

Original Article

## QUESTIONNAIRE BASED SURVEY OF GENERAL POPULATION TO ASSESS THEIR VIEWS ABOUT DISCLOSURE OF CANCER DIAGNOSIS AND REVIEW OF LITERATURE

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### ABSTRACT

**Objective:** To ascertain people's views regarding disclosure of cancer diagnosis and whether they would like to share this information with their family. The study also looked at whether if their parents were diagnosed to be suffering from cancer, would they like this information to be communicated to them.

**Study Design:** Questionnaire based survey.

**Main Outcome Measures:** Proportions of various views.

**Results:** The total number of persons surveyed were 520. Fifteen persons refused to participate in the survey, hence they were excluded and 505 respondents 299 male and 206 female were analyzed. Ages of the respondents were between 18 to 80 years. The study population belonged to different socio-economic groups in the society. Three hundred ninety-one (77.4%) responded positively that they would like to know if they ever suffer from cancer, while 112 (22.1%) said No and 2 (0.39%) said it doesn't matter. Three hundred seventeen (62.7%) wanted their family to be informed while 187 (37.0%) said No and the attitude of 1 (0.19%) was Indifferent. One hundred seventy (33.6%) responded positively that if their parents were diagnosed to be suffering from cancer they should be told about it, whereas 334 (66.1%) did not wish their parents to be informed and 1 (0.19%) was indecisive. All those who were indifferent were elderly, above the age of seventy years. Majority 326 (82.6%) who wanted to know the cancer diagnoses were literate and interestingly 57 (50.8%) who didn't wish to be informed were also literate.

**Conclusions:** Most of the people in the survey 391 (77.4%) wanted to know the diagnosis, if they ever suffered from cancer. Again 317 (62.7%) wished this to be disclosed to their family. Only a small percentage 170 (33.6%), wanted to tell the bad news of cancer diagnosis to their parents if they ever suffered.

**KEY WORDS:** Cancer, diagnosis disclosure, family, literacy.

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## INTRODUCTION

Cancer is one of the unique illnesses, which continue to evoke deep-rooted fear and a sense of helplessness. It carries the reputation of death sentence accompanied with tremendous pain and sufferings and the negative stigma attached to the word cancer is so strong that its mere mention may be considered callous, rude and even disrespectful. A well-known physician in Jena and Berlin, Christoph Wilhelm Hufeland (1762-1836) is reported to have said that "to prophesy death is to cause

it".<sup>1</sup> Even the first code of ethics by the American Medical Association (1847) had incorporated that "A physician should not be forward to make gloomy prognostications..... but he should not fail, on proper occasions, to give notice to the friends of the patient timely notice of danger when it really occurs; and even to the patient himself, if absolutely necessary".<sup>1</sup>

The Italian Medical Association code until 1989 stated that "A serious or lethal prognosis can be hidden from the patient but not from the family".<sup>2</sup> A survey in Americans conducted in 1950s had also revealed that almost 90% of physicians preferred not to inform the patients about their cancer diagnosis.<sup>3</sup>

There has been a dramatic change and rapid shift in the cultures of the developed world during the last three decades. Studies by Novek and Oken's in 1971 showed that 90% of physicians would disclose the truth to cancer patients as opposed to 10% in the previous study.<sup>4</sup>

For a long time, it was felt that disclosure of cancer diagnosis to the patient meant accelerating their psychological and physical death. The quality of life of such patients will be severely affected; hence the healthcare professional by and large refrained from disclosing cancer diagnoses to the patients as well as most of their family members. Even Hippocrates encourages physicians to conceal most things from the patient while attending them.<sup>5</sup>

Previously patients had little or no participation in decision making about their treatment. A good patient was supposed 'to do as they are told' without questioning the treating physician's decision. However the situation has now changed a lot. With the revolution in information technology, the patients and their family members are much better informed. Many patients particularly those with higher education wish not only to be informed of their disease and its treatment but also want to actively participate in decision-making about management. It is no longer possible for the treating physician to hide the cancer diagnosis and there is an increasing urge among the patients to look at the alternate methods of treatment even if they offer a remote hope.

For too long doctors have treated patients with strict paternalism. The divine position that the healthcare professionals used to enjoy for a long time no more holds good. The doctor patient relationship, which was based on principle of beneficence and non-maleficence in which doctors used to take decisions regarding treatment in the best interest of patients is now being increasingly questioned. This study was conducted to find out the views among our general population whether they would like to know if they ever suffer from cancer and whether they would like to share this information with their family. The study also looked at whether if their parents were diagnosed to be suffering from cancer, would they like to share this information with them.

## SUBJECTS AND METHODS

For the purpose of this study the main author conducted a close-ended questionnaire survey among 520 persons both male and female selected at random. Out of this 15 refused to participate in the survey, hence they were excluded. The remaining 505 respondents 299 male and 206 female were analyzed. The participants were explained in detail about the questions in their mother tongue, its significance, relevance and purpose of study. The following three questions were asked.

1. Do you want to know if you are suffering from cancer?
2. Do you think your family should be informed?
3. If any of your parents is diagnosed as suffering from cancer, would you like that they should be informed?

The respondent replied in Yes, No and Indifferent. The people surveyed belonged to different socio-economic groups. The exclusion criteria were only age less than 18 years and diagnosed cancer patients. Apart from seeking answers to these questions other demographic information like age, sex and education were also recorded. All those who had primary and above education were included

in the literate category.

## RESULTS

A total of 505 persons, which included 299 (59.2%) males and 206 (40.7%) females participated in the survey. Majority of the persons 391 (77.4%) wanted to know the diagnosis if they were suffering from cancer. Similarly 317 (62.7%) desired that this information should be shared with their family. However majority 334 (66.1%) were of the view that in case their parents were diagnosed to be suffering from cancer they should not be

informed (Table-I)

Majority of those who wanted to know cancer diagnosis were literate 362 (83.3%) while 57 (50.8%) persons who didn't want to know were also literate. Similarly the majority of the literate persons in the survey 248 (78.2%) wanted to share this information with their family. (Table-II)

The response to all the questions from male as well as female who participated in this survey was almost identical to the three questions in their respective perception (Table-III).

Table-I: Response by the respondents to the questions

Question Asked	Total No. (%)	Total No. (%)	Total No. (%)
	Yes	No	Indifferent
Q#1: Do you want to know if you are suffering from cancer?	391(77.4)	112(22.1)	2(0.39)
Q#2: Do you think your family should be informed?	317(62.7)	187(37.02)	1(0.19)
Q#3: If any of your parents is diagnosed as suffering from cancer, would you like that they should be informed?	170(33.6)	334(66.1)	1(0.19)

Table-II: Literary status of the respondents

	Total No. (%)	Total No. (%)	Total No. (%)
	Yes	No	Indifferent
Q#1:	391(77.4)	112(22.1)	2(0.39)
Illiterate	65(16.6)	55(49.1)	2(100)
Literate	326(82.6)	57(50.8)	0(0)
Q#2:	317(62.7)	187(37.02)	1(0.19)
Illiterate	69(21.7)	43(22.9)	1(100)
Literate	248(78.2)	144(77.0)	0(0)
Q#3:	170(33.6)	334(66.1)	1(0.19)
Illiterate	53(31.6)	46(13.7)	1(100)
Literate	117(68.8)	288(86.2)	0(0)



Table-III: Response to the questions according to sex

	Male			Female		
	Total No. (%) Yes	Total No. (%) No	Total No. (%) Indifferent	Total No. (%) Yes	Total No. (%) No	Total No. (%) Indifferent
Q#1	241(80.6)	57(19.0)	1(0.3)	150(72.8)	55(26.6)	1(0.4)
Q#2	181(60.5)	117(39.1)	1(0.3)	136(66.0)	70(33.9)	0(0)
Q#3	106(35.4)	192(64.2)	1(0.3)	64(31.0)	142(68.9)	0(0)

DISCUSSION

Treatment prospects for cancer were very bleak until late 1970s, hence vast majority of healthcare professionals considered it inhumane and damaging to the patient to disclose the bad news about the diagnosis.<sup>3,6</sup> It was felt that breaking the bad news to cancer patients meant 'hitting the patient over the head' or 'dropping a bomb'.<sup>7</sup> By late 1970s, majority of the physicians were open about talking to cancer patients regarding their diagnosis.<sup>4</sup> Various studies also showed that patient desired to have additional information. A survey among 1,251 Americans published in 1982 showed that 96% wished to be told if they had a diagnosis of cancer and 85% wished that in case of grave prognosis they should be given realistic estimate as to how long they were going to survive.<sup>8</sup> European patients wishes were similar to those found among American patients. A study of 250 patients in an oncology center in Scotland showed that 91% and 94% of patients respectively wanted to know the chances of cure and side effects of cancer therapy.<sup>9</sup>

It is now generally believed that diagnosis of cancer may lead to uncertainty, fear and loss which can be alleviated by information<sup>10-12</sup> which has increasingly been considered helpful to the patients to cope with cancer.<sup>13-17</sup> In the past faith in the doctors competence precluded the need for further information as it was felt that medical knowledge was too difficult for the patient to understand particularly

so among the elderly who felt that search for additional information could be dangerous making the already difficult situation worse.<sup>18</sup>

Value of hope and quantum of information

The value of hope in managing chronic diseases is very well established.<sup>19,20</sup> Hope is considered essential for coping and this could be maintained by avoiding to communicate potentially negative information. Hope is also considered indispensable for survival.<sup>18</sup>

Various studies have also highlighted that there is significant difference about the quantum of information which the cancer patient want to know while some studies highlight that patient wanted as much information as possible. Patients from the affluent areas wanted more information as compared to those from the deprived areas.<sup>9</sup> This is in contrast to findings in our survey wherein no significant difference was observed. However the above study<sup>9</sup> was conducted among cancer patients, while our survey was carried out among the general population, which is an important difference in these two studies.

Study by Qidwai et al.<sup>21</sup> among general practitioners revealed that 64% of them were in favour to disclose diagnoses to the cancer patients. This strengthens our findings that majority of the patients wanted that cancer diagnoses should be disclosed to them. Here again the difference between these two studies is that while our study was conducted among general population, study by Waris

et al. was conducted among general practitioners to ascertain their views on bioethical issues. This has also been documented that patients anticipate that the doctors would be honest and respect their confidence.<sup>22</sup>

Patients generally complain that doctors don't listen to them patiently and they are not told about their disease.<sup>23</sup> A study in England showed that many physicians failed to tell patient if they had cancer. A survey among gastroenterologists in Britain also revealed that one third of them could not tell the patient that they had cancer unless specifically asked for.<sup>24</sup> A postal questionnaire survey of doctors during 1984 showed that 44% of consultants and 25% of General Practitioners do communicate the cancer patients their true diagnosis.<sup>25</sup> Another survey among young patients receiving radical chemotherapy for uncommon tumours with good prognosis showed that they wished more information.<sup>26</sup>

### *Who should communicate the bad news?*

A question that is often asked is as to who should communicate the bad news of cancer diagnosis to the patient? Despite the fact that specialist nurses and counselors in many countries particularly in the West, are doing a commendable job and are considered important member of the cancer management team, most of the patients still desire to be told about their cancer diagnosis by the consultants.<sup>9</sup>

### *Cancer diagnosis and psychiatric disorders*

The mere mention of cancer is extremely stressful both for the treating physician as well as for patients. There could be many reasons why doctors avoid communicating bad news. Some feel that it will precipitate depression.<sup>27</sup> At times the doctors feel that treating patients should be their first priority rather than communication. Some doctors don't feel at ease while discussing serious illness and the threat of death instead they resort to using words like 'tumor', 'growth', 'cyst' and 'lesion'.<sup>28</sup>

There is another viewpoint that protecting patients from knowing the truth could be

counter productive. Lack of information can increase anxiety, dissatisfaction, stress and uncertainty.<sup>29</sup> Studies have also shown that the level of psychological distress in seriously ill patients is far less when they think that they have received an adequate information.<sup>11,30</sup>

In North America, the principles of informed consent, patient autonomy and case law have created clear ethical and legal obligations to provide patients information about their illness and treatment as much as they desire.<sup>31,32</sup> Physicians may not withhold information even if they suspect it might have a negative effect on the patient thereby seriously affecting their quality of life.

### *Guidelines on breaking bad news*

Several groups have prepared guidelines on breaking bad news and preparing patients for relevant investigations.<sup>33-36</sup> These guidelines are based on patient's expectations, their need and information preferences. It is important for the healthcare professional to find out a way of providing information, which is appropriate for patients who may benefit from knowing about their illness and its treatment. Some of them may not be interested to find out everything about their illness at all times. It is reported that in 1980 an oncologist Ingelfinger who was also the editor of New England Journal of Medicine didn't want to know all the available information nor face the uncertainties of different treatment options, which were offered to him.<sup>37</sup>

### *Communications Skills*

Poor communication skills among the healthcare professionals is considered their important weakness, which is a major cause of complaints about them. The importance of teaching communication skills, which is considered an essential component of Continuing Professional Development (CPD)<sup>38</sup>, has recently been realized. Now College of Physicians and Surgeons Pakistan (CPSP) has also made it mandatory for all the Post Graduates to attend workshop on communication skills before attempting FCPS Part II.

Tesser and others in their studies conducting psychological experiments have showed that the bearer of bad news often express strong emotions such as anxiety, a burden of responsibility for the news and fear of negative evaluation.<sup>39</sup> This stress creates reluctance to deliver the bad news, which is named as MUM effect. It is particularly strong when the recipient of bad news is already perceived as distressed.<sup>40</sup> As such it is not at all difficult to imagine that these very factors may operate when bad news is communicated to the cancer patients.

With the passage of time cancer patients can expect better surgical technique, improved radiation outcome, chemotherapy with manageable morbidity besides exciting advances in their care from gene therapy. All this highlights the importance of taking patients into confidence while making decisions about their treatment. Hence, the need to communicate cancer diagnosis.

### *Benefits of diagnosis disclosure*

The benefits of diagnoses disclosure are many.<sup>41-43</sup> Conteno-Cortes et al<sup>44</sup> showed that there was no increase in perceived symptoms of anxiety, despair, sadness, depression, insomnia or fear in the group of informed patients as compared to uninformed patients. Almost 75% of informed patients were able to share their concern about their illness and its consequences with their relatives whereas only 25% of those who were not informed were able to do that.

Communicating the cancer diagnosis to the patients enables them to take certain important decisions in their life relating to their families, business, making a will and emotional adjustment to the illness. It is also helpful to the patient in symptoms control and their satisfaction with care. Informed patients experience lower levels of pain interference with daily life and such patients were also more satisfied with cancer pain management provided by nurses and physicians.<sup>45</sup>

In Japan family members are often the first to be informed by physicians of the cancer patient diagnosis, condition and therapeutic

program. The family members then discuss whether the diagnosis should be disclosed.<sup>46,47</sup> The family decision is greatly respected often in deference to that of patient.

At times disclosure of a diagnosis of cancer may cause conflict between treating physicians and family members. A study by Ajaj A et al<sup>48</sup> among the elderly patients showed that 88% wanted to be informed of the diagnosis.

In the days to come it is very unlikely that the physicians would be able to withhold diagnosis from patients. With better education more and more people would like to control their own health. It is felt that the doctors should seek permission to speak to the patient alone to ascertain what the patient want to know rather than to force the bad news on the patient. The bad news is best broken by someone who is very dear and close to patient and has some degree of continuity in their caring preferably someone who has a rapport with the patient and the family. It is not at all desirable to 'break a bombshell' and walk away from the scene.

## CONCLUSION

In our culture, the families usually take the decision on behalf of the patients particularly the elderly. At times the decision by the family members is directed by their own vested interests, which may vary like inheritance of property etc. As such it will be much better if the patients are well informed so that they can take such important decisions on their free will in their lifetime.

The present study has certain limitations. Firstly the survey included general population as compared to other studies, which were conducted in cancer patients. Secondly the number of respondents is not very high. The findings of this study however do show an indication that a vast majority of the population particularly those who are literate wish that they be informed of cancer diagnosis if they suffer from such a dreaded disease. There is a need for much larger studies to confirm the above finding in our population.



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