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### Patient Privacy Versus Teamwork and Surrogate Decision Making

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**Professor Woodcock provides thought-provoking case studies to help train intensivists on how to handle the sometimes complex legal and ethical issues affecting decisions over patient privacy.**

Isobel is an unmarried 20-year old student. She was on her way to the Hospital to undergo termination of an unwanted pregnancy when a car driven by an alcoholintoxicated woman left the road and struck her. She was admitted to Intensive Care for further treatment of a severe head injury. Her parents have arrived at the hospital, and wish to be told about her condition.

**Question:** You will of course explain the extent of Isobel's injuries and the purpose of treatment to her parents, but will you tell them about the pregnancy?

The European Society of Intensive Care Medicine's "PACT" educational program (ESICM, PACT Ethics Module, Woodcock and Sprung) introduces students to 'Patient Challenges' like this one as a way of drawing the student's attention to the solution of real-life problems. This method of education is particularly well suited to ethics and law, and in this article I will use the method to explore some inconsistencies within the concept of an incompetent adult patient's right to respect for her private and family life. When I put the above scenario to an international group of critical care doctors and nurses, I found general acceptance of the appropriateness of the following answer:

**Answer:** Your first duty is to your patient Isobel and you may only share confidential information about her to the extent that you judge she would wish to share that information in the circumstances. If she has not informed her parents of the pregnancy and her decision to terminate it, you should respect her privacy on this matter.

Now, however, the story becomes a little more complicated.

Isobel loses signs of brain stem function; now the decision is between withdrawal of assisted ventilation or organ donation or maintained cadaveric pregnancy.

**Question:** How and by whom is this choice to be made?

**Answer:** The circumstances are changed; we need to consider what Isobel would wish to happen in the event of her certain death. It may now be appropriate to disclose the existence of her pregnancy, and to hear family views on Isobel's values and likely wishes. Where there is unanimity of family view, and law allows, that view should be respected. Where there is dispute, negotiation and mediation can be tried, but the advice of a Court may ultimately be needed.

The international audience generally agreed that the changed situation shifted the balance of competing considerations so that Isobel's state of pregnancy ought to be disclosed to someone close to her. The interests of an unborn child are given different legal weight in different countries of the European Union, but few would doubt the interests of her fetus deserve consideration (Sheikh and Cusack 2004)

A sophisticated audience also sees a number of other interesting ethical conundrums in this developing scenario; why do reproductive matters seem to be so much more 'sensitive' than other biological functions? When brain function fails, do we think the situation is changed because Isobel has died or because she is dying or because she is alive but now disabled? What does this reveal about our attitude to the concept of brain death? Would we confirm brain death by apnoea testing if we know Isobel is carrying a viable pregnancy? Acknowledging that apnoea-associated acidosis and hypercarbia is extremely injurious, should we be more concerned about subjecting severely braininjured patients to this test before we are convinced of the irreversibility of the patient's condition?

In the European context we turn now to consideration of Isobel's Convention Right expressed in Article 8 (European Convention on Human Rights web page.);

"everyone has a right to respect for his or her private and family life, his home and his correspondence." "... except ... prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedom of others."

It is clear that Isobel's personal information can be legitimately shared among the treating professionals to the extent that it is necessary 'for the protection of health'. Teamwork is a fashionable concept, and one cannot imagine its proponents concluding anything other than that it benefits patients. The concept could, however, be used to justify disclosure of more information than is strictly necessary to more people than is strictly necessary. The limits of need to know will be different for the various health care disciplines, and according to the proximity of the team member to the delivery of care for Isobel. An interesting group in this context are students; disclosure of her private information to them cannot be said to be justified by the need to protect her health, and certainly not to protect her morals or anyone else's! What are the policies in your intensive care unit for information disclosure to students?

Are your policies compatible with your patients' Convention Rights?

Private and family lives are not of course inseparable. We would expect Isobel's closer family members to be able to advise us on her expressed wishes and likely personal values, but we do not expect them to know all her most intimate affairs, and so we do not regard everything we learn about Isobel as disclosable. We do, however, look to family members when law or custom requires a surrogate decision maker. We must then share with them all the facts necessary to inform the decision. What of the father of Isobel's unborn child? Should we presume that her decision to terminate the pregnancy indicates her rejection of a relationship with him? Reflection on human relationships indicates that this is not always the case. But if we are to disclose information about Isobel to him, might his personal interest in the pregnancy be expected to colour any view he might then express on Isobel's likely choice or best interests? Let us ask another question about Isobel and her boyfriend.

Microbiology cultures reveal that Isobel has gonorrhoea.

**Question:** What factors would you take into account when deciding whether or not to inform Isobel's boyfriend that she has a venereal disease?

**Answer:** Weigh the public interest in the integrity of medical confidentiality against the public interest in protecting other people from a contagious disease. You will take into consideration the severity and treatability of the disease, and your proximity to or duty of care to the person at risk.

Disclosure of confidential information without the agreement of the patient can be justified in some other circumstances which are alluded to in Article 8. The prevention of disorder or crime is mentioned, though curiously the apprehension of perpetrators is not. At Southampton, the Clinical Ethics Group have worked with our regional Police to develop policies and procedures to enable evidence to be collected from the person of a seriously injured patient who is unable to consent to, for example, the collection of body fluid specimens or forensic photography. As we saw above, the protection of health can include the health of others, but to outweigh the public interest in medical confidentiality the disease would have to be of substantial seriousness. Finally, there is consideration of the rights and freedoms of others. We finish with some general questions, unrelated to our friend Isobel, for you to contemplate. I do not provide answers!

**Question:** What factors would you take into account when deciding whether or not to inform the authorities that your patient confided with you that he had killed his wife before taking a potentially lethal overdose?

**Question:** What factors would you take into account when deciding whether or not to disclose a patient's verbal threat to inflict harm on a named person?

This paper is based on a lecture given at the European Society of Intensive Care Medicine's Annual Congress in Berlin, October 2004.

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