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Robert Scott Stewart BA, MA, Ph.D.
Cape Breton University, scott_stewart@cbu.ca

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Telling Patients the Truth

Robert Scott Stewart, BA, MA, Ph.D.

Professor of Philosophy
Cape Breton University

Abstract

This article discusses the ethical necessity of health care workers telling their patients the truth about both their diagnosis and prognosis. This necessity is based upon respect for persons, utility, and kindness. Within this ethical obligation to tell the truth, however, there are several different ways in which the truth can be told. In particular, this paper stresses that telling patients the truth is best thought of as a process that unfolds over time, and which is driven by what the patient knows and what they want.

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Telling Patients the Truth Introduction

David Thomasma (1994) suggests that there are three reasons why, in general, individuals ought to tell the truth, and/or be told the truth: respect for persons, utility, and kindness. This research paper follows him in his assessment and discusses the issue of truth telling to patients within his model.

Respect for persons

According to Immanuel Kant, respecting human dignity follows from the fact that humans have a special capacity to live autonomously. That is, humans live not only by laws that are imposed upon them, whether by nature or by legislatures, but humans also have the unique capacity to decide what laws or rules will govern them, which is the literal meaning of autonomy. To make decisions for others, then, is to fail to respect a person's autonomy. Over the past number of years in North America, society has seen the impact of this idea in many ways. In terms of models for the physician-patient relationship, society has moved from a paternalistic model to an informative one (Emanuel and Emanuel, 1992). In the paternalistic model, on the basis of his/her particular expertise, the physician was empowered to act in the best interests of his/her patients. As such, it was not uncommon for physicians, when working under this model, to withhold information from patients in some situations, such as when there was a bad prognosis, for the patient's 'own good'. Indeed, as Braddock notes (1998), "In 1961 only 10% of physicians surveyed believed it was correct to tell a patient of a fatal cancer diagnosis...". "[By] 1979, 97% felt that such disclosure was correct." On the one hand, this is in keeping with what patients want. "For instance, 90% of patients surveyed said they would want to be told of a diagnosis of cancer or Alzheimer's disease" (Braddock, 1998).

As health care has moved away from a paternalistic model toward an informative model over the past thirty years, the principle of patient autonomy has been taken more seriously (Emanuel & Emanuel, 1992). In this model, patients are conceived as having the right to be involved in decisions about their health care, and indeed ultimately to provide informed consent for any treatment option. Despite disagreement regarding how much information is necessary for a person to have in order to provide such informed consent (Randall & Downie, 2006), clearly withholding information that the patient has a serious illness such as cancer, or that they are in fact palliative, is far beyond any reasonable standard of informed consent. Hence, if health professionals assume that cancer needs to be treated – even if this treatment is limited to palliative care – then morally and legally, informed consent must be provided, and it is impossible to achieve this when the patient’s basic diagnosis and prognosis are withheld from him or her.

Hence, under the principle of respect for persons it is clear that at some point within the course of some process, which this paper discusses further below, competent patients must be informed of both their diagnosis and prognosis.

Utility

Utility concerns weighing costs and benefits and acting in such a way as to maximize benefits over costs. Traditional utilitarian theory equated costs with pain or unhappiness and benefits with pleasure or happiness (Bentham, 1789/2007; Mill, 1863/2007) and in contemporary bioethical theory utility is typically associated with the principles of non-maleficence and beneficence which obligate health care workers to “do no harm” on the one hand, and to pursue positive outcomes on the other (Beauchamp & Childress, 2001). Under the paternalistic model,

physicians often used this principle in order to justify withholding seriously bad diagnoses from patients, and patients' families continue to use this rationale when urging physicians and other health care workers to do so. Writing in 1979, physician Mack Lipkin employs this sort of reasoning in his defense of deceiving patients. In the first place, he argues, it is impossible for patients to be told the "whole truth" because they do not have the medical expertise to understand it. One result of this is that patients can actually be misinformed by information. "Cancer" or "heart trouble", which can range from curable and non-serious to incurable and fatal, can mean a vastly different array of things to different patients. Because patients are already anxiety ridden and vulnerable, they are likely to misunderstand the doctor's diagnosis and prognosis and indeed, "[t]he news of serious illness drives some patients to irrational and destructive behavior" (Lipkin, 1979). This fact, he says, justifies withholding information. The fact that there is a demonstrable placebo effect that can have incredibly positive effects on a patient's health justifies a great deal of what society would now call spin, if not outright lying (Lipkin, 1979).

As Cullen and Klein (2000) point out, however, there are several problems with Lipkin's argument. First, his claim about patient's not possessing sufficient medical knowledge to understand fully their diagnosis and prognosis is disingenuous. There are many occupations where the expert has much more knowledge than the customer – from lawyers to car mechanics and computer software specialists. This does not give these professionals the right to withhold information or 'spin' the truth: rather, it obligates them to be honest and to find ways in which to articulate points in ways the individual will understand. Most importantly, however, in attempting to promote a patient's good, arguments such as Lipkin's completely ignore the respect owed to patients as autonomous beings. People faced with imminent death have a right to

that information and, moreover, it may actually be good for them to know their prognosis in at least two ways. First, “most treatments for serious diseases require the full cooperation of the patient” (Cullen and Klein, 2000). Second, in cases where no cure is at all likely, “good” for a patient may consist in planning for his or her death. This might include a variety of activities from entering palliative care, securing child care for dying patients who are also young parents, reconnecting with lost loved ones, to making out a final will. Hence, Cullen and Klein argue, telling patients the truth ought to be considered the “default position”, which can be overridden only in special cases and/or for a limited amount of time. At times, patients themselves may explicitly request that they not be told the truth about their condition if it is very dire.

Withholding the truth in such a case as this is actually an instance of respecting the patient, not overriding it for some other purpose. At other times, deceiving a patient may be justified, in the short term, in order to have the best chance to restore a patient to health. This would require that the physician know his/her patient’s personality well enough that he or she know that the patient cannot handle bad news and that telling him or her such bad news will lessen the chances of patient recovery. Physicians ought to be cautious in using such a justification for failing to tell the truth. In the first place, health professionals rarely know other people that well, and, in general, they tend to underestimate’s people’s ability to handle bad news. Secondly, this argument is at best a defense of telling the truth in a process over a period of time, not for withholding information indefinitely or lying. Indeed, Freedman (1993) refers to such a process as “offering truth”.

Unlike the more typical situation where the physician, having ascertained that the patient is competent, proceeds to tell the patient everything about their diagnosis and prognosis in one sitting, “offering truth” conceives of truth telling to patients as a process over a period of time.

As Freedman says: “A patient’s knowledge of diagnosis and prognosis is not all-or-nothing. It exists on a continuum, anchored at one end by the purely theoretical ‘absolute ignorance’ and at the other by the unattainable ‘total enlightenment’. Actual patients are to be found along this continuum that vary in response to external factors (verbal information, non-verbal clues, etc.) as well as internal dynamics such as denial” (Freedman, 1993). The best way to begin this process, Freedman suggests, is to find out where the patient is on the continuum by hearing “from the patient himself or herself, so that [the health care team] can confirm what he or she knows or clear up any misunderstanding that may have arisen”(Freedman, 1993). Beginning here, the health care team will not only know what the patient him/herself knows (which is often much more than the family thinks the patient knows), they can also get a sense of how much the patient wants to know. Surely knowing this can only help in promoting the patient’s good.

Kindness

Thomasma (1994) looks upon kindness as a kind of virtue, and virtue ethics are typically thought to differ in an important respect from deontology and utilitarianism discussed above under the rubric of respect for persons and utility. In virtue ethics, the focus of concern is on the character of the persons involved and of the relationship between various actors (as opposed to deontology and utilitarianism where the focus is on specific judgments such as does this action produce the most utility or would this action promote respect for persons). In virtue ethics, then, individuals want to consider truth telling within the context of relationships. Clearly, it would be hard to develop a real friendship, for example, with a person who often deceived the other person in one way or another. Similarly, it would hard to imagine a trusting relationship being built and sustained between a health care worker and a patient if the patient could not trust the health care worker to tell him or her the truth. Of course, this leaves open the possibility that the relationship

would not be negatively affected if the truth never came to light. Thomasma offers an example of such a case where a dying victim of a car crash is told in his last minutes of life that his family in the car with him are being taken care of even though all of them are in fact dead (Thomasma, 1994). Typically, however, the truth of the situation will come out, even in the typical palliative care case. The prominent and extenuating features of the car crash case are that the person came to the hospital as an emergency patient and will die almost immediately. These are important because, (1) emergency cases do not typically demand the sort of informed consent that competent patients do, and (2) the patient will die before any further measures have to be taken that would demand his consent. Even palliative patients typically do not present in this fashion. That is, it would be quite uncommon that an undiagnosed cancer patient arrived at the hospital minutes or hours before his/her death from his/her cancer. There is almost always a much longer period of time between diagnosis and death. Even if that period is only a few days or weeks, there will be decisions that have to be made – such as the one whether to transfer the patient into a palliative care unit. In such cases, it is very unlikely that the patient will not somehow, perhaps unintentionally, discover their diagnosis and prognosis. In such cases as these, health professionals are presented with a worst case scenario. Whatever benefit was to come of concealment is not met, and they have hence disrespected the patient for no compensating benefit. Moreover, the health professionals have been unkind and jeopardized the possibility of a fruitful and wholesome relationship between health care team members and the patient. Moreover, a further point can be made. Asking health care professionals to withhold information or lie to patients puts them in a moral dilemma and can lead to moral distress and residue. Over time, this can even threaten the very moral identity of health care workers and cause them to

leave their profession or to stop caring for patients in the way they had previously. (Kelly, 1998; Rubin & Baylis, 2000).

Conclusion

This article has argued that the default position for physicians and other health care workers is to tell their competent patients the truth. The basis for this are: respect for persons, utility, and kindness. Telling competent patients the truth need not be done, however, 'all at once'. Indeed, in many situations, it is better to think of telling the truth to patients as a process, which typically begins by getting the competent patient to tell his/her own account of what he/she understand about his/her condition and how much he/she wants to be told. Given that patients have a right rather than a duty to be told the truth, patients can decide for themselves that they do not want to be told the truth and that their proxies should make decisions for them. This may be especially true for those cultures that do not value truth telling and autonomy as much as is currently the case for the majority in North America (Buker, 2003; Asai, 1995). Cases where the truth will be withheld for long periods of time will be extraordinarily rare and the burden of proof will fall squarely on those who want to withhold the truth.

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