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INSIDE THE ETHICS COMMITTEE

1. Treating a Jehovah's Witness

RADIO 4

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PARRY
As medicine becomes ever more complex so do the ethical dilemmas faced by medical staff, patients and their families. What makes these problems especially hard to deal with is that in many cases there is no right or wrong answer, just shades of grey. And that's where a clinical ethics committee comes in. Only four years ago such committees were rare, with only 20 in UK hospitals but this is changing rapidly as their value is recognised and now over 70 hospitals have onsite teams to advise medical staff on tough ethical choices.

In this new three-part series: Inside the Ethics Committee, I'll be presenting real life medical cases to three different panels, each consisting of experts who sit on clinical ethics committees. We'll be hearing testimonies from those involved in each case and showing the process by which the panel weighs up the ethical dilemmas and then gives their advice.

And having heard the evidence you too will have an opportunity to give us your thoughts. I'll be giving you the details of how to do that later on.

In this, the first programme of the series, my guests today will consider a case involving religious belief, where a patient was refusing not the whole treatment but in this real life case just part of it. The patient is a man in his mid-40s, who was admitted to hospital with suspected anaemia, in fact he was diagnosed as having acute myeloid leukaemia. This is a form of blood cancer in which abnormal white blood cells crowd out the normal ones in the bone marrow, so preventing it from making new blood cells. The doctor who made the diagnosis, a haematologist, takes up the story and explains the ethical dilemma here.

HAEMATOLOGIST
After we confirmed the diagnosis of acute myeloid leukaemia in this patient we offered him chemotherapy with blood products because that is the standard treatment. Blood transfusions are essential in the treatment of this disorder because the chemotherapy will kill not only the bad cells but also the good cells and will render the bone marrow empty. Once it does that, to keep the patient alive, one has to give them blood transfusions till such time as their bone marrow normally regrows the good cells back again. When we offered him this treatment, which was chemotherapy and blood transfusion, he disclosed that he was a Jehovah's Witness and he had a living will which basically meant that he would decline any blood transfusions. However, he was very keen that he was treated with chemotherapy.

PARRY
Jehovah's Witnesses who number about 150,000 in Britain have strong religious beliefs about blood and refuse transfusions. The governing body of Jehovah's Witnesses has established hospital liaison committees. These are groups of elders who support Witnesses faced with treatment decisions involving blood. We now have testimony from one of these elders.

ELDER
Our belief is based firmly on what the Bible has to say, just as the Bible, as everybody knows, forbids things like adultery and stealing and lying, it also tells us to abstain from blood. In a number of places it mentions this command and most especially in Acts chapter 15, in verse 28 and 29 the apostles of Jesus Christ wrote: "For it has seen good to the Holy Spirit and to us to lay upon you no greater burden than these necessary things, that you abstain from what has been sacrificed to idols and from blood and from what is strangled and from unchastity." So on the basis of that we feel the need to obey that command, as well as all the others in the Bible to abstain from things which God says are wrong. The reason that we would refuse blood is because we feel that it would endanger our standing with the Almighty, that it could have an effect on our everlasting future and we're convinced of course that this life is not all that there is, we're convinced that there is a life beyond this and we want to preserve our good relationships with the Almighty so that the judgement he would render would be in our favour. But if one of Jehovah's Witnesses such as myself were diagnosed with a leukaemia, such as acute myeloid leukaemia, then we would be eager to accept chemotherapy as appropriate, but rather than our blood counts being supported by blood or blood products then we'd want our blood counts or our platelet counts to be supported by alternatives.

HAEMATOLOGIST
I was uncomfortable about this patient's request, mainly because to treat acute myeloid leukaemia with intensive chemotherapy is almost impossible without giving blood transfusions. It is almost like trying to get to the moon without travelling through space. We offered this patient the option of chemotherapy with whatever alternatives to blood products we have, making it very clear that the outcome was not likely to be successful and that the treatment itself could lead to fatality. The other option was to offer no treatment at all. The patient felt that he would take the chance with chemotherapy, he understood fully what the problems were and that the outcome was not likely to be successful, but however, did feel that he had an outside chance of being able to achieve a remission. He was fully informed and gave informed consent and so we went ahead and treated him with conventional chemotherapy but without blood transfusions. I did feel very uncomfortable because obviously the patient had declined a potentially life-saving intervention but also he was a conscious competent adult and obviously it was his right to make that decision. However, I did take this to the local ethics committee in our hospital because I felt that giving partial treatment would actually not be in the patient's interest, was more likely to cause him harm rather than good and also the quality of life was likely to be much worse with chemotherapy rather than with supportive care alone.

PARRY
So having outlined the problem there let me welcome today's panel. They're Bobbie Farsides, who is a senior lecturer in medical ethics at King's College, London. The Reverend Philip Carrington, hospital chaplain for South Tees Hospitals NHS Trust. Diana Howard, a nurse specialist who runs the palliative care team at St. Mary's Hospital, Paddington. And Anne Slowther, a GP in Oxford with a special interest in medical ethics who's also closely involved with the UK's clinical ethics network.

Let me start with you Bobbie Farsides. Am I right in saying that the first thing that has to be established in these cases are the legal parameters?

FARSIDES
I think that's right, it's very helpful to start with an understanding of what you can and cannot advise in a legal sense.

PARRY
And would there be a lawyer on the ethics committee?

FARSIDES
Ordinarily I think people go to great lengths to have a lawyer or one of the legal advisors from the trust involved.

PARRY
Now I know in this case that the patient was found to be competent, given that the patient is competent is the law supportive of a patient's refusal of treatment?

FARSIDES
Yes it is, I mean I think it's one of the clearest rights one has as a patient, in terms of English law, to refuse treatment. And if you've been shown to be competent you don't even have to provide reasons for your refusal and you certainly don't have to expect your reasons to be scrutinised and objected to.

PARRY
So completely irrational or no reason the law still supports you.

FARSIDES
As long as you're shown to be competent yes.

PARRY
Now let's just go to consent because Anne, that's a vital part of this whole process.

SLOWTHER
Yes, I think this is a key part of this process and a valid consent or a valid refusal of treatment for it to be acceptable needs - it requires that the patient is competent, which we've already mentioned, that they're free to make that decision, so they're not being coerced and that they have adequate information on which to make the decision. For a patient to be competent they need to understand the information that they're being given and to be able to evaluate that information to make an informed choice.

PARRY
Now this patient had severe anaemia, doesn't that cause confusion?

SLOWTHER
There are physical conditions which can affect competence and make consent a problem, and anaemia can in some circumstances because it reduces the oxygen concentration in the blood and that can sometimes cause confusion, it would have to be very severe anaemia.

PARRY
We also know, I should tell you, that the doctor did speak to the patient on his own, he felt that he was making his own decision, he wasn't being pressured by others. But coming back to you Bobbie, the patient isn't actually refusing the whole treatment here, they're only refusing part of the treatment, so where does that put us in a legal sense?

FARSIDES
I think that's part of what makes this such an interesting case because you could say that the fact that the patient is only saying they want to refuse a component of the treatment puts more of an emphasis on the clinical judgement of the doctor. Does the doctor feel that they're going to be doing something clinically appropriate and in the patient's best interest if they offer this partial treatment, whether the patient has consented to it or even seems to be demanding or requesting it?

PARRY
Now you've mentioned those words "best interests", what does best interests mean, I mean it sounds rather paternalistic?

FARSIDES
Yeah I think we do have to be careful, we think of it as associated with doctors knowing best but actually I

think nowadays people make an effort to have a very broad idea of best interests. The doctor's primary responsibility is probably to think in clinical terms but they're also going to think about the best interests of this patient, given who they are and the views that they hold.

PARRY
And that's where religious belief presumably comes in, Reverend Carrington?

CARRINGTON
Absolutely. All our decision making is based on our beliefs and if someone has a particular religious belief and feels it very strongly then it undoubtedly is in their best interest to make decisions bearing in mind that religious impact.

PARRY
What would the impact be here if this Jehovah's Witness had this treatment?

CARRINGTON
He's been told he has a disease which is potentially life threatening, so he's looking towards the end of life and the beginning of his new life in paradise. So how does he prepare himself for paradise? So how he makes decisions about his treatment will be affected by what his long term future is, which is not only in this world but also in the next.

PARRY
Now you're a Church of England chaplain, how can you represent Jehovah's Witnesses?

CARRINGTON
You were kind enough to introduce me as a hospital chaplain, in fact I'm the manager of the department of spiritual care and chaplaincy, which means I'm responsible for all faiths within the trust I represent. All faiths in the sense that I'm the only one who's full time, so if there is an issue today then someone will page me and ask for a response, so I have to know what each faith is about. Now I can't necessarily speak for them but I can advise others what their religious perspective would be. So if this became an issue and say the doctor concerned here had rung me and asked for my opinion before he began this treatment I would have given the Jehovah's Witness's point of view but also put him in touch with the hospital liaison committee we talked about earlier, to make sure that he was absolutely sure of that decision making process and what lay behind it.

PARRY
Okay. Let's go back to the medical facts of the case here because as we've heard from the doctor there are two key issues about the treatment this patient wants. The first is that the doctor believes it probably won't work but the second is that he thinks the treatment could actually be harmful. Now the facts about acute myeloid leukaemia are clear, it's a very treatable condition, even curable, in someone of this age and using the standard regime of chemotherapy plus blood product support about 80-85% of those treated could be expected to go into remission and there's roughly a 40-45% chance of cure. Now those figures are based on hard evidence obtained through clinical trials but what are the evidence that this type of leukaemia can be treated without blood products? Let's return first to the testimony of the Jehovah's Witness elder and then we'll come back to the treating doctor.

ELDER
In my experience I have known a case where an individual refused all blood support and blood product support, accepted the chemotherapy and is now, as we speak, in remission. However, it is true that it is more likely that the individual would lose their lives within weeks or months. But in view of our conviction and our faith then we're willing to accept that risk.

HAEMATOLOGIST
Although there may be anecdotal reports of treatment of Jehovah's Witnesses there really is very little evidence suggesting that their treatment without transfusion, whatever other supportive therapy is given, leads to a good outcome. If you look at the populist literature there is only one survivor which has been

reported out of about 10 or 12 cases which have been published and that survivor was four to five months after diagnosis, which is not long term survival in any case. So the overall outcome of treatment of acute myeloid leukaemia in this group of patients is extremely poor. Also this patient's request is likely to hasten the patient's demise and lead to a marked deterioration in his quality of life.

PARRY
So we've heard really that there's only anecdotal evidence at best to support this patient's wishes, from an ethical point, Bobbie, can a patient request treatment that the doctor believes is probably futile?

FARSIDES
They can request it but then I think the important question is, is the doctor under any obligation to provide it? And we increasingly are moving towards the position where we want evidence to suggest that something that is going to be given will be of benefit and certainly won't be harmful with no hope of significant benefit. But of course the complication in this case is we're not just talking about medical benefits, we're talking about the benefits that this person wishes to pursue because of their religion.

CARRINGTON
And that's vitally important because how we define the word futile, the doctor may say this is futile but from the perspective of the patient nothing will be futile.

PARRY
So when we were talking about the legal bit of this case we were saying that the patient didn't have to have any reason at all to refuse treatment but in terms of giving treatment there has to be some evidence for his belief?

FARSIDES
Yes I think the legal issue here is in a state of flux at the moment because in the past we've had the very clear legal position that people have no right to demand any form of medical treatment. A recent case that challenged some GMC guidance on withdrawing and withholding treatment has now brought this question up for legal review. But I still think ethically many doctors would feel that the decision about whether or not to provide treatment is a clinical decision that should be based on clinical evidence, even when there are very powerful reasons to suggest that to keep hope alive, to keep someone - to give someone the possibility of living a bit longer you'd like to give it a go.

PARRY
We heard in the doctor's testimony a moment ago that using the chemotherapy in the absence of blood products was not just likely to be useless but actually harmful, Anne, tell me why that is.

SLOWTHER
Well I think first we just need to remember that this disease itself - acute myeloid leukaemia - is very harmful, the disease destroys the red cells and the white cells within the patient's blood, so they will become very anaemic, they may bleed and not be able to stop bleeding and they will be very susceptible to infection. However, the treatment for acute myeloid leukaemia, the chemotherapy treatment, specifically works by destroying cells, so it destroys the bad cells but it also will destroy the good cells. So in addition to the disease you have the treatment actually destroying all the cells and therefore making the symptoms of anaemia, bleeding and infection much more likely and much worse.

PARRY
So it's a kind of double whammy then?

SLOWTHER
Yes.

PARRY
Now Diana Howard you're a palliative care nurse and you've looked after people in this sort of situation, what are the implications of this request in terms of quality of life for this patient?

HOWARD
Well clearly chemotherapy itself can have unpleasant side effects - vomiting, hair loss, sore mouth - that would be unavoidable whether the patient had supporting blood products or not. The implications of choosing an option without the supporting blood products are that the side effects and symptoms can be even worse. For example, the bleeding - that can be bleeding from the nose, from the gums, which is unpleasant but perhaps not life-threatening but could be a life-threatening bleed within the gut or within the brain. The patient will also be very vulnerable to infections, which will make him feel absolutely awful, will mean that he has to be nursed in a side room, with restricted visiting from family and friends. And may become very unwell and potentially die very quickly.

PARRY
So this is a very unpleasant way to die?

HOWARD
Certainly.

PARRY
Surely under the Hippocratic oath doctors have a duty to do no harm to their patients, so isn't it unethical Bobbie to give only a partial treatment?

FARSIDES
Well as Diana suggested we often give treatments that we know have harmful side effects but we do it because we're pursuing what we consider to be a substantial benefit that is highly probable in that case. Here, the problem is we've been asked to compromise the treatment we're giving, thereby increasing the risk of harm for very, very little chance of benefit.

PARRY
Reverend Carrington, is it more then in this case about giving hope?

CARRINGTON
Absolutely, but you've got to remember that the Hippocratic oath that you just mentioned a moment ago is also a religious statement, it begins with the phrase: "By Apollo and all the gods ..." and goes on to the rest of the statement. So in the whole of the context of the decision making and the care of this patient that religious context is paramount.

PARRY
So as far as the patient is concerned this is not a harmful treatment, this is a treatment that might give him hope?

CARRINGTON
If he denies himself the treatment he may close the door to paradise for himself ...

PARRY
Because that's their belief.

CARRINGTON
.. because that's their belief. By going through this treatment he is trying everything possible so will be able to face the judge at the beginning of his new life with his head held high.

PARRY
So he accepts the harm?

CARRINGTON
Yes.

SLOWTHER
I think this issue of hope is very interesting but if we just sort of extend the examples away from specifically Jehovah's Witness there are cases where people would want to have treatment for their cancer which doctors felt was very unlikely to be effective or give them only another extra two or three months of life, where we don't give that treatment even though it would give hope to that patient.

PARRY
So to summarise where we've got to so far in this discussion, we have a man who is a Jehovah's Witness, he has acute myeloid leukaemia, he's refused blood products but he wants to have chemotherapy. We've covered the legal issues and we've looked at the ethics of whether he can request a treatment that the doctor believes is futile and we've explored some of the reasons why the patient's interest may differ from those of the doctor. Now let's move on to that very thorny issue indeed, which is resource.

HAEMATOLOGIST
When this patient demanded alternatives to blood transfusion there were obviously cost implications to this treatment as well. The alternatives that we have are extremely expensive, as well as the fact that currently there is very little evidence that in this set up they actually deliver the goods. If there was clinical evidence that they were beneficial in such cases then I think it would be entirely reasonable to use it, however, there is no clinical evidence of their benefit and so it could almost be felt to be wasted resources. Obviously over and above that is the cost of chemotherapy drugs, with the cost of nursing, with the cost of isolation rooms etc.

PARRY
Diana, you've had direct experience of this, what are the financial implications of this sort of treatment request.

HOWARD
Well clearly the chemotherapy drugs themselves cost money, but also all the other slightly hidden costs of the treatment - nursing involves quite intensive care, often one-to-one nursing, often in a single side room, hospitals don't have enough side rooms and single rooms as it is, and so it's going to potentially deprive another patient of that.

PARRY
So perhaps somebody with MRSA or something like that.

HOWARD
Exactly, we have a finite resource.

PARRY
Okay, but what are the wider implications in terms of other patients, what might the knock on effect be for them?

HOWARD
You might potentially - I mean those other patients can't have chemotherapy at the appropriate time, they can't have the appropriate rooms and resources, so they're having delays in their treatment. You've also got the implications of patients seeing a patient having a treatment that's making them worse, I think we forget that patients are very aware of what's happening to their peers.

PARRY
So there's a wider harm to society, quite definitely, in this case?

HOWARD
I would say so.

PARRY
What if the patient had requested the same partial treatment on non-religious grounds, would that ethically

be the same Bobbie?

FARSIDES
Well the patient would probably feel that they had good reasons. Say, for example, someone had a morbid fear of being infected by blood products, they might think that they have evidence to suggest that this is a valid fear and they may make a demand on the basis of that. But I think in that case the doctor might be more confident about actually discussing the basis for the refusal and actually in a sense standing up against it because they would feel that they were talking the same language, the person might have got it wrong slightly in a field that the doctor is actually more confident about.

PARRY
Actually here having religious beliefs is an advantage in getting resources, doesn't not having religious beliefs disadvantage a patient?

FARSIDES
I try to resist making anecdotal statements myself but I have been told recently that people are beginning to suspect that some people are pretending to be Jehovah's Witnesses because of their fears about blood products and wishing to avoid transfusion.

SLOWTHER
We have to look at the issue here of the effectiveness of the treatment as well. In this particular case the treatment was thought very much to be ineffective. If it was in a slightly different situation where the doctor felt the alternative treatment of blood products could be effective but it wasn't normally given and it was more expensive then it might be much more difficult to say no to the patient in that case.

FARSIDES
I think it's particularly important to understand how key the blood products are to the chemotherapy. It's different from a situation say where somebody is a bit anaemic after an operation or after childbirth where transfusion would be helpful but may be we could wait and see how they go, maybe some iron tablets will help. This is a very specific local situation, I think the patient needs to understand how integral the blood is in the treatment.

SLOWTHER
Well I certainly would agree with that. There's just one other point I'd like to make about effectiveness though. Although I think it's quite clear that alternatives to blood products are not nearly as good in this case, although we have no good evidence that the alternatives to blood products are effective we don't really know that they're completely ineffective, that's a slightly different question.

PARRY
You seem to be suggesting that doctors are rather wary of making ethical decisions where religion is involved?

SLOWTHER
I think that's probably in general true. Many doctors don't share the religious beliefs of their patients and can therefore find it quite difficult to put themselves in the position of their patients, so they see things very much from their point of view.

PARRY
Bobbie, would you say that actually religious belief can cloud ethical decision making?

FARSIDES
I think we have to be very careful because as Reverend Carrington has said we've got to understand for this Jehovah's Witness there is a very coherent sense to their beliefs and a very fundamental basis for it in their understanding of the biblical texts and as Anne says if we don't share those beliefs it's difficult for us to get into that story in an effective way. But I think once you know that somebody has profound religious beliefs you do still have to test, for example, that they're not being put under due pressure by those who share the

same beliefs on this particular instance, people change their minds, particularly when faced with death, they might actually question the teachings themselves. As I understand it there's a lot of debate within the Jehovah's Witnesses at the moment about blood products and distinctions are made about different types of blood products and views have changed in the past, in the past they weren't allowed immunisation or organ transplant - now they are. So I think it's a difficult one.

CARRINGTON
It's important to recognise not only their religious belief but also those who have no belief, if there was a humanist on the team they're going to have a completely different point of view. However, sometimes challenging things either from a religious perspective or from a non-religious perspective can bring about benefits and we were talking about resources and certainly the Jehovah's Witnesses because of their challenge of use of blood products have come up with some incredible technology for cleaning blood, which we use generally in surgery, not exclusively for Jehovah's Witness patients but for all patients. So there are times when a religious challenge can bring about that long term benefit.

PARRY
Now I'm glad you've mentioned resources again because we seem to have wandered off. Can I come back to you Anne? Can ethics committees make decisions that have major resource implications?

SLOWTHER
Well ethics committees don't make decisions as such, they provide advice and support.

PARRY
Forgive for saying this but if they only provide advice and support what's the point of ethics committees?

SLOWTHER
Well I think that's a very good question. The ethics committees actually provide a forum for reflective discussion of these issues, they can facilitate the discussion, help to support the decision makers in the actual decision they make for them to understand why they're making that decision and to be able to justify it. And they also have a slightly wider role of maybe identifying issues that need some guidance or policies that it may be at an institutional level to help support health professionals.

PARRY
When you're talking about resources in ethics committees does that make you feel uncomfortable, would you prefer to make your - or consider your advice in the absence of resource implications or is that simply not possible?

SLOWTHER
I think most ethics committees feel uncomfortable in discussing resource issues and would prefer to just focus on - very much more on the clinical situation and the patient's interest. However, in a health service where we have limited resources it is impossible not to at least be aware of the resource implications of the issues that we're discussing.

PARRY
Bobbie, is that something you feel strongly about?

FARSIDES
I actually think it's one of the useful functions of a clinical ethics committee that you can discuss resources without embarrassment and without risk of damaging the relationship between the clinician and the patient because it's a very difficult thing for patients to understand that the choices made for them are made in the context of wider resource decisions.

SLOWTHER
And certainly we've had cases brought to our committee that have huge financial implications, I'm not sure about actually what the treatment for this particular gentleman would cost but we've had patients who have wanted drugs that have cost a quarter of a million pounds a year for the rest of their lives.

PARRY
And how on earth does an ethics committee cope with the sort of half a million pound type of treatment request that comes from some patients?

FARSIDES
Well I think it's very difficult for an ethics committee to be making decisions or giving advice on resources in an individual case but they are able to feed into the hospital policy for future cases, so that maybe it will be easier for future cases to be decided because there will be a framework. And also because of the national clinical ethics network these ethics committees can feed these difficult issues through to a wider forum where perhaps policy can then be set at a national level for some of these difficult issues.

PARRY
So resource, even though it's something that perhaps we don't like discussing about, really a major part of ethical committee discussions all the same?

CARRINGTON
Absolutely.

PARRY
We talked earlier about the patient's interests but the one factor that we haven't yet considered is the impact on the medical staff caring for this man. Can we now then hear testimony from the nurse that gave the man his treatment?

NURSE
It was extremely difficult administering this patient's intensive chemotherapy because within myself I felt quite certainly that this patient was going to die from the side effects of the intensive chemotherapy because always during the period of bone marrow suppression, which is a natural consequence of the intensive chemotherapy, while we're waiting for new blood cells to generate the patient is always supported with blood products and in this case we were unable to give the patient that treatment and it left all the nurses involved feeling extremely helpless and it was an extremely distressing time for all those involved. I have to be frank and admit I couldn't begin to comprehend the enormity of this patient's religious beliefs but I did respect the patient and the fact that his belief was resolute and he didn't waver from that at any time.

HAEMATOLOGIST
The emotional strain which was placed on both me and the entire team cannot be underestimated, to see the patient do downhill, to see the patient suffering from anaemia as well as bleeding when the treatment for it is at hand but cannot be given because we were banned from using it was very disturbing and very ethically challenging.

NURSE
We all felt torn between absolute duty of care for this patient and respecting their wishes and quite frankly a dreadful gut reaction that this patient was unlikely to survive.

PARRY
Now that haunting testimony and they were clearly very, very distressed by it, Diana is it right to put nursing staff or medical staff indeed through an experience like this, is that ethical?

HOWARD
That nurse is clearly describing that she feels she's been asked to do two things that are harmful to the patient, she's been asked to actually administer a treatment that's going to make him feel very, very unwell with the bleeding and the sepsis. She's also been asked to give a treatment that is likely to hasten his death. And that goes against the Hippocratic oath that the doctors have but also the codes of conduct that nurses and other healthcare professionals have which are very much about giving safe care, protecting the patient and being answerable for our own actions. We've talked that the key relationship as being between the patient and the doctor but that decision, whatever it is, has implications for the nurses, for the junior

doctors, for other patients and for the family of this patient who've not really sort of discussed within this context yet.

PARRY
But let me press you on that point: is it right to put nurses through that?

HOWARD
I think the nurse has to be very sure that the patient has really fully understood the implications of the treatment or the partial treatment he's asked for. If I was that nurse I think if I was happy that the patient really has made a competent decision I would give that treatment but it would be with a very heavy heart.

PARRY
Reverend Carrington, how can heavy hearted people like Diana be supported?

CARRINGTON
The support is there in lots of different ways but it depends on the institution, many of our hospitals have multidisciplinary teams of which chaplains are part, so they're fundamentally part of that decision making and the support network. And on an individual basis any member of staff who feels that they need to talk something through in this way do have within the NHS the opportunity of doing that. But I'm not absolutely certain that this is what the patient wanted and part of the nurse's rationale in there was trying to understand herself whether or not that was what the patient wanted. What the patient didn't want was to make a decision not to receive treatment, now this is an understanding of the faith group in which this patient belonged. I'm not here today to support any particular faith, not even my own, but I am here to make sure that the wishes of patients are fully understood. And I just wanted to question here, I'm not quite sure whether we absolutely fundamentally understood what the patient was saying, we heard what he was saying in the context of treatment but whether we fully understood in the context of his religious faith and belief where others would make a decision for him that enabled his integrity, his decision making to remain intact.

PARRY
So do you mean there that somebody in your position who would be able to explain the basis for that decision needs really to talk to all those involved in his care to make sure that the understand the basis for that?

CARRINGTON
This is one of the big issues again of the ethics committee and those who are associated with it, in that we can have these conversations out with the direct involvement of treatment.

PARRY
Diana, presumably one of the key points here is that this decision making and the understanding of the decision making trickles right through to the most junior member of the team.

HOWARD
And patients' wishes can change over time and they can be expressed to different members of the healthcare team in different ways. Patients will have a different conversation with the staff nurse who's looking after them for a 12 hour shift day in, day out than they will have with the consultant who they see for a brief consultation. So I think that's where the teamwork side comes into it, that everybody needs to understand what the aims of treatment are and what discussions have been had and not feel that one consultant has made a unilateral decision.

PARRY
Anne, could there have been anything else that this patient was offered instead of this treatment?

SLOWTHER
Yes, we've illustrated this as a stark choice between this very life threatening treatment and no treatment and they just are left to die but in fact palliative care would be another option ...

PARRY
Just explain what you mean by palliative care.

SLOWTHER
By palliative care I mean not actually treating the patient with a view to curing the disease but supportive treatment for them.

PARRY
Diana, this is your special interest and of course you're treating people like this everyday, do you think a palliative care expert should have been involved from the outset?

HOWARD
Certainly, we could have been involved in the decision process and also really making sure that the patient and his family and the team understood that the option treatment is not just doing nothing and abandoning the patient but instead is offering positive help towards dealing with the physical symptoms of the illness, dealing with the practical implications of the illness. For example, we could begin to talk to the patient about where he might want to be, if he has this chemotherapy option he's by necessity tied to an isolation room in an acute hospital, if we go for the palliative option he has the chance of being at home or in a hospice or travelling to wherever he wants to be.

CARRINGTON
May I just jump in here? I fully support palliative care and for the majority of religious groups and non-religious groups palliative care is fundamentally important. For a Jehovah's Witness unless it's active care he wouldn't even consider it.

PARRY
Well I think that draws it nicely to a close and I hope that we've represented in this very, very short time the main issues that you would have considered during your ethical committee meeting on this particular case. And now what I'd like you to do is to sum up for me. Reverend Carrington, briefly what would the one point be that you would want people to take away from this?

CARRINGTON
To recognise patient choice, to recognise how that patient choice is being made, whether it's from a religious or a non-religious perspective, the context in which it's being made and that they may be looking beyond this life to a final say in their life.

PARRY
Anne.

SLOWTHER
I would reiterate that but I'd like to just make a broader point, that for a clinical ethics committee this is an opportunity to identify lessons to be learned for future cases, including education and guidance for health professionals.

PARRY
Diana.

HOWARD
For me it's an issue about informed consent and making sure that the patient really understood how unpleasant this treatment option might be and really that there were alternatives.

PARRY
Bobbie.

FARSIDES

I think I'd like to think a bit more about the point Reverend Carrington was making that sometimes by refusing to give somebody something we save them the difficult decision about whether or not to have it. In this case if the doctor and nurse had been able to be in a position to say I'm sorry we can't proceed with a treatment like this the patient would not have had to refuse it, it simply wouldn't have been there and maybe it might sound like a wishy washy compromise but maybe it would have been a better way forward.

PARRY
Okay, thank you very much indeed all of you.

So what happened in the real case? The chemotherapy effectively emptied the man's bone marrow, preventing formation of new blood. Falling levels of the red blood cells which carry oxygen round the body made him more and more breathless and confused and the reduced number of platelets needed for clotting caused internal bleeding. In fact he became so ill that the treatment had to be stopped. He quickly lapsed into unconsciousness and died soon afterwards.

If you were on this ethics committee what would your advice have been in this case? In this programme our panel have tried to give you the key points of the discussion that would normally take many hours, if not days, to consider. If you'd like to let us know what you think visit our website at bbc.co.uk/radio4, when you get there you can find Inside the Ethics Committee listed in the programme A-Z or you can call us with your comments on the Radio 4 information line 08700 100 400.