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An Extra Reason to Roll the Dice:
Balancing Harm, Benefit and Autonomy in ‘Futile’ Cases

Short title: An Extra Reason to Roll the Dice

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Abstract / Introduction

Oncologists frequently have to break bad news to patients. Although they are not normally the ones who tell patients that they have cancer, they are the ones who have to tell patients that treatment is not working, and they are almost always the ones who have to tell them that they are going to die and that nothing more can be done to cure them. Perhaps the most difficult cases are those where further treatment is almost certainly futile, but there remains an extremely slim chance of yet more aggressive treatment having a near-miraculous effect. In such situations, it can be difficult for the oncologist to decide how to explain things to the patient, and how much to tell them. It can also be very difficult to achieve the correct balance between respecting the patient’s autonomy and not exposing them to harm. This paper examines an example of one such case and makes three suggestions. First, that respecting autonomy cannot be achieved by maximising information-sharing only to deny patients the chance to make decisions based on that information; second, that the simplistic application of the principles of nonmaleficence and respect for autonomy can lead to erroneous conclusions about the most ethical course of action; and third, that there is an extra reason, in addition to respecting patients’ autonomy, for attempting near-futile last-ditch interventions: when treating rare conditions, useful evidence can be generated that will benefit future patients.

The case

Zoe is a 13-year-old girl who initially presented with a rare type of tumour (details changed to protect anonymity). At this point, the chance of cure was about 90%. She underwent chemotherapy and surgery, but after 10 weeks the cancer returned more aggressively. At the point, the chance of cure was about 10%. She underwent chemotherapy and surgery again, and again her condition improved, but after 10 weeks the cancer had metastasised to her abdomen with multiple solid tumours. The chance of cure now was difficult to calculate, with the only evidence of cure being in a very small sample of a different patient population who were subjected to very toxic chemotherapy and another round of surgery with limited success: at the very best, Zoe's chances of cure are now less than 1%. Her oncologist, Dr Williams is of the opinion that the best option is palliative chemotherapy that will allow her to live the last few weeks (anticipated to be less than 10) of her life with some dignity. He also explains to Zoe that the curative chemotherapy would be very nasty for her, leading to a lot of suffering, and might actually accelerate her death.

Zoe, however, will not countenance any discussion whatsoever of any options other than attempting to cure her. She leaves the room whenever the palliative option is mentioned, and her parents are very emotional and say they will support her decision. Dr Williams must decide whether to grant Zoe's request and attempt to cure her one more time.

Respecting autonomy and denying treatment

Dr Williams brings the case to his local clinical ethics committee for discussion. He states that he will not be bullied into giving her the chemotherapy if he believes it is futile, but that he is open to suggestions. The first question that is asked is "Is Zoe competent?" Dr Williams suggests that her refusal to even be in the room when palliation is discussed could be used to argue that she does not have enough information to make a valid decision. However, it is clear that she has enough information about the option that she is interested in, so this argument doesn't seem to work. But perhaps she is in denial about her impending death, and the shock of this news has rendered her incompetent. Although she has refused to see a psychologist, there seem to be insufficient grounds for any such declaration, and Dr Williams concedes that she is certainly competent to make a decision about treatment.

Why did Dr Williams tell her that there was a very slim chance of cure if he had no intention of giving her that treatment? It seems surprising that a doctor would adopt such a course of action. He argues that the principle of respect for autonomy requires doctors to information-share as much as possible, and that doing so incurs no obligation to provide any particular option; otherwise the National Health Service would operate according to the whims of patients' demands. The problem with this argument, however, is that Zoe's condition has not changed relevantly since he told her about the possibility of a last-ditch attempt. It is reasonable to mention a future option to a patient and then say that option is no longer suitable due to a change in their condition, but to mention an option then deny a patient the chance to choose it when nothing has changed is to disrespect their autonomy. There is no point in telling a patient about an option that you have no intention of offering them – unless you know that another doctor elsewhere might consider doing so, in which case a referral might be in order Nevertheless, it is hardly fair to Zoe to say "there is one last thing that we could try" only to insist the next day that "it's not worth the risk". It might appear ethical for a doctor to fully inform the patient of all the options while still deciding whether one of them will be offered, but in fact doing so is unethical for two reasons: it disrespects the patient's autonomy by offering an option only to then deny it, and it also offers false hope, which is particularly bad in Zoe's case when she is so set on going for a cure. Implausible as it seems, Dr Williams genuinely believed that mentioning the option was the right thing to do. (Interestingly, Dr Williams says he would be happy to refer her to a 'neutral doctor' but he wouldn't refer her to a doctor who he is certain would agree to treat her – is this respecting her autonomy?)

Nonmaleficence versus autonomy

This brings us to the key dilemma in Zoe's case: is attempting cure again worth the risk? The previous two attempts at chemotherapy and surgery have both failed, and there is no evidence of success with the proposed interventions in girls with Zoe's condition. On the other hand, there is the aforementioned very small amount of evidence suggesting some efficacy in boys. The dilemma for Zoe's doctor is that the extremely slim chance of cure seems insufficient to justify the suffering that the last line of chemo will certainly cause Zoe, the risk it poses of actually shortening her life (compared to palliation), and the consequent loss to her of a potentially valuable last few weeks of relatively good life. If Zoe were not competent, and it fell to Dr Williams to make a decision in her best interests, it seems likely that he would opt for palliative chemotherapy. But as we have seen, she is competent, and clearly wants to try for a cure one last time. Dr William's view is that this is a direct conflict between the principles of non-maleficence and autonomy.

Is this actually correct? Williams argues that giving Zoe what she wants would be to harm her, because the chemo will drastically reduce her quality of life during the last few weeks of her life. In fact, this summary is only correct if we are certain that the chemo and surgery will not work; given that there is a chance that it will, there is a possibility that we will benefit Zoe, and the principle of beneficence also comes into play. But even this analysis misses out some key factors. While it is certainly the case that the chemo will harm Zoe to some extent, it could well be argued that denying Zoe her chosen option would also harm her psychologically; she will feel abandoned and disrespected. Furthermore, the most accurate analysis available to us can be achieved if we look at the whole situation from Zoe's perspective. Zoe is faced with the ultimate harm of death. If she is not given the chemo, this harm becomes a virtual certainty (spontaneous remission being even less likely than cure with chemo), to which must be added the aforementioned harms that flow from not respecting her autonomous choice. If she is given the chemo, there is at least a chance of avoiding the ultimate harm, at the cost of additional physical distress caused by the attempt and the attendant risk of the chemo actually shortening her life. (There is also the benefit of having her decisions respected, although it is not clear that this should really count as a benefit, as it should be automatic). While Dr Williams should certainly not feel bullied into giving Zoe the treatment, he doesn't have a great deal of choice – he told Zoe it was an option, nothing clinically relevant has changed and she remains competent.

In addition, Dr Williams attempts to frame the case using only two of the four main principles of biomedical ethics. What about the principles of beneficence and justice? The latter principle is concerned more without equal treatment of patients and resource allocation, but it does appear in this case that Zoe is being treated unjustly inasmuch as it is unfair to mention an option then refuse to offer it. With regard to beneficence, while there is a risk that the treatment will actually harm Zoe, there is a chance (and this is why she wants the treatment) that it will either cure her or at least lengthen her life. Avoiding or delaying death is an immense prospective benefit, however slim the chance of achieving it. It is understandable that Dr Williams focused on autonomy and nonmaleficence, as the patient wants something that he believes will almost certainly harm her, but it is perhaps because of this narrow framing of the question that the current dilemma arose

An extra reason to roll the dice

It appears that the most ethically sound course of action is to give Zoe one last cycle of chemotherapy and the necessary surgery. But if the power of the principle of respect for autonomy was not enough to sway Dr Williams, there is an extra reason to roll the dice one last time – not just in Zoe's case, but in any relevantly similar scenario where further treatment seems virtually futile. This reason is only an additional one, and would be insufficient in itself to decide one way or the other, but in very finely balanced cases (and in the end, Zoe's was not so very finely balanced) it might have some ethical weight. The reason is that attempting cure one last time will generate new data that might eventually help patients in situations similar to Zoe's, either through a published case report or private communications between specialists. If, as unfortunately seems likely, the chemo and surgery are ineffective and she dies, there will at least be more evidence that such third-line attempts are likely to fail. In fact, given the paucity of evidence for patients like Zoe, this would be the first evidence either way. And if, as seems unlikely, Zoe is cured or at least lives longer than would otherwise have been the case, the evidence is much more important: although it is only one case that might be due to chance, it means that another doctor faced with a similar case will at least have some evidence that one last try worked for someone. If, on the other hand, Dr Williams refuses to give Zoe what she wants, we simply have one more situation that adds nothing further to the evidence base: it is already well known that if you give up, the patient almost always dies.

So far this sounds like a doctor's reason for giving one last round of chemo, and it should probably remain so; the patient must make her own choice, and it would be inappropriate for a doctor to suggest to a patient that she should go for the chemo because it will improve the evidence base; this would be to cross the line into coercive research on dying patients. But it is nonetheless also a reason for patients. Zoe wants the chemo because she wants to exhaust every last option for cure; she doesn't want to die having given up the fight. It might give her added comfort if, after having made her decision, Dr Williams tells her that what she is doing might well help other patients in the future. Equally, this thought might occur to some patients before they make their decision; in essence, going for the intervention rather than accepting death offers hope not only to the patient, but potentially also to patients now and in the future who face similar choices. Even if the patient dies, they have died helping others. This is obviously not reason enough to submit to an unpleasant intervention, but it is also not without ethical weight. (In addition, of course, this article would not have been written had Zoe not chosen to keep fighting.)

Conclusion

Zoe was given the chemotherapy in accordance with her wishes. She did suffer more than she would have had she opted for palliative chemotherapy, but the side-effects were not as bad as anticipated, and the curative chemo had a remarkable effect: the tumours all shrank a great deal. Zoe was content, but Dr Williams suspected that the cancer would again return after 10 weeks. In the meantime, he was faced with a new problem: the surgeons had said they were happy to operate on Zoe again if she responded to the chemo, but that was in large part because they thought she wouldn't; now that it has worked, which surgeon would be brave enough to operate on her again? But Dr Williams was willing to keep looking until he finds a surgeon who would. This is just as well, considering that the chemo has resulted in what is pretty much the best possible outcome; if he were now to tell Zoe that the chemo worked but no surgeon is willing to operate on her, she would be right to argue that the chemo plus surgery option should not have been presented if surgery was always going to be denied even if the chemo had a much better effect than anticipated.

Whatever happens to Zoe in the future, her case is instructive. It illustrates why doctors should be very careful about which options they mention as possibilities to their patients, as the patients will be well within their rights to claim that their autonomy is being violated if they are denied an aforementioned option and nothing clinically relevant has changed. Equally, doctors should be wary of attempting to divine the ethical course of action via application of the four principles; using the principles can be challenging even in simple cases, and in cases like Zoe's it can be easy to make a mistake. And finally, patients faced with choosing between palliative care and one last throw of the dice actually have an extra reason to go for the latter. The main reason will always be that they have not given up, and have tried every option; but another is that they will be contributing towards the evidence base that future clinical care is based upon, and might well be helping other people live longer, as well as themselves.

This case is based upon one that was referred to a clinical ethics committee.
The details have been changed to protect anonymity.