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Consent in terminal sedation

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Abstract

For the majority of patients at the end of life, their symptoms can be relieved through good palliative care. However, for an unfortunate few, these symptoms become intractable despite the best holistic interventions and in such cases terminal sedation is considered. The use of this intervention remains fraught with controversy, particularly around the subject of consent. A clinical scenario is used to propose that under such circumstances, given the physical and psychological stress to which these patients are subject, it is neither useful nor meaningful to ask for the patient's informed consent. Instead, physicians caring for such patients should act in the patient's best interests, in accordance with the Best Interest Principle, to alleviate such suffering.

The concept of consent has evolved from being an ideal to "informed consent", a concept with legal significance (1,2). Informed consent refers to consent when "one is competent to act, receive a thorough disclosure, comprehend the disclosure, act voluntarily and consent to the intervention" (3: 285,. This position has led some to refer to it as the sacred cow of medical ethics. In truth its venerability is exaggerated especially when considering informed consent in the context of conditions that call for terminal sedation. This paper will seek to justify the primacy of the Best Interest Principle in such circumstances, based on the fact that most patients in this state cannot satisfy the basic requirements of informed consent.

Terminal sedation and the duty of palliative care

The term terminal sedation is defined as "the intention of deliberately inducing and maintaining deep sleep but not deliberately causing death in very specific circumstances. These are for the relief of one or more intractable symptoms when all other possible interventions have failed and the patient is perceived to be close to death OR for the relief of profound anguish (possible spiritual) that is not amenable to spiritual, psychological or other interventions and the patient is perceived to have a prognosis of less than 1 month." (4: 257) Refractory or intractable symptoms refer to "symptoms that cannot adequately be controlled despite aggressive efforts to identify a tolerable therapy that does not compromise consciousness." (5: 89) Such a diagnosis is made when "the clinician must perceive that further invasive and non invasive interventions are incapable of providing adequate relief or associated with excessive and intolerable acute or chronic morbidity, or unlikely to provide relief within a tolerable time frame." (6:31) When this diagnosis is confirmed, and the need for terminal sedation established, the medical professional's duty shifts from cure and prolonging life to maximising comfort, function and quality of life (6).

Despite significant advances in guidelines on this subject, and their implementation and monitoring, concerns about terminal sedation persist. This is particularly so when obtaining consent from patients with intractable symptoms which will affect cognition and thus the consent process (7,8). Such a situation ought not exclude patients in the decision making process but it does call for closer scrutiny of the consent that is obtained, while stressing that all decisions must be taken with due consideration of the patient's best interests.

The demise of the sacred cow

I suggest that true informed consent cannot be obtained from patients with intractable symptoms at the end of their lives. Nor can consent, if obtained, be construed as legitimate (7,9). I therefore suggest that when terminal sedation is considered, the Best Interest Principle should be applied. The following case highlights some of the issues that arise in such a situation.

Patient A is a 24-year-old man with cancer of unknown origin involving his lungs, liver and brain, precipitating severe shortness of breath, pain and agitation. All efforts to ameliorate his symptoms have failed. His anxiety and agitation have continued to worsen despite generous doses of sedatives and eventually require him to be physically restrained. His father asks only for his son to be made "comfortable" adding that his son's only wish was to be "free of suffering". He is aware that hastening death is illegal and will not be condoned by the medical team.

Given A's condition, obtaining any form of consent at this juncture, simply to ward off paternalistic decision-making, would be an exercise in futility at best and at worst replacing one form of paternalism with another. Indeed, given A's circumstances, any decision that he might make would clearly be questionable and unlikely to satisfy any of the criteria required for informed consent, much less be justifiable, "respected" or likely to be upheld (9-11).

In such circumstances, the requirement of consent to commence treatment constitutes an infringement of the patient's autonomy. This requirement may be viewed as being paternalistic. However, it has been deemed necessary, and is understandable given the physician's duty to verify the validity of any consent, particularly one made in such circumstances.

I suggest that in such a situation, when consent cannot be obtained, or is not considered to be voluntary and informed, a physician is ethically obliged to act in the patient's best interest. This is so even in the absence of consent - or even despite the patient's apparent refusal, especially if this refusal is made under conditions such as in the case of Patient A whose case is discussed above. In such a situation, the physician who does not intervene in the patient's best interests has failed in the duty to care, and in the duty to not abandon the patient (12).

Given this obligation, physicians are obliged to provide care that meets the patient's needs and is in the patient's best interest. In order to do this, the physician must have the appropriate training and clinical experience, and wherever possible the care should be provided through a multidisciplinary team (13,14). Within a palliative care medical team, experienced healthcare professionals from various specialisations assess patients to establish what is in their best interests, and to decide upon the appropriate line of care. A team-based approach also protects against any maverick decision-making.

Dissecting the sacred cow

One of the main reasons to re-examine the issue of informed consent is the question of competence. A patient's competence depends on the person's ability to perform a task and also on how well these abilities match the particular decision - for instance A may wish to decline oxygen therapy believing that he will cope without it, when in fact he will become distressed and confused once hypoxia sets in (7). Studies have shown that up to 80% of terminally ill patients suffer some cognitive impairment, affecting insight and hence their ability to give informed consent (15,16). These factors, coupled with these patients' particular physical, psychological, spiritual, social and economic situations, impede their ability to act in a manner that protects their best interest, leaving them susceptible to external influences, compromised voluntariness* and impaired decision making capabilities (17).

At the same time there has been much discussion on the amount of information that ought to be provided to a patient. Some have argued against the full disclosure of information under the Principle of Beneficence but insist instead that information should be conveyed piecemeal, to protect the patient from unnecessary distress. This view is not current, but it has some truth particularly for patients for whom terminal sedation may be considered, when both the patient and the family are under extreme emotional and physical burdens. In such circumstances, it may be justified to exercise the "therapeutic privilege" where the physician acts paternalistically in the patient's best interest simply to improve A's quality of life (18,19). Gillon has argued that the distress caused by conveying complete information violates the principle of non maleficence. He states that certain types of information are merely "guesstimates" and the physician who imparts this information places an unreasonable burden on the family - as well as on himself (19).

This problem might have been better addressed with the use of advanced medical directives (AMDs). However AMDs are not commonly issued, and can be vague, without specific guidance regarding the patient's wishes in various possible scenarios Further, it has been argued that a person's values and goals change over time and may contradict previous arrangements, wishes or goals that may be stipulated within the AMD.(20,21)

The Best Interest Principle

The Best Interest Principle is a means of considering the "value of the life for the person who must live it" (7). Whilst the questions of how, when and by what means such an estimation should be made will not be examined here, I argue that the position of "the who" should be occupied by the physician. Given that only 13% of family members are aware of a patient's treatment preferences, the medical profession has a legal and social duty to protect the rights and opportunities of the vulnerable (22, 23). Furthermore, given the scarcity of AMDs and the well-documented fallibility of proxies and surrogates in making end of life decisions, the patient's best interest should be determined by the physician in charge, who should be guided, whenever possible, by the advice of proxies and surrogates (24). Indeed, even when the courts give proxies and surrogates decision making authority, I argue that physicians ought to continue to ensure that any decision taken is in the patient's best interest - this is part of their duty of non-abandonment. Such a paternalistic stance may be considered a cause for conflict between the medical team and proxies, but this is rare, and even where such conflicts do occur, 79% of cases arrive at amicable settlements (25, 26).

Furthermore I hold that in a terminally ill patient with intractable symptoms, where there is a conflict between the patient's well being and his self-determination, the former should trump the latter (24,27). The reason is that patients making these decisions may not be competent or fully aware of the repercussions of such decisions, which is not surprising.

The physician's decision making on the patient's best interest can also be justified, albeit tenuously, using the principle of autonomy. It can be argued that the patient's acceptance of a referral to and attendance of a palliative care unit amounts to presumed consent. Here, in the face of worsening symptoms and attenuation of treatment options, terminal sedation ought to be discussed with all patients as a possible last resort intervention; non-refusal may then be considered passive consent.

The second defence of the best interest principle within the Principle of Autonomy lies within the ideals of positive and negative liberty. Consent is an example of positive liberty, which is understood to be assisting in attaining a patient's goals through the provision of appropriate resources (27). Since the patient's goal is relief from symptoms and this would require terminal sedation, it follows that administration of terminal sedation is in keeping with positive liberty and, as such, exercising the patient's autonomy.

Meanwhile consideration should also be granted to the professional. Indeed, the notion of professional autonomy assumes that professionals have a moral obligation to use their knowledge and expertise to treat patients in the most effective and safe manner. The proven efficacy and low morbidity and mortality of terminal sedation thus justifies its use as an exercise of "knowledge driven professional autonomy" (15,28). Additionally, another element of professional autonomy pertains to integrity; a physician must maintain an unwavering commitment to moral values and obligations. It is therefore incumbent upon the physician to act to protect the patient's best interests.

The words "intractability" and "suffering" are susceptible to different interpretations and perspectives, making them dependent on value judgments. Yet for the most part intractable symptoms are relatively easily recognisable by their very definition. It would be wrong of a physician to fail to control these symptoms by not delivering terminal sedation in such circumstances, even in the face of prior objections, which may not be made in a state of competence. However, it is acceptable to override previous or present dissent (made in the face of intractable symptoms) only if it is in keeping with "societal concepts of reasonableness" and standards of medical practice (27). Here, too, working with a multidisciplinary team will aid the physician in detecting the need for action, confirming the diagnosis and managing the situation.

Conclusion

When providing care to a patient whose diagnosis and symptoms warrant the provision of terminal sedation, the physician cannot depend on informed consent when making certain decisions. This is because, for the most part, the presence of intractable symptoms is liable to cloud the patient's judgment, vitiate competence and negate his ability to fulfil the requirements for informed consent. Similarly, the provision of information to patients, a topic of much debate, is also affected by medical, psychosocial and cultural factors, further affecting the quality of the consent obtained. Unsurprisingly, then, in these circumstances most patients are either unlikely or unable to provide meaningful consent. At the same time, other sources for attaining consent, or at least approval, such as proxies, surrogates, AMDs and living wills, are either undependable or lacking.

For this reason, the decision to provide terminal sedation falls upon the physician who must make it based on experience, impartiality and knowledge to ascertain the best outcome for the patient. The physician should ideally be operating within a multidisciplinary set up and be guided by the patient's family in making this decision.

In such scenarios the principle of "informed consent" may be replaced by the best interest principle. This paper does not suggest replacing informed consent with best interests consistently; it suggests that this is necessary only when informed consent is found wanting. In specific conditions, such as those in which terminal sedation is indicated, the best interests principle should take precedence, given that the issue here is that of the physician's basic office of providing the most appropriate care for her patients to ameliorate their suffering.

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Endnote

* There is a need to re-examine the concept of voluntariness specifically within the Asian context where, for cultural and possibly religious reasons, families are involved in decision making particularly at the end of life. Otherwise the danger that many Asian patients will simply be deemed to be not acting voluntarily and hence not meeting criteria for informed consent.

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