

# The Impact of Culture and Religion on Truth Telling at the End of Life

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## Abstract and Introduction

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### Abstract

Truth telling, a cardinal rule in Western medicine, is not a globally shared moral stance. Honest disclosure of terminal prognosis and diagnosis are regarded as imperative in preparing for the end of life. Yet in many cultures, truth concealment is common practice. In collectivist Asian and Muslim cultures, illness is a shared family affair. Consequently, decision making is family centred and beneficence and non-maleficence play a dominant role in their ethical model, in contrast to patient autonomy in Western cultures. The 'four principles' are prevalent throughout Eastern and Western cultures, however, the weight with which they are considered and their understanding differ. The belief that a grave diagnosis or prognosis will extinguish hope in patients leads families to protect ill members from the truth. This denial of the truth, however, is linked with not losing faith in a cure. Thus, aggressive futile treatment can be expected. The challenge is to provide a health care service that is equitable for all individuals in a given country. The British National Health Service provides care to all cultures but is bound by the legal principles and framework of the UK and aims for equity of provision by working within the UK ethical framework with legal and ethical norms being explained to all patients and relatives. This requires truth telling about prognosis and efficacy of potential treatments so that unrealistic expectations are not raised.

### Introduction

Death is an inevitable and frequent event in the renal setting. Prevalence of end-stage renal disease (ESRD) in Europe in 2009 has risen to ~932 per million population, carrying with it a 5-year survival probability of 48%.<sup>[1]</sup> Furthermore, the incidence of ESRD is increased 3- to 4-fold in a number of ethnic minority groups.<sup>[2]</sup> This disproportionate burden of ESRD among ethnic minorities has in part been attributed to an increased incidence of hypertension and diabetes, susceptibility to the development of diabetic nephropathy and to that of tuberculosis.<sup>[3,4]</sup>

London for example, typified by its multicultural society and population, has a resident non-UK born population of ~40%.<sup>[5]</sup> Almost two-thirds (63%) of all migrant Londoners are from BAME (Black, Asian and Minority Ethnic) groups; they also comprise one-fifth (22%) of London's UK-born population.<sup>[6]</sup> Around 50% of patients on renal replacement therapy in London are from ethnic

minorities, predominantly South Asian.<sup>[7]</sup> With such a diverse population, encounters between patients and physicians of different backgrounds are common and often challenging. Both patients and physicians bring to the clinical encounter their own languages, explanatory illness models, religious beliefs and ways of understanding the experience of suffering and dying.<sup>[8]</sup> This is particularly pertinent in the renal setting where the high mortality associated with ESRD demands nephrologists to frequently engage in end-of-life discussions with their patients and their families.

As the speciality of palliative care has advanced, many have issued calls to recognise it as a fundamental human right.<sup>[9]</sup> As contentious as these calls are, there is little disagreement on the benefits palliative care provides.<sup>[10]</sup> For many patients, recognising the end of life facilitates meaningful advance care planning discussions, enabling strengthening of interpersonal relationships and control of their illness, so as to achieve the best quality of life for the patients and their families and, ultimately, to attain a good death.<sup>[2,11,12]</sup> Renal palliative care has become increasingly recognised, as the significant morbidity and mortality associated with ESRD and renal replacement therapy are acknowledged and as concerns grow regarding the futility of treatment leading to prolonged dying and needless suffering. Joint annual educational palliative care and renal meetings, as well as the publishing of literature providing guidance to aid nephrologists in facilitating as good a quality death as possible, are important milestones.<sup>[2,13]</sup>

Truth telling to competent patients is a cardinal rule widely affirmed in Anglo-American medical practice.<sup>[14]</sup> For example, truth telling has been encouraged by the Gold Standards Framework in the UK primary care setting as a necessary component of the care of the dying, enabling a point of entry into palliative and end-of-life care.<sup>[15]</sup> This moral (ethical) stance, however, is not echoed worldwide, nor has it always been so in the West historically. Paternalism and beneficence were the overarching principles underpinning medical ethics at the start of the twentieth century.

Subsequently, respect for autonomy became the salient ethical principle influencing Western thought, and hence, deception became the epitome of unacceptable physician paternalism.<sup>[14,16]</sup> In failing to provide the truth, physicians deny patients the right to exercise their autonomy.<sup>[17]</sup> Explaining the truth about diagnosis, prognosis and treatment options generates the basis for freedom of the individual's choice.<sup>[14]</sup>

Britain's end-of-life strategy [18] reflects the core values of Britain's dominant culture— independence, individualism, autonomy, fear and futility of relentless efforts extending poor quality life.<sup>[13]</sup> Not all patients and families, however, share these values and concerns. In many ethnic communities, physicians and families often feel that withholding medical information is in the best interests of the patient. This reflects the predominance of the ethical paradigm of beneficence in those cultures as opposed to the predominance of autonomy in Anglo-American culture. For cultures where beneficence dominates, concealing the truth is more humane and ethical, avoiding the loss of hope and unnecessary emotional distress inherently linked with disclosure.<sup>[8]</sup>

The tenet of 'open and honest communication is always the best policy' is, therefore, a controversial one. The priority given to truth telling and thereby respecting autonomy (versus beneficence or non-malfeasance) is culturally and individually determined.<sup>[17]</sup> Culture fundamentally shapes patients' views and belief systems. It shapes how we make meaning out of illness, suffering and dying and our preferences around decision making, receiving bad news and end-of-life care. Britain's emphasis on patient autonomy, informed consent and truth telling is, therefore, often at odds with the beliefs and values of a significant proportion of its population, who may place greater value on family involvement in decision making.<sup>[19]</sup> Truth concealing can cause difficulties for treating

physicians who have to make decisions balancing conflict with patients and their families, respecting differing cultural beliefs with denying patients their right to autonomy and the ethical paradigm of justice by pursuing futile treatment in a health care system limited by resources.

## **Concealing the Truth**

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In many cultures, families and physicians are readily prepared to conceal the truth regarding patients' illnesses. The ethics of a number of Asian and Eastern countries require any fatal diagnosis or prognosis to first be disclosed to a family member.<sup>[16]</sup> Subsequently, following discussion with the treating physician, the family judge whether communicating the truth is in the best interests of the patient. The truth is often concealed for fear that it will extinguish the patient's hopes, leading to despondence, physical suffering, mental anguish and a hastened death.<sup>[20]</sup> Truth telling is, therefore, regulated by the prevailing concern for patient beneficence.

In several southern and eastern European countries, much of Asia and the Middle East, physicians and patients often feel that withholding medical information is more humane and ethical.<sup>[8]</sup> In Ethiopian culture, for example, there are fears that patients can die from the shock of bad news;<sup>[21]</sup> the family is responsible for managing the information and patient experience during illness. Indeed, Plato recognised the value of 'merciful lies', used to maintain hope, and forbade anyone but physicians to lie.<sup>[16]</sup>

There is general agreement, even in Eastern cultures, of the benefits of truthful communication between physicians and patients.<sup>[22]</sup> Yet, there remains resistance to the disclosure of grave diagnoses and prognoses. Authors of an Iranian paper acknowledged 'without any doubt' the right of patients to autonomy and the truth regarding prognosis on the imperative condition, however, that 'he or she should be able to tolerate the truth with minimal psychological and somatic damage'.<sup>[23]</sup>

It is accepted that the majority of patients are aware of their bodies and poor health and will have contemplated bad news. For many, a diagnosis of a shortened life expectancy or life-limiting disease, while attended by a natural sadness, is more of a confirmation rather than a traumatic unexpected event. For a minority, the news is unexpected and a few may have a more extreme, although short-lived, emotional response. In the Anglo-American autonomy-dominant paradigm, it is considered that open communication and initial sadness are necessary in order to address unspoken fears, openly discuss treatment and care options and plan for the future and ultimately death. Indeed, studies in patients with advanced kidney disease have demonstrated that open and honest information sharing enhances hope.<sup>[24]</sup> Others argue that such information destroys hope.<sup>[25]</sup> Studies from India,<sup>[26]</sup> Turkey<sup>[27]</sup> and Iran<sup>[25]</sup> have all found significantly lower psychiatric morbidity and/or quality of life in patients who were 'unaware' of their fatal prognosis.

Concealment of the truth, to many Westerners, appears unquestionably disrespectful of patients. However, Beyene argues that 'no one is more able than patients themselves to judge failing health'.<sup>[21]</sup> She suggests that, contrary to the Western way, not all cultures are concerned with 'overtly preparing for death'. For many Muslim patients, it is God who permits death, hence giving up hope is against religious teaching, amounting to the loss of faith in God.<sup>[21,28]</sup> Consequently, discussing the probability of death is considered disrespectful to their religion and to their belief in God's power.<sup>[22]</sup>

Physicians are also influenced by their own cultural and personal values. Studies have demonstrated the personal difficulties some physicians encounter with Western truth-telling practices.<sup>[29]</sup> The

ETHICUS (End-of-Life Practices in European Intensive Care Units) study found physicians from southern European regions displayed more paternalistic patterns in end-of-life decisions and communicated less with patients and their families.<sup>[30]</sup> Patients predominantly rely on physicians to guide them into end-of-life care, infrequently initiating such discussions, thus, studies which have found that the cultural values of the physicians influence truth-telling practices are of significant concern.<sup>[31]</sup> Ultimately, the medical responsibility resting with physicians must surely outweigh their own self-interests.

## Cultural Compatibility of Bioethics

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In Islamic ethics, family and community are intrinsically linked with each individual's well-being.<sup>[32]</sup> Similarly, in many Asian cultures, illness is a shared family event rather than an individual occurrence.<sup>[33]</sup> The family provides a source of strength, hope and connectedness to others. Accordingly, the principle of autonomy does not bear the same weight as it does in many Western cultures and thus the family is the locus of the decision-making process.<sup>[34]</sup> A Japanese study [35] found that 46% of the population felt it was the family's duty to provide 'a protective role in shielding the patient from a painful diagnosis'.<sup>[36]</sup> Equally, in Ethiopia and Saudi Arabia, information regarding a patient's illness belongs to the family, who then use the information in the best interests of the patient.<sup>[21,37]</sup> Physicians, consequently, respect the 'autonomy of the family as a unit'.<sup>[34]</sup>

Autonomy constitutes, along with beneficence, non-maleficence and justice, the popularly accepted 'four principles'—put forward by Beauchamp and Childress in the USA to fulfil a 'culturally neutral approach to thinking about ethical issues'.<sup>[38]</sup> Medical practice in the UK is built closely on the ethics these principles denote. However, a number of authors have argued that while the above principles themselves may not be at odds with differing cultures, importantly, it is the priority and credence given to each principle which causes cross-cultural incongruence.<sup>[20,39,40]</sup>

The founders of 'the four principles approach' draw caution in their analysis of truth concealment behaviour, pointing out the paternalistic nature of non-disclosure.<sup>[41]</sup> Yet, Macklin argues that disclosing the truth to all patients is also a paternalistic act.<sup>[41,42]</sup> Autonomy is a right, not an obligation, thus imposing decision making or truth telling on patients who are unwilling or unprepared to participate is a violation of integrity. This is the rationale for advanced training in communication so that professionals are trained to respond to a patient's request for information or resistance to information. Furthermore, it has been suggested that the growing preoccupation with patient autonomy and individual rights neglects family values and physician responsibility, reflecting the Western cultural bias of the bioethical community.<sup>[43]</sup> Attempts have been made to redress this, both in the UK end-of-life strategy<sup>[18]</sup> and *Mental Capacity Act (2005)*,<sup>[44]</sup> where the role and importance of involving the family (with the patient's consent) is highlighted. The resuscitation guidance by the General Medical Council<sup>[45]</sup> acknowledges the requirement for patient and family discussions in decisions but concludes that it is ultimately a medical decision whether or not to treat.

## Futile Treatment

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While health care professionals seek to accentuate and respect the patient's culture and autonomy, they face a further source of conflict with their duty to prevent prolongation of the dying process, in order to prevent unnecessary distress, and to the appropriate distribution of limited resources (i.e. to

the principles of non-malfeasance and justice) when patients request futile treatment at the end of life. Sanctity of life in religions, such as Islam, results in every living day being of value.<sup>[39]</sup> The patients' and their families' trust in God may therefore deter them from making decisions about life and death. Their reluctance to discuss and accept fatal diagnoses and prognoses means they are often unwilling to consider forgoing life-prolonging/sustaining futile treatment. Instead, aggressive therapy is sought, prolonging life at all costs, even when invasive manipulation of the patient's body is involved to which the patient has not consented and which confers no benefit.

In Islamic ethics, as noted above, death only occurs when God permits.<sup>[40]</sup> Health care providers must, thus, do everything in their power to prevent premature death and save life.<sup>[33]</sup> It is the duty of the physician, in Islam, to search for cures and to provide care and pain relief for patients.<sup>[32]</sup> In Saudi Arabia, for example, futile treatment is advocated by many and often requested by relatives.<sup>[20,37]</sup> This is, however, a subject of great dispute, even among Islamic scholars. Some actively do not advocate treatment if it is to merely prolong the final stages of life. Moreover, they stress that delaying death with futile treatment is unacceptable in Islam [28]—the Qur'an encourages the recognition of one's own limits.<sup>[32]</sup> Islamic law, therefore, permits the withdrawal or withholding of futile or disproportionate treatment when consent is obtained from a family member, allowing death to take its natural course.<sup>[32]</sup> Significantly, there are only a minority of hospitals in Saudi Arabia with a 'Do Not Resuscitate' protocol allowing for a dignified death.<sup>[37]</sup> Of importance, a study in Lebanon, looking at withholding and withdrawal of treatment in an intensive care unit, highlighted concerns that the shift of focus to palliative care was taking place inappropriately late in the course of the patients' illnesses.<sup>[46]</sup> There is thus recognition that delaying the inevitable death of a patient is neither in the patient's nor in the public's (limited resources) best interests.

According to Islam, the physician needs to be certain of the inevitability of the impending death or else life should be sustained.<sup>[36]</sup> Futility of end-of-life treatment, however, can be difficult to define. This is due to several factors such as the effect on quality and length of life, emotional costs, financial costs and likelihood of success. Value judgements are therefore used in the subjective evaluation of futility of treatment with resulting uncertainty regarding the usefulness in defining such a term.<sup>[47]</sup> Consequently, many physicians in Saudi Arabia, for example, who are less experienced than American physicians in distinguishing between medical utility and futility, are unwilling to declare their certainty of an impending death.<sup>[37]</sup> Perhaps, this goes some way in explaining the trend highlighted in the Lebanese intensive care unit, of delayed shift from curative intent to palliative care.<sup>[44]</sup>

The concept of medical futility is more widely accepted in Western cultures; in the UK, General Medical Council guidelines state that physicians are not ethically obligated to provide futile treatment.<sup>[45]</sup> Within the UK paradigm, medical decisions of futility and benefit ultimately dominate, although patients and family must be given the opportunity to understand the reasoning. This means it is beholden on the health care team not to burden the patients and family with the guilt of decision making; this is especially opposite in situations where cultural beneficence dominates. Health care professionals are therefore not asking for permission to act or withdraw but are instead informing or discussing what decisions have been made and why.

Some evidence supporting the above approach comes from a recent study by Zhang *et al.*<sup>[48]</sup> which found that terminally ill patients who had engaged in end-of-life discussions had greater quality of life and death, fewer futile interventions due to advance decision making and significantly lower health care costs in their final week of life. This study highlights the loss to the patient (with a lower

quality end of life and death) and to the health care system (of wasted resources) associated with the pursuit of futile disproportionate treatment.

As explored above, patients and their families, who favour concealing the truth may actively request futile treatment. This causes conflict for the physician who has to decide between respecting the patient's (or their family's) autonomy, the beneficence of relieving suffering, the non-malfeasance of not inflicting the harm associated with the side effects of treatment and justice of fair distribution of limited resources. Furthermore, while weighing the above arguments, physicians must recognise both their own and the patient's/family's perceptions of the benefit, goals and values gained from the treatment decision.

## Conclusions

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In a time of rapid globalisation and growing cultural diversity, it is inevitable that clashes of belief systems will occur. It is a challenge for health care professionals to find ways to adapt their medical practice and ethical models in order to meet the needs of patients from different cultural backgrounds. For countries where the benefits of truth telling are embedded in medical practice, it may be challenging for physicians to understand the cultural demands of patients unwilling to communicate about end of life. The importance of respecting these patients' values is crucial to respecting their autonomy. At times, this may test our engrained moral values and ethical codes. No matter how set in stone medical practices are, we should always revisit them and question whether they are in the best interests of the patient. Conversely, we need to be aware of dangers that could arise from too readily adapting to differing cultural values. Proceeding with futile treatment is neither in the best interests of the patient nor of our health care system. The key to progressing is good communication and access to advanced skills training.

Having evolved from a Western secular origin, it is of little surprise that the rather 'white' bioethical structure of principalism fails in achieving cultural neutrality. The challenge is to provide a health care service that is equitable for all individuals in a given country. The British National Health Service provides care to all cultures but is bound by the legal principles and framework of the UK and aims for equity of provision by working within the UK ethical framework. While acknowledging different cultures, the concept of a multi-tiered system and treatment based on money, race, linguistic ability or different cultural norms is not possible or desirable. Part of the duty of the health care professional is to achieve equity of care; this entails careful explanation of our legal and ethical norms to all patients and relatives. This requires truth telling about prognosis and efficacy of potential treatments so that unrealistic expectations are not raised.

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