

# Cancer in Sri Lanka: The Question of, "To Tell or Not to Tell"

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## ABSTRACT

**Introduction** Cancer is an important cause of death in Sri Lanka and revealing the truth about cancer diagnosis has become difficult due to many factors.

**Objectives** To find the attitudes of Doctors, cancer patients and their close family members about informing the diagnosis of head and neck cancer at TH Anuradhapura.

**Method** A descriptive, prospective study was carried on histologically diagnosed cancer patients, their first degree relatives and doctors treating them.

**Results** Ninety three percent 93.6%(29) of the patients wanted the diagnosis of cancer to be told to them, 45.5%(12) relatives had the same view and 58.3%(21) of the doctors said that they would inform about the cancer to the patient.

**Conclusion** Our study indicates that cancer patients in Anuradhapura have no inhibition of accepting their diagnosis of cancer and its complications.

**Keywords** attitudes, cancer, revealing the diagnosis

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## INTRODUCTION

Cancer incidence has increased steadily in the past few years. It has also become an important cause of death in Sri Lanka<sup>1</sup>. Despite the significant improvements in cancer treatment it is still often perceived as a death sentence<sup>2</sup>. This makes the cancer information disclosure a challenging situation<sup>3</sup> and leaves the doctors, who diagnose, with the problem of whether to tell or not to tell about the diagnosis.

## METHODOLOGY

This descriptive, prospective study was carried out at the Teaching Hospital Anuradhapura for a period of 6 months. The study sample consisted of histologically diagnosed cancer patients, their first degree relatives and doctors treating them. The patients and relatives were selected consecutively from the Otorhinolaryngology and head and neck clinic and ward after getting informed consent for the study. The doctors were selected randomly from the units managing cancer patients. The information was collected using a questionnaire. Ethical clearance for the study was obtained from the Faculty of Medicine and Allied Science Rajarata University of Sri Lanka.

## RESULTS

A Total of 89 people were included in the study. All the patients diagnosed during the study period consented to be included in the study. The population included 31(34.8%) patients, 22(24.7%) first degree relatives and 36(40.4%) doctors. It included 26(29.2%) females and 63(70.8%) males. The mean age was 45(std16) years. Ninety three point six percent (93.6%(29)) of the patients wanted the diagnosis of cancer to be told to them, 45.5%(12) relatives had the same view and 58.3%(21) of the doctors said that they would inform about the cancer to the patient. Fifty four point six percent (54.6%(12)) of the relatives and 41.7% (15) doctors felt it was best to inform the relatives regarding the diagnosis before the patient, but only 6.4%(2) patients agreed to it.

Seventy one point seven percent (71.7%(38)) of patients and their relatives wanted the word "cancer" to be used directly when informing about the diagnosis, while only 52.8%(19) of the doctors adhere to this practice. Forty five point seven percent (45.7%(16)) of the doctors said they would accede to the family's request not to tell the patient the diagnosis of cancer.

A total of 88.7%(79) from the whole study population wanted the doctor to disclose the information to the patient while 8.9%(8) wanted a family member to do it. Out of the doctors 62.8%(22) were comfortable in discussing the diagnosis of cancer. Seventy five percent (75%(40)) of patients and their family members wanted the information of cancer to be given to them in the first visit while 60%(21) of the doctors preferred to tell them gradually using many visits.

Most (>94%) of the patients, relatives and doctors agree that prognosis and treatment methods should be discussed. Seventy seven point four percent (77.4%(24)) patients wanted the possibility of death to be discussed while only 27.2%(6) of the first degree relatives and 32.4%(11) doctors liked to discuss about death.

## DISCUSSION

Telling the truth about cancer diagnosis has become difficult due to many factors like the growing sensitivity of ethical and legal issues about patient's rights, the fear of health professionals to destroy the patient's hope and the lack of appropriate skills and education among health professionals for breaking bad news.

Another factor which profoundly affect "telling the truth" about diagnosis is in the context of cultural values<sup>4,5</sup>. One of the most influential cultural variables is family members and relatives<sup>4</sup>. The family is the strongest support system for patients, usually eager to protect the patient from any harm. This exert extra pressure on the health professional on how the information should be divulged even if they are not opposed to complete information disclosure to patients. This is seen in our study with 54.6%(12) of relative not wanting the information to be given to patients and 56%(30)not wanting to discuss about death.

In the west, it is common for the doctors to tell the diagnosis of cancer to the patients. But still they are confronted with the problem of how to break the news to the patient<sup>6</sup>. Our study revealed that 37%(13) of the doctors were not comfortable in disclosing the diagnosis of cancer.

In the East, like in Japan informing is equated to "pronouncing the death sentence"<sup>7</sup> and some doctors even feel that it should be legal to operate on cancer patients without informed consent<sup>8</sup>. Physicians attitude of non-disclosure are reported from studies in Greece<sup>9</sup>, China<sup>10</sup> and Japan<sup>11</sup>. In a multinational

survey conducted by Members of the International Psycho-oncology Society in Africa, France, Hungary, Italy, Japan, Panama, Portugal and Spain, it was estimated that only about 40% of their colleagues reveal "cancer" to their patients and instead use euphemisms such as tumour, growth, lump; whereas oncologists from Austria, Denmark, Finland, the Netherlands, New Zealand, Norway, Sweden and Switzerland estimated that more than 80% of their colleagues use the word "cancer". The majority of doctors (>90%) tell the family the diagnosis<sup>12</sup>. In our study group 58.3%(21) of the doctors said they will inform about the cancer to the patient, 52.8%(19) will use the word "cancer" to describe the condition and the majority (91.7%(33)) would tell the family the diagnosis.

More recently a considerable amount of studies in western countries showed that most of the people prefer being informed about their diagnosis,<sup>13,14</sup> although in other countries (e.g. Japan<sup>11</sup>, Southern Europe<sup>15</sup>, Greece<sup>16</sup>, Italy<sup>17</sup>, and Poland<sup>18</sup>) still the patients do not ask about their diagnosis or simply are not informed. This attitude seems to be grounded in some western countries based on respect to individual autonomy in contrast to other cultures principle of family beneficence for patient<sup>19</sup>. In the last decades there is more emphasis on patients' right to have autonomy of knowing the information related to their disease and engaging in the process of decision making<sup>20</sup>. The preference of Sri Lankan cancer patients, as seen in our study is more of a open view, with 93.5%(29) of them wanting to know about the cancer, 75%(40) wanting the information about cancer to be discussed on the first visit and 77.4%(24) patients wanting to discuss about prognosis and death.

The study has many draw backs such as it having a small population and as it is done in one hospital, not being able to generalize its findings to the whole country. However it gives the view of the study population where the patients in Sri Lanka unlike in other eastern countries wanting a more open view of their cancer diagnosis.

## CONCLUSION

Our study indicates that cancer patients in Anuradhapura have no inhibition of accepting their diagnosis of cancer and its complications contrary to the wishes of their close relatives and some doctors attending to them.

## REFERENCES

1. Cancer Incidence Data: Sri Lanka Year 2001-2005, Cancer Registry National Cancer Control Programme, Sri Lanka.
2. Powe BD, Finne R. Cancer fatalism: the state of the science. *Cancer Nurs.* 2003; 26:454-65.
3. Mills ME, Sullivan K. The importance of information giving for patients newly diagnosed with cancer: a review of literature. *J Clin Nurs.* 1999; 8(6):631-42.
4. Mystakidou K, Parpa E, Tsilika E, Katsouda E, Vlahos L. Cancer information disclosure in different cultural contexts. *Support Care Cancer.* 2004; 12:147-54.
5. Surbone A. Persisting differences in truth telling throughout the world. *Support Care Cancer.* 2004; 12:143-6.
6. S E Lind, M J DelVecchio Good, S Seidel, T Csordas, B J Good. Telling the diagnosis of Cancer. *J Clin Oncol* 1989; 7(5):583-9.
7. Long SO, Long BD. Curable cancers and fatal ulcers. Attitudes toward cancer in Japan. *Soc Sci Med.* 1982; 16(24):2101-8.
8. Hattori H, Salzberg SM, Kiang WP, Fujimiya T, Tejima Y, Furuno J. The patient's right to information in Japan--legal rules and doctor's opinions. *Soc Sci Med.* 1991; 32(9):1007-16.
9. Mystakidou K, Parpa E, Tsilika E, Kalaidopoulou O, Vlahos L. The families' evaluation on management, care and disclosure for terminal stage cancer patients. *BMC Palliat Care.* 2002; 1:3.
10. Li S, Chou U. Communication with the cancer patient in China. *Ann NY Acad Sci.* 2010; 809:248.
20. Lee A, Wu HY. Diagnosis disclosure in cancer patients-when the family says "no". *Singapore Med J.* 2002; 43:533-8.
11. Uchitomi Y, Yamawaki S. Truth telling practice in cancer care in Japan. *Ann N Y Acad Sci.* 1997; 809:299.
12. Jimmie C. Holland, Natalie Geary, Anthony Marchini and Susan Tross. Psychosocial Issues: An International Survey of Physician Attitudes and Practice in Regard to Revealing the Diagnosis of Cancer. 1987, Vol. 5, No. 2, Pages 151-154.
13. Bolund C. Crisis and coping with cancer psychosocial aspects of oncology. In: Holland JC ZR, editor. *Psychosocial aspects of oncology.* New York, Springer-Verlag, 1990.
14. Novack DH, Plumer R, Smith RL, Ochitill H, Morrow GR, Bennett JM. Changes in physicians' attitudes toward telling the cancer patient. *JAMA.* 1979; 241:897-900.
15. Thomsen, Wulff HR, Martin A, Singer PA. What do gastroenterologists in Europe tell cancer patients? *Lancet.* 1993; 341:473-6.
16. Mystakidou K, Liossi C, Machos L, Papadimitriou J. Disclosure of diagnostic information to cancer patients in Greece. *Palliat Med.* 1996; 10:195-200.
17. Giraldi T, Messina EG, Magnani K, Valle E, Cartel G. Physicians' attitudes to and problems with truth telling to cancer patients. *Support Care Cancer.* 2000; 8:40-5.
18. Meyza J. Truth telling, information, and communication with cancer patients in Poland. *Ann NY Acad Sci.* 1997; 809:468-79.
19. Akabayashi A, Kai I, Takemura H, Okazaki H. Truth telling in the case of a pessimistic diagnosis in Japan. *Lancet.* 1999; 354:1263.
20. Schaffner A, Bronstein A, Jellin N. Information and shared decision-making are top patients' priorities. *BMC Health Serv Res.* 2006; 6:21.