

ASK AN ETHICIST

Broken telephone? Being out of the loop? Or Houston—we have a problem!

by Blair Henry

CASE SITUATION:

I am a nurse on an inpatient gyn-oncology unit. Recently we had a situation that was very upsetting for all of us, as nurses. A woman with end stage ovarian cancer was admitted to our floor and the doctor offered her an experimental treatment, which she accepted. But we knew this treatment would have side effects and it would mean that she probably would not go home again if she took it. Yet, she was talking about going home, taking a vacation with her family next summer, and sewing a dress for her daughter's graduation in three months. We were sure she would not be able to do any of these things. Her husband and her two daughters kept talking about these things too when they came in to visit her. None of them seemed to realize how ill she was and how close to death. We really were not sure how to proceed. Some of us thought we ought to talk with her about our concerns and others thought we should not and leave things alone. What is your advice?

RESPONSE FROM BLAIR:

Thanks for bringing forward this interesting case. First, let me address this from a “systems” perspective: I am always saddened when I hear this type of issue being addressed by a member of the inter-professional (IP) team. This is the type of information all members of the IP team should share and understand about their patients if we want to provide the best care possible for them. When

decisions like this are made without all team members knowing the conversations that went into making them and how “informed” decisions are, it creates a lot of distress for health care professionals (HCPs). Having other HCPs present when discussing treatment options or writing a well documented chart note to outline how decisions are made can go a long way: we may not like the choices our patients make, but we at least know how they made them.

As for the issue at hand, I thought I'd use an ethics framework to model how these situations can be addressed. There are many ethics frameworks out there, but the one I'd like to use here is called the I.D.E.A. Framework. It came out of some work done by the Toronto Community Care Access Centre and has been subsequently adopted by several health care services.

I.D.E.A. is a mnemonic that represents four distinct steps in ethical deliberation: *Identification* of the facts, *Determining* the relevant ethical principles/policies/laws/professional standard that need to be considered, *Explore* the various options in light of the facts and relevant information and then, *Act* on the option that offers the best direction and evaluate as you move forward.

In the case presented, here is how it might play out:

Identify facts (sometimes it is not just what's been presented but seeking out what you don't know as well!)

- What is the trial phase of the experimental drug? What is the evidence/past experience with it? Do you think

her limited prognosis is due to her underlying illness or the potential side effects of this experimental drug?

- Why would she not be able to go home if she takes this experimental drug?
- Identify what conversations have taken place in the past, and what they have actually been told
- What are the patient's goals of care—are they truly what they express? What do they express in the presence of family?
- What is the physician's understanding of prognosis?
- Could there be other reasons why she is talking about these seemingly unattainable things?

Once the above information has been obtained and further discussed, try and land on the actual ethical issue about this case. My sense of the ethical issue here is: Has the patient provided full and informed consent to this plan?

Determine the relevant principles, policies, laws, etc.

- Autonomy would be one of the issues that might have strong bearing on how best to proceed
- Determine that full and informed consent, as required by law, has been provided
- Explore the impact of coercion—it may be at play in this situation
- Is therapeutic optimism impacting judgment here?
- Additionally, is there a need for the health care team to work as a unit and not distress patients and families? Working this out within the team is important, as a first step.

Exploring the options

- The first step is to ask that this issue be addressed at a team-only level initially (preserve team unity)
- Seek out clarification from the most responsible physician (MRP) on the experimental drug and what

ABOUT THE AUTHOR



Blair Henry, M.T.S., Ethicist, Sunnybrook Health Sciences Centre, Faculty, Dept. of Family and Community Medicine. Member, Joint Centre for Bioethics, Toronto, ON

determinant factors played out in the patient's decision to proceed with this trial (determine if full informed consent underpins the patient's decision)

- Develop a plan on how to respond to the observed/perceived “misunderstandings” of the patient and family. Perhaps another meeting is needed with the MRP and patient to provide further clarification and information.
- Support patient choice if this is what she wants and she truly understands the risks.

Act

- Discuss with the Gyn-Onc staff/resident (together as a team) your concerns. If the patient is making a decision based on incorrect data, then a new plan of action would be required. If the patient has heard all the information and has chosen to proceed and to be optimistic, we need to support that choice. However, consent is a process and she needs to be reminded that she can choose to stop her involvement with the study on her own.

- Also, a suggested referral to palliative care to assist in symptom management and having the crucial conversations might be a good adjunct in these cases.

Working with a patient who has “chosen” to hear only the positive elements of a treatment plan or to be “overly optimistic” about the prospects of research study isn't easy to attend to, as a health care professional. In those cases we need to clearly understand where our “duty” begins and ends. Doing that in a team is much easier!

DEMANDEZ À UN ÉTHICIEU

Malentendu? Sentiment d'exclusion? Ou bien, il y a problème!

par Blair Henry

SITUATION :

Je suis infirmière dans une unité d'onco-gynécologie aux hospitalisées. Nous avons récemment vécu une situation qui a complètement bouleversé le personnel infirmier. Une femme atteinte d'un cancer de l'ovaire en phase terminale a été admise dans notre unité et le médecin lui a proposé un traitement expérimental qu'elle a accepté. Mais nous savions que ce traitement aurait des effets secondaires et cela signifiait qu'elle ne pourrait jamais rentrer chez elle si elle le suivait. Pourtant, elle parlait de retourner chez elle, de partir en vacances avec sa famille l'été prochain et de coudre une robe pour la cérémonie de remise des diplômes de sa fille qui était dans trois mois. Nous étions certaines qu'elle serait incapable de faire ces choses-là. Son mari et ses deux filles ne cessaient de parler eux aussi de ces objectifs lorsqu'ils

venaient lui rendre visite. Ils ne semblaient pas réaliser à quel point elle était malade et même mourante. Nous ne savions pas quoi faire. Certaines d'entre nous pensaient que nous devrions lui parler de nos inquiétudes tandis que d'autres pensaient le contraire et que nous devrions laisser les choses comme elles étaient. Que nous conseillez-vous?

RÉPONSE DE BLAIR :

Merci de me communiquer ce cas des plus intéressants. Laissez-moi tout d'abord l'aborder dans une perspective systémique: cela m'attriste toujours lorsque j'entends dire qu'un membre de l'équipe interprofessionnelle est confronté à ce genre d'enjeu. Il s'agit là du type d'information que tous les membres de l'équipe interprofessionnelle devraient partager et comprendre au sujet de leurs patients s'ils veulent leur fournir les meilleurs soins possibles. Quand des décisions de ce genre sont prises sans que tous les membres

de l'équipe ne soient au courant des conversations qui les ont précédées et la mesure dans laquelle ces décisions sont «éclairées», cela crée énormément de détresse pour les professionnels de la santé. Il peut être très utile de s'assurer de la présence d'autres professionnels de la santé lors de la discussion des options de traitement ou encore de rédiger une note de dossier bien documentée soulignant la façon dont les décisions sont prises: il se peut que nous n'aimions pas les choix faits par nos patients, mais au moins nous savons comment ils y sont arrivés.

En ce qui concerne l'enjeu que vous avez présenté, je me propose d'utiliser un cadre conceptuel d'éthique pour montrer comment on peut aborder des situations de ce genre. Il existe beaucoup de cadres d'éthique mais celui que j'aimerais employer dans le cas présent s'appelle le cadre I.D.E.A. Il résulte de travaux réalisés par le Toronto Community Care Access Centre et a été par la suite adopté par divers autorités de soins de santé.

I.D.E.A. est une astuce mnémotechnique qui représente les quatre étapes distinctes des délibérations éthiques: Identification des faits, Détermination des principes éthiques/politiques/

AU SUJET DE L'AUTEUR



Blair Henry M.É.Th., Éthicien, Centre des sciences de la santé Sunnybrook, professeur, Département de médecine familiale et communautaire. Membre au Centre conjoint de bioéthique. Université de Toronto, Toronto, ON