Rights theory in a specific healthcare context: "Speaking ill of the dead"

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Generally physicians have a legal and ethical obligation of keeping confidentiality regarding their communication with patients and it is clear that we all have rights. The application of rights theorem, which usually refers to the recognition of individual human rights, to the deceased offers possible answers to the problematic question of patient confidentiality after death. Philosophical considerations broadly support utilitarian ideals concerning the 'common good'. However, it may be possible to rank rights according to a hierarchy of need and thus preserve individual rights where they do not impinge upon the public's right to protection from harm and the physician's right to tell the truth. This has broad implications for confidentiality, anonymity and health care information in general for patients, their families and healthcare workers. We discuss these issues, with specific reference to an individual case.

"We owe respect to the living; to the dead we owe only the truth"—Voltaire¹

Modern societies preserve individual freedoms, although rights are often confused with desires, expectation and/or needs. Rights, philosophically and objectively considered, may be viewed in the context of the individual as only those justifiably moral considerations that flow from respect for the person. However, rights are not precluded by dislike or disdain for the individual patient or relative, but flow from the *prima facie* right to exist. A physician's duty of care extends this right to healthcare as a qualified—not universal—right, as enshrined in the Hippocratic oath.

Ergo: "a right may be a *justified claim* that individuals and groups can make upon others or upon society".² Rights provide protection of life, liberty, expression and property, as first set out by John Locke.³ Duties follow from rights and there are categories of rights including the right to confidentiality.⁴ In any discussion of rights it is important to define what exactly we mean by a "right". The online Oxford dictionary describes a right as '(1) *that which is morally right*, (2) *a moral or legal entitlement to have or do something*'.⁵

Also, although philosophically rights are applicable universally and thus need to be examined universally, an individual's rights may vary according to circumstance. Each player in any case has a perspective and this must be both addressed

and justified. The body of works concerning the rights of the individual and the rights of society will be referred to as a generic: rights theorem.

This paper aims to assess the importance of rights theorem within healthcare, citing an example of the type of dilemma that may be faced by the practising physician.

Rights issues arising from the example to be discussed are:

- Does a dead patient have an (extrapolated) right to confidentiality?
- Do family members have a right to know that the patient was diagnosed with HIV?
- Is HIV different to other disease(s)? Do sequelae (morbidity/mortality) affect rights to confidentiality?
- Can the patient's right for confidentiality outweigh public healthcare issues—that is, should the deceased patient's sexual partner(s) be informed of his positive status?
- Does anyone in fact (including healthcare professionals) have a right to know the patient's HIV status, since at the time of his death he himself was ignorant of it? Is there a hierarchy of "right to know"?
- How is the individual right of healthcare professionals to tell the truth affected by patient confidentiality? What is the ethical difference between a lie and stonewalling when the result is the same?

Although a specific example is cited in this paper, it is essential that we recognise that ethically each case needs to be examined individually in order to make a judgement as to the best action or reaction.

AIMS

1. Assessment of rights in the context of the individual (with a cited example)
2. Assessment of rights in the context of society.

The major problem with individual rights post-mortem may be stated as follows: they do not adequately address the question "Whose rights are more important?". Clearly the rights of individuals may conflict with each other. Unless we have a ranking system of rights we cannot reach a conclusion. This is reflected in the United Nations doctrine on Human Rights: the UN has only one unqualified right—that of the right not to be tortured.⁶ Rights to life and liberty are in fact qualified by the UN.

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Figure 1 An ordinal hierarchy of patient rights.

In order to create a workable ranking of rights it's necessary to examine the rights of each party—the individual (patient), the physician and the rights of society.

The patient

The patient may employ value judgements according to his or her needs within a number of healthcare settings—for example, accident and emergency (A&E) (conscious); elective surgery (conscious; unconscious); or retain ethico-legal rights intrinsic to the body of the patient—for example, A&E (unconscious) or dead on arrival (DOA).

Thus the patient's wishes may be represented as:

1. The right to respect and the preservation of dignity
2. The right to treatment appropriate to the condition
3. The right to decide
4. The right to confidentiality
5. The right to freedom of information.

The physician

The physician's perception of patient rights may be seen as being dependent upon that patient's ability to enjoy those rights within the context of the rights and needs of society. Such juxtapositions may be exacerbated within the healthcare situation due to the immediacy of problems—for example, life-threatening illness—and/or sequelae if left unaddressed—for example, infectious disease. Thus, theoretical dogma may become subjugated to (William of) Ockham's razor; a pragmatic approach to healthcare. Within this context each individual physician must set the foundations for a patient's extant rights once statutory ethico-legal requirements have been fulfilled.

A patient's hierarchical scale of rights to confidentiality could be constructed around their expressed wishes, if alive and responsive, or be reflective of their physical ability to make rational decisions. The former may be prey to accusations of supposition of inference, the latter is not. A principle-based approach based up on autonomy, beneficence, common justice and duty (of care) would favour the latter approach—giving increasing responsibility for guardianship to the physician proportional to failing "self-awareness" of the patient.²

Thus the physician's perception of patient ethical needs may be:

1. Sentient, conscious
2. Sentient, impaired
3. Sentient, unconscious
4. Deceased.

Society

Seemingly disparate hierarchies of rights for the individual and the physician may not serve to satisfy society's perceived needs for both individual and universal justice. It may be that the physicians independent role as a "contractual" healthcare professional,⁷ as implied by the diminishing authoritarian role of doctors and an increase in patient versus healthcare professional litigation, may allow respect for patient autonomy to persist through informed consent; and the doctor to be seen as society's provision of an advisory, consultative outlet. The physician may therefore be said to be society's representation of the patient's interests, choice of treatment and ultimately, physical welfare.

In this context, medical paternalism would require a combined hierarchy of rights protecting both the patient's and the doctor's interests. However, it should also reflect the right of society to protection from the individual.

Thus, a hierarchy of rights may be postulated with the preservation of society rights outweighing individual rights (fig 1).

In the context of extant rights, the example of patient "P" is demonstrative of the type of rights dilemma typically encountered by the practising physician. P died suddenly following a short illness. HIV was diagnosed post mortem. There had been no indication from P of his wishes with regards to telling his friends and family. Similarly, he had denied any risk factors for HIV. A week following his death P's sister visited from overseas and asked to see a doctor to discuss the cause of her brother's death. She also wanted to know specifically if he had been infected with HIV. P's sister was subsequently informed only of his heart failure and not of his HIV status.

The question of extant rights here is not clear. Before seeing her, the treating physicians were told by a representative legal body that: "the duty of confidentiality to P persists after his death—we may talk to her about the cause of death only as it appeared on the death certificate" (which did not mention HIV). This position stems from the World Medical Association's International Code of Medical Ethics, which states that "confidentiality is an absolute requirement, even after the patient's death".^{4,8} This would appear to imply that only publicly available information may be revealed. P's HIV status was therefore sacrosanct, positive or negative, as it had no bearing on the health or welfare of his sister.

DISCUSSION

The example of patient P raises the following ethical questions: Primarily, does a dead patient have a right to confidentiality? If this is the case, the doctor owes a duty of confidentiality to the deceased. However, if this is not the case, then the doctor

should primarily consider the mental and physical welfare of his relatives. His sister appeared to already suspect that he had AIDS. Does his sister have a right to know, and should Kant's ideal of truth prevail in this context?" Should the "public health" issue negate the rights of P—that is, should his sexual partners be informed? Does anyone (including the healthcare professionals) have a right to know P's HIV status since he himself did not know before his death? Finally, does the doctor have rights—for example, the right to tell the truth?

The right to confidentiality of the dead

This is perhaps one the most subjective issues confronted by guardians of patient welfare and information. We have the following factors in favour of respect for this right.

One of the arguments for maintaining confidentiality is the patient's trust in the medical professional. Patient P's right to confidentiality has moral supremacy, as he is the patient with the problem and the vulnerable should be protected. His trust in the doctor, that was inherent in their professional relationship, is preserved by maintaining privacy and discretion. His right as the patient overrides the wishes of his sister, or the doctor's right to tell the truth.¹⁰ Because his wishes were not known before his death, and because he did not know his HIV result, the moral supremacy of P's rights should prevail to protect him. However, is it appropriate to test someone if they are in end stage disease and are thus unlikely to benefit from the result? In such a case is the test for society's benefit? And if so, should the "result" have supremacy over an individual's right to confidentiality? If P's HIV result had been negative, would the physician have felt more justified in revealing that fact to P's sister? The fact that a test is either positive or negative is surely immaterial. It exists, *de facto*, and has an owner. The question is not how socially relevant is a test result or what stigmas does a disease state possess, but whether any piece of patient related data obtained while under medical care should be subject to public scrutiny. It may be prudent to seek guidance concerning the fate of diagnostic results "should the patient be unable to receive it themselves" during the counselling session before HIV testing or during the initial consultation.

Some would argue that P's right to confidentiality persists in the same way as his right to respect for his body and a dignified funeral. Thus a limit is placed on how P is treated, regardless of the wider good that might be achieved by breaking doctor/patient confidentiality.¹¹ In other words it is the "least interfering" way of acting. Furthermore, giving P a right to confidentiality might be a reflection of the desires he would have had were he alive—P is being treated as an autonomous being after his death. Dworkin describes it thus:

"The former capacity for self-respect requires that we treat with dignity now, in relation to Alzheimer's patients."¹²

The importance of P's right to confidentiality is re-enforced by its recognition in domestic law, hence the medico-legal advice. Moreover, the very fact that his right is to confidentiality may be widely understood in many different cultures and societies suggests that there is something inherent in our humanity that understands the importance of maintaining this right even in death. This may not extend to an objective morality but it certainly adds weight to the argument; as indeed does the fact that the patient's right to confidentiality is also a generally accepted right in healthcare—healthcare professionals accept the corresponding duty to maintain confidentiality and make efforts not to breach this right.

However, there are several factors which go against P's right to confidentiality. The most important of these is his death—he

has no capacity to suffer or reason and has no intrinsic ongoing interest; he has relinquished his rights by dying—therefore according to some he is excluded from the language of rights altogether. Tooley calls this the requirement for self-consciousness. He explains that "A has a right to X" is synonymous with "A is the sort of thing that is a subject of experiences and other mental states, A is capable of desiring X, and if A does desire X, then others are under a *prima facie* obligation to refrain from actions that would deprive him of it".¹³ He also explains that it is the conceptual capability to desire X, and not the desire itself, which is important. This allows exceptions to be made for people in emotionally unbalanced states, temporary unconsciousness and situations where individuals' desires have been distorted by conditioning or indoctrination. Clearly, at the very moment of his death P gave up the capability to desire. Although at one time P had the conceptual ability to demand a right for confidentiality, he now no longer does, and more importantly, *never will again*. Perhaps it is this last fact which may be overriding in the argument that his rights should be relinquished.

Also the moral supremacy of living instructions or wishes may decline or perish with the owner of those wishes postmortem or be subsumed by a greater need—for example, society's right to protection from the individual. If harm persists beyond the death of the individual and by compromising the wishes of the deceased such harm may be ameliorated, do we not owe the living a stronger duty of care than the deceased? Is the doctor compromising his vow of "first do no harm" by denying others the very treatment or protection he was prepared to offer P?

The rights of the public

The public health issue could also be seen as a moral imperative in this scenario; P's rights are justifiably infringed to protect people that he may have infected with the human immunodeficiency virus (HIV). Although this can be viewed simplistically as the rights of the public prevailing, it appropriately conforms to utilitarian ideals. It highlights again the conflicts between the rights of each party and confirms that there are very few cases where a right can be justified as absolute.⁴ This can only act to weaken individual rights. Similarly, the right of P may depend on the nature of his illness. If he had a non-infectious disease would his right to confidentiality be greater?

The American and British Medical Associations have modified the World Medical Association's rules on absolute confidentiality to reflect doctor's obligations not only to their patients but also to others. The British Medical Association's guidance on confidentiality states: "The ethical duty of confidentiality extends beyond the death of the patient, although legislation covering records made since 1 November 1991 permits limited disclosure to be justifiable based on the particular circumstances and knowledge of the patient's wishes...often a decision to disclose will not be based on the interest of the subject but is made to protect other people or the public at large."

The decision to disclose is based partly on a balancing of several moral imperatives, including the risk and likelihood of harm if no disclosure is made, and the need to maintain the trust of the patient.¹⁴ This makes it clear that doctors are responsible not only for the harm they do, but also for the harm they fail to prevent, though there is a clear distinction between withholding information and a lie.^{8 15} This pragmatic description of obligations without reference to rights may be appropriate within this circumstance.

The right of relatives to know the truth

P's sister was asking the doctors to be honest about something she had already suspected. Armed with the truth she could

possibly have gone to his friends and prevented further suffering or death. As his nearest living relative, and with no other apparent motive than understanding the truth, did she have a right to know? If so this would have resulted in infringement of P's right to confidentiality, and again this raises the prospect of the ranking of rights.

Ownership of the test result

Since P was not given his HIV result before his death, it could be argued that no one has a right to know it, and it should not be released at all. He could have died before the test was taken, in which case it would only have been done at postmortem examination if it was thought to be relevant to the cause of death. So who owns test results after someone's death? If this had been a different infectious disease with less mystique and media spin attached to it, would that have altered P's "right" to confidentiality? Why were the doctors allowed to discuss the cause of death (on the death certificate) without the permission of the patient? That could also be seen as a violation of his rights. If the test result had serious social sequelae should the state take possession of the result for the greater good? Democracies are based upon the principle of majority decision—the majority holds the imperative; surely this should apply to public health issues irrespective of the patient's state of being?

The rights of the doctor

The right to tell the truth (or not to lie) may be viewed as important here if the doctor feels moral unease at withholding the truth. The doctor's rights may be in direct conflict with the rights of the patient. Conflicting rights may co-exist where patient rights are seen to be paramount and subjugate other moral rights, but in this case the doctor's right to autonomy equate with the truth being told. Kant argued that lying was the "obliteration of one's dignity as a human being" and held that the rule against lying was absolute.^{9 11} Moreover, withholding the truth concerning a dead patient is unlikely to be something that Kant would consider justifiable.⁹ One might argue that the moral rule not to lie has to be qualified by circumstance.

Further, Kantian reasoning considers the expression of truth to be a moral imperative. To wit: "Act on that maxim through which you can at the same time will that it should become a universal law".⁹ To assess the morality of an action any maxim describing that action must comply with the conditions of the categorical imperative before it is deemed moral.¹⁵ The ethics of patient confidentiality may simply be summarised by the maxim "tell the truth". The withholding of information (stonewalling) does not conflict with the maxim whereas lying or deception would. The absence of confirmation is not the same as denial. However, in the face of incontrovertible facts the truth must become subject to reason. Rights cannot realistically exist where they have no foundation in fact—that is, the truth is damaged by repression when physical evidence exists to the contrary. Where something is known, the right has no substance, its application becomes unnecessary.

The strengths of rights theorem

Rights have been thought of as moral trump cards when an ethical question is in dispute—this was first set out by Ronald Dworkin, who stated that, "rights are best understood as trumps over some background justification for political decisions that states a goal for the community as a whole".¹² In this way, an individual's personal rights may override the overall consequences of an action or situation. This obviously conflicts directly with the quantitative utilitarian viewpoint that proposes morality based on maximum happiness for the maximum number of people.

Every individual involved in this case has been considered in terms of his or her rights and therefore any rights theory may be seen as an appropriate substitution of representation of the moral theory within the healthcare context. Furthermore, rights theory allows the "victim's" viewpoint to be the primary focus and protects P's interests, despite the fact that he himself cannot champion them owing to his death.

Rights and obligations are correlative; an obligation flows from a right, and this provides clarity in action. For example, if it can be agreed that P has a right to confidentiality, then it is clear that the doctor has a duty not to breach this.

A rights theory would provide a moral framework for law—for example, the rights of P to have a legal backing. This legal aspect is an essential component of healthcare because it protects the weak and here, rights are compatible with a wider social responsibility.

Finally, the concept of rights is generally understood to be philosophically sound—that is, it has a commonality and consensus; but the acceptance and application of such rights to the individual may too often be subject to expedient interpretations where the beneficiary of such interpretations may be neither clear nor morally justified.

The weaknesses of rights theorem

Rights theories are often criticised because of the disagreement over "who or what" has rights; this is particularly relevant in relation to abortion, for example, but it is also significant here. Some would argue that the capacity to reason is a necessary condition for possessing rights; this would obviously exclude P from having rights. Similarly, having interests has been used as a requirement for rights, and again could exclude P from having rights because he is not alive and is therefore unable to pursue personal interest.

Next, human rights are applied to individuals. As a sequitur of this, rights may neglect communal interests and public health, and this may be observed here. Rights may be entirely incompatible with social ideals and they do not account for the moral significance of motives and virtues. As a result, they may be seen as minimalist—that is, simply statements of the minimum enforceable rules to be observed, thus rendering any theory incomplete.

Further, rights may eventually be diminished or relinquished. Although this could be seen as a strength because it allows flexibility, it can also be argued that it invalidates the immutability of rights; in this case several people's rights must be relinquished to reach a conclusion. Beauchamp and Childress call this an infringement (a justified action overriding a right) rather than a violation (an unjustified action against a right).¹ When the infringement clashes with another's rights, this weakens current theorem. Indeed pragmatism, jurisprudence and objectivity daily direct medical practitioners to intercede or impose actions outside of the scope of direct patient consent, for example, the treatment of unconscious subjects or the use of medicines to prevent the spread of pathogenic disease within a community.

The emphasis on rights tends to encourage pursuance of moral demands at the cost of neglect of duties.³ Rights theorem have been criticised here because of the adversarial attitude encouraged, whereby affection, sympathy and trust between the parties are undermined. In the context of healthcare this is particularly pertinent.

Scales and ranking of rights

Russell sums up his efforts to arrive at an objective ethics in the following fundamental propositions and definitions¹⁷:

- Surveying the acts which arouse emotions of approval or disapproval, we find that, as a general rule, the acts which

Learning points

- Individuals have rights during life, but these may or may not apply after death.
- Patients and their families have rights, but doctors do too and withholding information is different to a lie.
- As the patient is the one who suffers and is most vulnerable, their wishes have moral supremacy.
- After death the patient has no capacity to suffer and has relinquished some rights.
- In certain cases, such as HIV, there may be a public health right. An emphasis on rights, however, encourages moral pursuits, at the expense of affection, sympathy and trust.

are approved of are those believed likely to have, on balance, effects of certain kinds while opposite effects are expected from acts that are disapproved of.

- Effects that lead to approval are defined as “good” and those leading to disapproval are defined as “bad”.
- An act of which, on the available evidence, the effects are likely to be better than those of any other act that is possible in the circumstances, is defined as “right”; any other act is “wrong”. What we “ought” to do is, by definition, the act which is right.
- It is right to feel approval of a right act and disapproval of a wrong act.

We call a factual statement true only if it corresponds to a particular fact. However, ethical statements do not state facts and there is no question of there being corresponding confirmation as to any statement being true or false.¹⁸

Using such reasoning, it may be appropriate to hypothesise an ordinal scale of patient rights (expressing the ranked expectations of those who access healthcare and those who implement it) to guide contemporary thinking. From these two perspectives a single ranking may be extrapolated encompassing the needs of the patient and society (fig 1).

The language of rights serves to highlight inconsistencies and confusion in the pragmatic approach to P's problem; this is because it requires a ranking of rights, forcing the rights of some parties to be withheld and trumping the rights of others. It appears difficult to reach a widely accepted consensus on the ranking order, illustrating a problem with rights theorem in general. In addition it has not proved possible to determine whether the dead patient retains the rights of the individual at all. In conclusion, the application of rights provides few answers to the issue of a dead person's confidentiality. Different schools of thinking provide different scenarios and perceptions of rights. Ultimately we are left with over 50 years of medical socialism with equal rights for all but little fundamental thinking to guide their application within the field of healthcare. Perhaps it is worth looking to the United States, where there exists in law a “Duty to warn”. Prompted by the case of “Tarasoff vs. Regents of the University of California” (1976), a law was passed affirming the duty of healthcare professionals (in this case psychologists), to whitt: “the right to

patient confidentiality ends when public peril begins”. (McWhinney, Haskins-Herkenham, and Hare (1992)). The practical problem of the conflict between patient confidentiality and public health issues (as in the case of P), may yet be resolved in a similar way via UK legislature; until then, patient's rights will continue to fall under the guardianship of public employees with a duty to the individual and the state.

Conclusion

Based on bioethical reasoning, there is probably a hierarchy of rights, though the language used may often be confusing. However, the approach can be applied as a problem solving tool where the needs of patients, physicians and society collide. There are five major points in the consideration of any case:

1. Rights and morality overlap and individuals have the right to protection of life, liberty, expression and property and to respect and the preservation of dignity
2. The right to treatment appropriate to the condition
3. The right to decide
4. The right to confidentiality
5. The right to freedom of information.

It is probably not possible to avoid the political correctness of legalism, bureaucratic ethics, utilitarianism and resulting dislocations in quality of care between institutions. There is no absolutely correct answer to rights theorem when dealing with confidentiality issues surrounding dead individuals, but the principles used in life apply. There are no rights reserved.

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