

Truth-telling in the doctor–patient relationship: a case analysis

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Abstract

Using a real-life case involving an accidental discovery of misattributed paternity as a springboard for discussion, I reflect on several practical and theoretical issues on truth-telling in the doctor–patient relationship. I present the moral dilemma and identify arguments in favour of and against disclosure. I then examine the theoretical difficulties in balancing conflicting reasons and in establishing what constitutes the ‘truth’. I conclude that withholding the information from the patients would be ethically permissible and, more generally, that honesty is not always the best policy.

Introduction

This case, based on a real case published in the journal *Seminars in Dialysis* in 2002,¹ illustrates the fascinating complexity of doctors' decisions to disclose information. I will use it as a springboard to discuss several practical and theoretical issues relating to truth-telling in the doctor–patient relationship.

Medical background

An 18-year-old woman, Miss P, approaches the transplant centre stating that she would like to donate a kidney to her father. She appears to be highly motivated to donate, is healthy, and testing indicates that she is medically suitable.

The potential recipient, Mr P, is a 50-year-old man who has polycystic kidney disease. He has been on haemodialysis for six months but has noticed that his strength is deteriorating and that he does not feel well on dialysis.

Transplantation is considered the best form of treatment for his end-stage renal disease (ESRD). The waiting time for a cadaveric transplant is approximately four to six years and the results of transplantation from living donors are better than those obtained from cadaveric donors.

HLA testing shows that Mr and Miss P are a one-antigen match, which means they cannot be genetically related. The test is repeated and the results are confirmed.

Neither Mr nor Miss P give any indication that they believe they are not blood relatives. The testing was not done to establish paternity and, from a medical point of view, the findings do not preclude Miss P from donating to Mr P.

Psychosocial background

Miss P is a full-time student with a part-time job. She lives with her presumed father and stepmother. Miss P was born abroad and her parents were not married. When her parents separated, Mr P immigrated to North America with his daughter. Miss P has had no further contact with her birth mother. Mr P married six years ago, and Miss P states that she has a good relationship with her father and stepmother.

The main moral dilemma

A moral dilemma arises when an agent is morally required to perform two or more actions but cannot do one without failing to do the other(s). Although the present case raises several moral issues, the main dilemma concerns the transplant team's decision to disclose – or not to disclose – the non-paternity to Miss P and her presumed father. Should the team reveal the unexpected finding to their patients, thereby fulfilling one set of duties, or should they withhold the information, thereby fulfilling a different set of duties? Is this a genuine moral dilemma, where the weights of the competing duties pull equally in opposite directions, or does it merely resemble such a dilemma?

Analysis

In examining both horns of a dilemma, it is useful to discern the arguments for and against each alternative.

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Moral arguments in favour of non-disclosure

'More harm than good' This argument rests on the assumption that disclosing the information is more likely to harm the patients than to benefit them. The harm may take several forms:

- (1) The patients might become psychologically distressed by the news;
- (2) The daughter might refuse to donate her kidney, with dire consequences for her presumed father;
- (3) The presumed father might decline the kidney, with equally bad consequences as (2); or
- (4) The relationship between the family members may be irrevocably damaged and the wellbeing of each member may be reduced by the disintegration of the family unit.

These harmful possibilities may damage the morale of the transplant team. Furthermore, if the outraged patients argue that they never agreed to such a disclosure, the trust in the transplant unit may also be negatively affected. The patients may feel that their trust has been breached. This breach of trust may be considered a harm in itself, irrespective of any ensuing loss of trust.

'No duty to disclose'

Doctors do not have a duty to disclose *everything* about a patient's medical condition. If a patient with lung cancer asked his oncologist to tell him 'everything he knew' about the condition, the oncologist would be under no obligation to spend hours discussing the minutiae of molecular biology, sputum cytology, low-dose helical computed tomography, lung cancer epidemiology and so on. Such a request would clearly be unreasonable. Doctors should disclose medically relevant information which patients could reasonably expect to be told (i.e. the expectation of which would be supported by good reasons, as judged from an external perspective). This argument assumes that the non-paternity is irrelevant to Miss P's decision to offer her kidney, or that the patients' hypothetical expectation to be informed of this would be unreasonable. Moreover, as there is no way of knowing whether the patients would like to be told the news, disclosure might violate their right not to know. A right not to know entails a correlative duty not to disclose.

'Not the purpose of the test'

Even if the misattributed paternity were medically relevant, the test was conducted specifically to ascertain the tissue compatibility between Miss P and Mr P, not to discover whether or not the patients were biologically related. For this reason, the argument goes, the result should not be disclosed.

Moral arguments in favour of disclosure

'More good than harm'

Telling the truth, although distressing in the short term, will result in more benefit than harm in the long run. The patients may appreciate the honesty of the transplant team. Disclosing the information might also prevent a sub-

sequent fracas and loss of trust if the patients later discover the truth.

Another possible benefit is that Miss P might be relieved that, genetically free from polycystic kidney disease, she will not pass on the condition to any progeny. Mr P too may be relieved that Miss P did not inherit the rogue genes. Note, however, that their fears could be dispelled without revealing the non-paternity: 'You'll be pleased to know that you have not inherited the genes for polycystic kidney disease'.

Finally, one can argue that there is something intrinsically good about respecting people's autonomy (roughly, their ability to make deliberated choices for themselves). Providing the information and empowering patients to make informed decisions is itself a moral good, irrespective of the consequences. With regard to cases involving genetic relatedness, some have claimed that knowing one's genetic parentage is crucial to an individual's identity formation and thus that people have a right to know their immediate genetic lineage.²

'Necessary for informed consent'

To obtain valid consent, a doctor should disclose any details that will help the patient make an informed decision. A failure to reveal the non-paternity will mean that Miss P's decision to donate her kidney – and Mr P's decision to accept it – will be based on false information, unless they are already aware of this fact. Although many would disapprove of such an action, it is conceivable that Miss P would decline to offer her kidney in the newfound knowledge that she is not biologically related to her presumed father. Despite possible social and moral condemnation, it would be within her right to renege on her decision. Similarly, Mr P might decide to refuse the kidney if he discovered that she was not his 'true' daughter. As informed consent is a cornerstone of ethical medical practice, doctors have a duty to disclose enough information to facilitate such consent.

Case discussion

There are, it seems, good arguments both for and against disclosure. The next step in the ethical analysis is to assess the relative strengths of the various arguments and to examine the issues that they raise.

The harm–benefit calculus

Both the pro- and anti-disclosure camps appeal to a harm–benefit calculus to support their position. The analysis above reveals the multi-faceted aspect of harm and benefit. Harm is not limited to medical harm, but includes a range of other harms, from psychological distress to a breach of trust by the medical profession. Balancing these radically different types of harm is a notoriously difficult exercise. This is compounded by the fact that what is harmful is not necessarily morally wrong. One can harm a person without wrongdoing them (e.g. punching a violent aggressor in self-defence) and, conversely, one can wrong an individual without harming them (e.g. secretly stealing £10 from a multi-millionaire).³ From performing invasive

procedures to breaking bad news, distress is an unavoidable reality in medicine. Information about a patient's health should not be withheld simply because it will minimize distress.

The 'balancing act' itself – how one compares two or more radically different harms – is value-laden. When making decisions, agents may bring into their evaluation unspoken beliefs, assumptions and prejudices. The belief that patients want to be and *should* be told a bad prognosis, for example, reflects the dominant view in many Western countries but would be held by few in places such as China.⁴ In Lebanon, Singapore, China and Japan, it is not unusual for doctors to withhold a grim diagnosis from patients.^{4–7} Even in the West, Gordon and Paci have shown that the candid, individualistic 'American approach' to truth-telling to patients is viewed by many Italians as 'very harsh, irresponsible, lonely, naïve'.⁸ This inescapable ideological 'baggage' complicates the ethical evaluation, requiring an awareness of the often hidden assumptions on which the calculation is based.

Even with a clear understanding of what should count as harm or as benefit, there is much empirical uncertainty surrounding which of the two alternatives would lead to the most desirable state of affairs. For instance, how likely is it that the patients will later find out about their genetic non-relatedness and, if they do, that they will know that the transplant team were aware of the fact? Will such a realization necessarily lead to a loss of trust in the transplant team and in the medical profession as a whole? What is the probability of Miss P refusing to donate her kidney if informed of the non-paternity? These are hypothetical questions without clear-cut answers. Existing empirical studies may give the team some indication of what the answers might be, but they cannot guarantee that *these* patients will follow the trend depicted in general studies. The currently unknowable answers to these empirical questions inject a sizeable amount of uncertainty into the harm–benefit assessment.

If certainty is an unreachable ideal, our eventual decision will involve some degree of what Berlin calls 'moral risk'.⁹ Our choice, despite our best efforts, may lead to terrible consequences. In the present case, it is quite possible that, in the manner of a Greek tragedy, disclosing the information will 'ruin' the lives of the two patients.

It is unclear, in the present case, which of the two horns will cause less distress. Furthermore, I have claimed that distress is an insufficient criterion for making a decision. In light of this uncertainty, I should perhaps focus on whether the patients have a right to be told the truth.

Telling the truth

What does it mean to tell the truth? It cannot mean telling any old truth. If my partner asks where I was last night and I reply that the stethoscope was invented in 1816, she will not be satisfied – however correct I may be. Rather, we should tell the *relevant* truth. This raises another question: what is relevant? The case above highlights the ambiguity of relevance. The non-paternity is not relevant to the *medical possibility* of transplanting the kidney from Miss P to her father. For this reason, some will say that 'telling the truth' only involves informing the patients that the transplant can proceed.

On the other hand, the non-paternity is potentially relevant to her *decision* to offer her kidney (and Mr P's decision to accept it). It is also relevant in that it may alter her world-view and self-concept, and that knowledge of her genetic makeup may affect her decision to have children. Furthermore, whether or not she donates her kidney, the information is medically relevant: if she donates the kidney she will (probably) improve her presumed father's health while endangering her own; whereas if she refuses to donate, she will maintain her health but will not benefit her presumed father. There are health implications either way. Under this interpretation, 'telling the truth' will require disclosing the information. Depending on which sense of relevance one chooses, the non-paternity may or may not be relevant and this judgement will have knock-on effects on how one interprets 'telling the truth'.

Even if we accept that the finding is relevant in some respects, it is not obvious that there is a duty to disclose the relevant truth. On the bus, I may spot that the person next to me has his zip undone. I may deem this information relevant to him, yet I am under no obligation to correct his presumed false belief that he is properly zipped. The same applies if I overhear someone at the bus stop utter an incorrect assertion, even if I judge that it would be in his interest to be corrected. Alternatively, a patient may not wish to be told a relevant truth and, in many circumstances, we should respect this 'right not to know'. As I argued earlier, doctors have no obligation to volunteer everything that they consider relevant to their patients' health (e.g. the health benefits of various foods). There has to be a reasonable expectation that the relevant truth be told.

Applied to this case, the question is: if Miss and Mr P expected the transplant team to disclose the information, would their expectation be reasonable? The strong moral reasons in favour of disclosure suggest the answer is 'yes'. This holds true even if we believe that the countervailing reasons are weightier and that the information should be withheld. Their expectation *not* to be told the truth would also be reasonable, based on the arguments against disclosure listed earlier. In short, the patients can reasonably expect both to be told and not to be told. The notion of 'reasonable expectation' does not help much in such cases: the dilemma still remains.

The obligation to disclose relevant, reasonably expected truths is not absolute but *prima facie*. Under a pluralist moral framework, which acknowledges a plurality of moral values, there may be other considerations that trump the duty to tell the truth. If telling the truth is likely to endanger the life of a frail patient, for example, then my obligation of non-maleficence may trump my duty to tell the truth. In the case at hand, as various moral goods are in play (e.g. trust, personal autonomy, psychological and physical harm), it is again difficult to conclusively weigh the reasons for and against disclosure. The moral agent will have to exercise moral judgement.

Moral judgement

What is meant by 'moral judgement'? Sometimes called 'moral discernment' or 'moral wisdom', philosophers have used vague terms to describe moral judgement. Kant considered it a 'special talent that cannot be taught but only

practiced', while Aristotle saw it as a 'perception' of what is right and wrong.^{10,11} In the last century, WD Ross claimed that there are no rules to assess the relative stringency of conflicting *prima facie* duties. Instead, we have to rely on a 'sense of our particular duty in particular circumstances'.¹² More recently, Dancy stressed the central role of moral education in the acuity of discernment: 'a contentless ability to discern what matters where it matters, an ability whose presence in us is explained by our having undergone a successful moral education'.¹³

There is something mysterious and deeply personal about moral judgement, akin to a moral 'sixth sense' acquired gradually throughout life. Expanding our cultural, intellectual and emotional horizons is likely to develop this sixth sense. Sound moral judgement will sharpen the process of moral analysis, reducing the likelihood of misdiagnosing a problem as a moral dilemma when, in fact, a clear solution exists. Yet, some dilemmas are so complex that even the wisest of the wise will not find a clear-cut solution. As the philosopher Larmore writes, 'in many cases, judgment will be powerless to settle the [moral] conflict'.¹⁴

Personal thoughts and practical recommendations

So which horn of the dilemma would I choose, and why? I confess that I have struggled for the past two years over this case. I wavered on the relative weight that should be given to the principle of respect for autonomy. Depending on my mood, I opted for disclosure when I gave the principle significant moral weight and opted against it when I gave it a lower priority. In my current phase, no doubt biased by my fickle belief that I would not want to know myself, I would reluctantly choose the non-disclosure horn, based mainly on the potential detrimental effects of disclosure on the patients.

However frustrating, the persistence of my uncertainty reinforced my suspicion that this case represents a genuine moral dilemma. I *ought* to tell the patients about this incidental but profoundly important finding, and yet I *ought not* to tell them in case they do not want to be told and suffer terribly for the rest of their lives, but I cannot satisfy both *oughts*! Whichever horn I successfully avoid, I will be impaled by the other.

The transplant team are not, in my view, inescapably doomed. As long as they have duly identified and considered the relevant factors, and weighed them in a reasonable fashion with the intention of benefiting their patients, then any bad outcome – though regrettable – would not retrospectively make their decision morally wrong. If the decision to disclose the information turns out to yield catastrophic consequences, it does not follow that the team can be blamed for the decision. They would be unlucky, but not morally culpable. As it happens, the team decided to share their unexpected finding with the patients who, although initially shocked and distressed, were grateful for the staff's honesty. Miss P did not revoke her decision to donate the kidney.

Whatever the individual position on the case, all will agree that it is desirable to avoid such ethically (and emotionally) difficult situations. Although some moral dilem-

mas cannot be realistically avoided, the transplant team could take measures to reduce the likelihood of such situations arising again. Arguably, moral agents should not be blamed for making decisions in a genuine moral dilemma since there is, by definition, no preferable alternative, but they may be at fault if they are morally responsible for allowing the dilemma to occur.

One approach would be to set up procedures to resolve the issue prior to the emergence of the problem. A plausible solution suggested by the authors of the original paper would be to inform patients at the outset of the possibility of incidental but potentially important findings (such as non-paternity) and to ask them if they would like such findings to be revealed.¹ This would ensure that any disclosure is tailored to the informational preferences of the individual patient. Armed with this information, the present case would not be a moral dilemma, but a moral problem with a straightforward (though emotionally difficult) solution.

Conclusion

Although it is commonly heard that doctors should always 'tell the truth', it is not always clear what constitutes the 'truth' in any given context. I have argued that doctors have a *prima facie* duty to disclose relevant truths that patients could reasonably expect to be told. The American Medical Association's Principles of Medical Ethics, which state that a physician 'shall be honest in all professional interactions' and should 'strive to report physicians engaging in deception to appropriate entities' are thus misguided.¹⁵ Honesty, though generally desirable, is not always the best policy. The duty to tell the truth is not absolute but can be outweighed by other moral considerations, such as the obligation not to cause great and avoidable harm.

In some cases there will be equally compelling reasons to disclose and to withhold information (i.e. a moral dilemma). When moral agents suspect a moral dilemma, they should ensure that no morally relevant considerations have been omitted and that the justifications for their preferred position are well-argued. Open discussion with colleagues from different personal and professional backgrounds is desirable to appreciate diverse viewpoints, tighten one's arguments and heighten awareness of personal biases. Finally, moral dilemmas should always generate a further discussion about possible ways to avoid similar problems in the future. Asking patients early on in the doctor–patient relationship how much they would like to know is one way to tailor information to the preferences of individual patients.^{16,17}

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