

Right to know or Request to Withhold: Which should be Honored?

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ABSTRACT

A 45 y old male patient was admitted to ICU with CA stomach which metastasized to other body organs. He did not know about the disease and asked Health Care Provider (HCP) many times about his condition, but HCP did not tell him. Because, his family wanted to keep it confidential. After one month, the patient dies due to poor prognosis. If HCP have told him before his death, he might have been able to accomplish his important tasks. In this case, the reason behind the family's decision of keeping the diagnosis confidential to patient could be in a way that family thought that patient will be unable to cope after disclosure of actual diagnosis.

Keywords: Right to know; From the lens of family; Ethical principle; Verbosity; Confidentiality patient rights; Health care provider

INTRODUCTION

In the above scenario, three ethical principal: confidentiality, autonomy, and non-maleficence developed an ethical dilemma which produce guilt in HCP for not disclosing the information. Cancer is an intricate disease, and considered to be non-curable from three decades till now. In many ethnic groups, cancer is considered death. Therefore people tend to hide it from patient if diagnosed and the person is removed from life subconsciously. Currently, HCPs are being trained to inform the patients about their illness; however, practices vary from region to region and country to country. Though, HCPs still deceive the patients at times during treatment with clear lies, half-truths or molded proclamation of information [1].

The major sources of information to the patients are HCPs working around them. Sometimes, when patient belongs to any ethnic group of minority or villages with deprived health and education facilities and family is powered by the households, they do not allow HCPs to keep the patient informed about the disease. Importance of such issues has been widely acknowledged in healthcare practices. The most problematic ethical dilemma for HCP working with cancer patients is whether, how much, how and when to convey the patient about truth. Approach of truth telling has been perceived differently in different areas. Present case report is aimed to learn about the problems involved in releasing the sensitive information to the cancer patient and ethical dilemma involved in telling the truth [2].

FROM THE LENS OF FAMILY

There are evidences present which reveal that families avoid to tell a truth to cancer patients in various countries, societies, and

ethnic groups. Importantly, most studies revealed that most of the patients have desire to remain updated about their disease although they already know their current situation but possibly they want to know their ailment from HCP as they believe in them [3,4].

Families, on the other hand, are very much caring and concerned about their patient. Families although believe in HCPs even if they think that their patient will be mentally tortured a lot. Furthermore families do not want to see their loved ones hopeless. All responses shown by the family are dependent on the cultural values and norms of their society though refinement of behaviors is necessary with the advancement of time [5].

Perspective of truth telling from HCPs is very complex and based on the complete information regarding diagnosis and or prognosis. Describing the patient's perspective is an successful association between HCPs and patient, which is strongly dependent on true communication. True engagement of the patient leads a batter therapeutic adherence and which ultimately increase the level of healthcare. In present scenario, if HCPs would have informed the patient about the prognosis of his disease and patient might be able to think and plan accordingly, further, might have talked to his family, which may result in completion of his important tasks [6,7].

FROM THE LENS OF HEALTH CARE PROVIDER

Ethics is a small word with very deep standards of assessment, beliefs, and customs which is not based on the wishes of any individual therefore; it makes its own way of actions and decision makings. Positive performance of any organization is also replicated by its custom values and ethics. Additionally, defilement from customs of ethics may result in harmful outcomes for patient by

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HCPs which is not allowed at any cost [8,9].

Truth telling has been recommended as an ethical concern and it is thought to be a moral duty by most of the HCPs. Another perception supports the truthfulness and explains that it benefits the overall process of therapeutic relationship which ultimately establishes assurance between patient and HCP. Truth decreases the chaos in patient who is seeking standard advised treatment. On contrary harmful outcomes may be prevented by following the principle of veracity [10,11].

Health awareness to the family and patient has been reported to get familiar with different clinical situations. In United States, it is compulsory to inform most of the patients about their diagnosis while same is in Finland, Canada and England. While it is also pertinent that these countries have excellent healthcare systems in which HCPs have little choices there as far as potentially. Further they possess strong disclosure policies and bound to implement them. On the other hand in Japan, family of patient plays an important role in making the decision whether patient has to be informed about its diagnosis or not. A study reported that only 13% HCPs directly inform the patient about their disease if they are diagnosed with cancer while rest of the patients are totally dependent on their own family to seek true information. Any bad news sometimes is likely to change the situation considerably which may put negative effect on patient's future [12,13].

Organizational ethics are always part of standard operating procedures of every reputable organization. Most of the organizations endorse social norms, respect of patient and their morality which help the HCP to keep the ethics in mind during their job. On the other hand organizational policies must reflect the transparent policies and must not rely on personnel decisions. Since ancient times, truth telling has been remained in debates between philosophers and religious leaders, and truth has always been preferred usually if not crucial for relationships while any kind of deception needs justification [14,15].

In this case telling a truth to patients may result in early withdrawal of patient from treatment and instead of doing or thinking of his necessary deeds, he may go into a state of mind which may result in early loss of his strength [16].

JUSTIFICATION OF MY POSITION

To me telling a truth is good for cancer patient about his disease. Patients have been observed to perceive the situation for long time about bad events and news. On the other hand, knowing diagnosis of cancer among patients has been reported to reduce their lives with drastic results. Reports about the truthfulness of nurses have revealed that diagnosis and prognosis of patients is their responsibility [17,18].

Faulkner on the other hand wrote that person telling the bad news must be most trustworthy for the patient as patient stays comfortable with that person. In this case it may be the HCP who break the news. None of HCPs with the exception of few do, commonly break bad news in United Kingdom. Most of the HCPs also believe that role of communication about diagnosis or prognosis belongs to the other HCPs who are trained in disclosing such sensible information [19,20].

HCPs have strong communication with patients, particularly in oncology; the communication is thought to be the most significant part in patient's recovery. So, HCPs mostly have to play the role through communication with cancer patients. Hence, HCPs play

their role of supporting patient in all circumstances and keep the ability to safeguard patients and respect their desires by even listening at minimum [21,22].

On the basis of above discussion although I have a bad feeling in my heart that HCP did not tell the truth to patient. Studies proposed different possible remedies to tackle with such dilemmas for example Hagerty, proposed that many patients desire truthfulness from HCPs regarding their prognosis and they must be provided an opportunity to ask about possible treatment outcome. Similarly communication strategies could change the state of mind of people which enable HCPs to have discussion with families in a better perspective of patient's rights [23,24].

POSSIBLE CONSEQUENCES

Quality of life for patients is referred to its social, physical and emotional well-being so that they can perform day to day tasks accordingly. In advanced stage of cancer patients have limited time and it is very much important to maintain the quality of their life. Global incidence of cancers is surging day by day and may cross 20 million cases a year. Furthermore, while lack of preparedness has been observed, therefore, the disease demands attention not only on scientific endeavors but on ethical principles such as autonomy of patients which must be considered. Conclusively, HCPs must consider the effect of any disclosure on cancer patients [25-28].

RECOMMENDATIONS

This kind of scenario must be presented in institutional review boards for providing ethical guidance. However, HCPs must be sincere with their profession, patients and place of work. Place of work denotes the organizational structure, vision, mission, culture and quality of provision of healthcare.

CONCLUSION

Terminal cancer patients face challenges in their life at every stage. Although they understand their fate at the end, but sometimes do not ask due to fear of facing the truth. Although, practically they remain facing the consequences of disease. It is concluded that the patients must not be informed if any ethnic, cultural, or other values exist among the families. Although, right to know has greater value and could not be denied at all but sometimes more respect is given to the request to withhold as in present scenario.

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