telling.

The final item — about whether it is best to tell a patient — showed a large and significant difference between the sub-groups. However, there was absolutely no correspondence between what was considered ‘ideal’ and what people said they would do in Question 1. Among the ‘non-tellers’ 28 out of 50 students showed some level of agreement with the statement that it was best to tell.

The responses of the first and fourth year students were also compared. The only significant difference between the first and fourth year students was found in the statement concerning the patient’s decision-making responsibility. The first year students (mean 4.23 (1.75)) were less likely to agree with the patient being responsible for decisions than the fourth year students (mean 4.82 (1.29)) (2-tail t-test, P = 0.03).

**Discussion**

In this study, a little more than half of the medical students stated they would tell a patient that he/she had cancer, even when it was incurable. The figure in this study, of 54% in favor, was less than was found in the US data for physicians (80%), but much higher than was found in Japan (17%). However, there were still 40% of the subjects who favored telling the patient’s
family rather than the patient themselves. It was intriguing that the desire for being informed of incurable cancer was higher when a relative was involved (69%) and even higher when it involved the patients themselves (83%). The same findings were present in the previously cited Nepalese articles.[21,22]

Patients (49%) are significantly more likely than students (31%) to want a diagnosis withheld from a close relative if their cancer is incurable. Although there is no research data or anecdotal evidence, personal observation suggests that it is the usual practice in Nepal for a cancer diagnosis to be given to the patient’s family. It has been observed to be common practice for a family to ask the patient to wait outside the consulting room at the study hospital, when results of cancer tests are given. These data and practices are similar to those found in other Asian countries, as outlined earlier. This applies to highly-developed Asian countries such as Japan. This is despite the fact that a minority of patients (22%) have wanted the diagnosis withheld if they had an incurable cancer themselves.

This is not significantly different from the students’ attitudes (16%). These data are consistent with the results from the Kathmandu valley showing that between 63 and 80% of people will want to be informed of a personal diagnosis.[21,22]

There were large and significant differences in patients’ beliefs about the dangers of giving a cancer diagnosis, compared to those of the students. This was most evident in their strong belief that telling the patient would take away hope and lead to a quicker death. There was almost complete agreement among the patients that the family was responsible for making treatment decisions. These findings were consistent with the practice in Nepal, of families making decisions about paying for treatment and being responsible for signing consent forms. Doctors usually discussed these things with families and left them to decide what to tell the patient. Again, this was consistent with the Asian concepts of autonomy, previously discussed. The finding that students and patients had a similar general agreement with the concept that it was ‘better to tell’ is surprising. However, it was best understood in the context of questions 2 and 3, which showed the importance of prognosis as a factor in deciding whether to tell.

There was some evidence of a shift in attitudes during the medical training of these students. Students received teaching from the Departments of Psychiatry and General Practice in principles of patient-centered communication. This might have contributed to the fourth year students’ greater agreement with the patients’ role in decision-making. However, this was the only difference
identified between the first and fourth year students, both years expressing slight-to-moderate agreement with the idea that the patient was responsible for the decision-making. Culturally-based beliefs were only slightly modified by teaching ‘patient-centered’ communication.

The students tended to disagree with all of the reasons given for not disclosing a diagnosis. However, the group of ‘non-tellers’ was influenced by fears of causing depression, loss of hope, and a quicker death. The findings of this study supported the contention that these were the key fears that influenced the expectations of medical students and patients.

It seemed that families saw themselves as best placed to manage the problems of the patients’ reactions — and to filter their access to diagnostic information.

There is incomplete correspondence between the students’ beliefs about what is ‘ideal’ and what they think they would do. A majority of ‘non-tellers’ agreed with the statement that it was ‘best to tell’. This may reflect a belief that patients do not want to be told or that families are opposed to telling. This further underlines the gulf between what students state is appropriate for other people and what they would want for themselves.

There are limitations to this study. The research was carried out in a department that was known to teach patient-centered communication. This may have influenced some students to respond in ways that supported patient choice and disclosure of information. The patients were not familiar with surveys and Likert scales. Qualitative research would be useful to explore attitudes and beliefs in more detail. The patients were predominantly in the young and middle ages (86% less than 45 years of age). The study results might have been different with a greater proportion of elderly subjects.

**Conclusion**

In Nepal, even though culturally the family members and close relatives tend to filter the diagnostic information about incurable cancers, in this study the majority of patients and medical students stated that they would prefer to be informed of their own diagnosis. The results of this study can be used to guide the teaching on medical communication, particularly as it relates to end-of-life issues. There is tension between some Asian cultural beliefs and ideas of patient-centered communication — if these are framed in western terms. Issues such as the nature of autonomy and the role of the family need to be discussed and interpreted according to local practices and beliefs.

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