Disclosing the Truth
A Dilemma Between Instilling Hope and Respecting Patient Autonomy

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ABSTRACT
While medical ethics place a high value on providing truthful information to patients, disclosure of truth is far from being the norm between people, creating a moral dilemma between instilling hope and respecting patient autonomy. Through the review of relevant literature, an attempt to examine the difference in this issue worldwide will be made. The review also aims to ascertain the resulting factors of the differences. Various electronic databases were searched by the author and through systematic selection 19 articles were identified that this literature review is based on. There are many parameters that lead to the concealment and disclosure of the truth, ranging from human rights, family responsibility, to cultural background. The attitudes towards telling the truth to terminal-stage patients differ socio-culturally, based on the priorities assigned to patients' autonomy and the principle of beneficence and non-maleficence.

Keywords: *Ethical Dilemma, Non-maleficence, Beneficence, Autonomy*

1. INTRODUCTION

Autonomy is considered as the capacity to be one's person and to make decisions with one's will rather than being manipulated or distorted by external forces. Likewise, the ethical principle of respecting patients' autonomy refers to fully acknowledging patients of their diagnosis and prognosis, and enabling patients to get involved in making decisions about their health care and treatment [1]. According to Beauchamp and Childress [2], making autonomous decisions should be accompanied by sufficient and accurate understanding of the condition.

On the issue of disclosing or withholding the truth in terminally ill patients, paternalistic tradition plays a dominant role in the first half of the twentieth century, when patients and their families perceive doctors as the only decision makers with the right of withholding information from patients [3]. In contemporary society, though, the debate on non-disclosure of truth is at the core of medical ethics and there is no global consensus on this issue. The dilemma between disclosure and non-disclosure comes down to the interplay between autonomy and beneficence, and cultural differences also play an important role in this dilemma.

Some people argue that medical paternalism should not be recognized as beneficence, full information disclosure shows respect for patient autonomy. Others claim that beneficence should override patient autonomy when facing terminally ill patients, so information should be withheld from them because it may cause harm. Additionally, the truth-telling dilemma is also troubling different people from various aspects: doctors ' predicament is that truth-telling to terminally ill patients tend to decrease their work satisfaction and makes them feel incompetent and distressed [4]. Patients' family members always take beneficence and hope-instilling into consideration; from patients' perspectives, although a major of terminally ill patients want to be informed of their diagnosis, there are still plenty of them not willing to receive bad news.

Due to cultural differences, the attitudes towards disclosure and non-disclosure varies between countries. It is noteworthy that the common and socially acceptable choices of this issue is completely different between in different countries, and there is a gap between Western and Eastern countries. However, with the progress of globalization, there is a global trend towards revealing more information to patients. Evolutions are taking place in many countries, such as Italy, where attitudes towards

truth-telling are gradually turning from non-disclosure to disclosure [5].

While there has been much research on ethical principles of this issue, few researchers have considered other factors, such as the influence brought by different levels of degree in death education. Besides, It is notable that the research methods that the majority of research adopted are interview and scenario questionnaires, there is a lack of statistical analysis on this topic. Furthermore, there is also an apparent lack of a generally-accepted definition of instilling hope and autonomy, which left people jolting bafflement. Further research could discuss deeper sociological factors like education and family bond. Moreover, it could be interesting to explore how and why people's general view in one fixed place changes over time.

This review aims to explore the reasons regarding truth disclosure on terminally ill patients. As truth-telling touches the very essence of medical ethics, this article begins with patient autonomy. Then explore and explain the mainstream reasons for disclosure and non-disclosure. Afterward, the most significant contributing factors—cultural Influences, will be presented in detail.

2. PATIENT AUTONOMY

2.1 Legislation on Patient Autonomy

Kilbride MK *et al*. pointed out that historically, there was a common sense that it was the physician's main duty to promote the patient's beneficence, even at the expense of sacrificing the patients autonomy. [6]. But from legislation perspective, patient autonomy is partly getting protected in law over the course of history. For example, in America, a great number of laws are take into practice, such as the Americans with Disabilities Act of 1990 and the Health Insurance Portability and Accountability Act (HIPAA) of 1996. These legislation on patient autonomy have made remarkable achievements. Cohen IG *et al.* mentioned that the past few decades had witnessed the success of implementing HIPAA: permitting reasonable information flows for treatment, operations, research, and public health purposes make patients feeling safe [7]. Another example also shows the progress of legal protection for patient autonomy: Taiwan passed the Patient Autonomy Act in 2016, which is the first law in Asia protecting specific the autonomy of patients. Yet, there does not exist a law protecting patient autonomy in mainland China, but it deals with this issue with specific laws, such as the Tort Liability Law and the Law of Medical Practitioners, which set regulations on medical procedures and treatments [8], having impact on patient autonomy in a undirect way.

2.2 Reasons for respecting patient autonomy

Except for legislation protection, there are also various other factors contributing to respecting patient autonomy.

Many doctors or health professionals choose to conceal patients from potentially harmful diagnoses and prognoses, under the well-meant guidance of promoting patients' beneficence. However, Fallowfield, L. J., *et al.* [9] stated that truth may hurts but concealment hurts more. Withholding the truth intentionally could destroy the relationship between doctors and patients because once the patient interpreted the hidden information from any source, trust between patients and doctors collapses. Therefore, respecting patient autonomy plays a dominant role in developing doctor-patient relationships. Subsequently, the collapse of trust and doubt may negatively influence patients' adherence to therapy, and then the effectiveness of therapy will decline [10].

Besides, the "conspiracy of silence" have a high risk of resulting in a heightened state of fear, anxiety, and confusion, rather than expected results— calm and equanimity [9]. Doubt and misinterpretation will not benefit patients, instead, it usually cause immense suffering.

Meanwhile, knowledge empowers people. The development of new treatments, especially for those incurable diseases, makes it difficult for doctors and family members to cogitate the cost-benefit ratio for patients. So patients are indispensable to make their final decisions, which requires disclosure of patients' diagnosis and other information to make them properly involved in their treatment decision making [11].

Contributing factors for disclosure of diagonosis are summarized. See Table1

Table 1 . Contributing factors for disclosure of diagnosis

AUTHOR	ARGUMENT	TYPE OF FACTOR
FALLOWFILED ET AL., 2002	Build better patient-doctor relationship	Patient Autonomy
GOLD ET AL., 2004	Empowering patients' knowledge and respecting patients' right to make final decisions	
BESTE ET AL., 2005	respecting autonomy is a necessary condition for acting beneficently and fostering authentic hope	Beneficence
FALLOWFILED ET AL., 2002	Avoid anxiety and confusion brought by conjecture	
KAZDAGLIS ET AL., 2010	Improve patients' adherence to therapy	

3. REASONS FOR WITHHOLDING THE TRUTH

In contemporary medical practices, patient autonomy could be overvalued when more and more people think that patients are entitled to know their diagnosis. According to Entwistle, V. A. *et al.* [1], a strong focus on autonomy is problematic, especially when people over-stress patients' independence in decision-making. For instance, if independent decision-making is overvalued, patients who are not competent enough to process the information will feel abandoned rather than feeling autonomous.

Besides, many physicians proved that terminal illness can reduce a patient's capacity of making reasonable decisions, because the pain and fear brought by the illness just block them from processing information rationally [12].

Since the diagnosis and prognosis could be incomprehensible for patients, it can be regarded as a dereliction of doctors' duty when doctors purely left all the information to patients [11].

Meanwhile, people don't want to diminish hope, especially facing terminally ill patients. Research conducted in Taiwan based shown that both patients' families and doctors find it challenging to take away hope from patients and they tend to panic in dealing with patients' potential emotional problems [13]. In China, for example, many people believe that causing patients to lose hope by disclosing the truth will only hasten their death and that withholding medical information is of great beneficence to the patients.

Hence, some families and doctors usually choose to withhold the truth and instill hope for patients' beneficence. Another up-to-date research conducted by Mondal [14] also supports this idea. After conducting in-depth interviews with 108 terminal-stage adult cancer patients, 306 family members, and 25 physicians in the state of West Bengal, India, it has been found that even though 85.60% of the patients prefer full disclosure, only 22.03% are informed. The main factor behind non-disclosure is the family members' preference for principles of beneficence and non-maleficence over patient autonomy. Hence, only 9.32% of those 118 patients' family members have agreed to full disclosure of the truth.

Another important factor contributing to the concealment of truth is patients' will. Research suggested that there is evidence showing patients who just prefer not knowing the truth. For instance, a substantial minority of patients (13%) autonomously abandon their autonomy, they prefer to "leave it up to the doctor" or "to have information only if it is good" [15]. In this circumstance, keep disclosing information to patients is playing against patients' will.

Contributing factors for non-disclosure of diagonosis are summarized. See Table 2.

Table 2. Contributing factors for non-disclosure of diagnosis

Author	Argument	Type of Factor
Entwistle, V. A. et al., 2010	Incompatible patients can act autonomically	Patient Autonomy
Beste, J. et al., 2005	Severe illness robs patients of their autonomy	
Golden, M. et al., 2004	It's doctors' duty to process incomprehensible information for terminally ill patients	
Jenkins, V. et al., 2001	Patients are unwilling to know bad news	
Lin, C. C. et al., 2003	Avoid psychological morbidity	Beneficence

4. CULTURE INFLUENCE

Culture fundamentally shapes people's values and beliefs. In this issue, culture shapes how people think of illness, responsibility, end-of-life care, and death. The priority given to truth-telling and thereby respecting autonomy (versus beneficence or non-malfeasance) is culturally and individually determined [16]. Truth-telling reveals core values such as independence, individualism, autonomy, and so on; withholding the truth reflects the predominance of the ethical paradigm of beneficence — avoiding the loss of hope and unnecessary emotional distress is more humane and ethical.

Though demographic characteristics, like age, gender, education, etc., have marginal influences over the issue of truth-telling, culture plays the most profound and divisive role in this issue.

Although respecting patient autonomy act as a dominant norm in many Western countries, it is still far from being a globally-shared value. People's view on revealing the truth to terminally ill patients largely differs between different countries based on the priorities assigned to patients' autonomy and the principles of beneficence and non-maleficence.

A detailed and wide-ranging study surveyed citizen centers within Los Angeles County, California, and they

found that Korean Americans (47%) and Mexican Americans (65%) were significantly less likely than European Americans (87%) and African Americans (88%) to insist that a terminally ill patient should be informed his or her diagnosis. Moreover, they concluded that the main reason for the difference is that the former two old a family-centered model of medical decision making rather than the patient autonomy model favored by most of the African-American and European-Americans.

Another significant study conducted by Zhang, H. *et al.* focused on the cultural differences on this issue between China and the United States[17]. By analyzing four representative cases (two from China and two from the US) involving ethical dilemmas, they revealed that Chinese and American bioethics differ largely due to the impact of Chinese Confucianism and Western religions. Chinese ethics focus on the interdependence of family and the public good, which override the principle of respecting autonomy. In contrast, western societies place a high value on independence and individualism, leading to the accurate and truthful disclosure of information. Except the US, common disclosure also occurs in England, Canada, and Finland. The main reason is that in many Western societies, the right to be involved in decision-making is safeguarded by-laws [18].

However, non-disclosure can also happen in some Western countries where family-bond play a significant role. For instance, In Greece, although most doctors believe that informing patients is of great significance, they still avoid informing them about their true diagnosis directly. Moreover, driven by the motivation to keep them from anxiety and despair feelings, doctors usually follow family's wish to exclude them from the information [5].

On the other hand, it is investigated that nearly 60% of oncology physicians insist that terminally ill patients should not be informed of their condition [19]. This paternalism of Chinese doctors is rooted in the cultural background that protecting patients from depression is the priority.

Besides China, paternalistic practices also exist in many other cultures. In Saudi Arabia, 75% of doctors choose to discuss information with families, rather than directly talk with patients. Similarly, in Kuwait, 79% of doctors help conceal the truth after the request of patients' families [18].

5. CONCLUSION

This review examined factors contributing to disclosure and non-disclosure of diagnosis systematically, suggesting that truth-telling issue is incredibly complex facing terminally ill patients. In modern societies, it is widely accepted as a fundamental ethical principle, that patients should be informed about their diagnosis, prognosis, and treatment. But beneficence makes the ethical principle less straightforward. Cultural difference have a profound effect on the dilemma between patient autonomy and beneficence.

There is a lack of unanimity among researchers regarding the definition of hope, which is important for evaluating whether avoidance of truth-telling is an effective strategy of instilling hope. Besides, some demographic characteristics, like age, gender, education, etc., though they only have marginal influences over the pattern of truth-telling, should be studied further. Patients with terminal illness suffer from complex symptoms, beneficence and non-manificence are difficult to balancence under this circumstance. Therefore, research on exploring the factoes leadimnhg different attitudes and the diference between coutries are highly needed.

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