CASE REPORT

Confidentiality issues in patients who have misinformed their families

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SUMMARY

As medical practitioners, we occasionally encounter patients who have misinformed their families of their medical histories. We describe a case of a patient whose age is in the mid-40s, who we believe had factitiously constructed a serious illness. This patient had suffered an acute exacerbation of chronic asthma and later died. When the partner was informed, the partner reported that they understood the patient had been regularly visiting our hospital for cancer treatment. No record of this could be found. This created an ethical dilemma of what could be told to the family. The patient was on the Organ Donor Register and would have been suitable to act as a donor, but to do so may have indirectly alerted the family to the patient's true condition. There was also the issue of whether the patient's children might seek unnecessary screening.

CASE PRESENTATION

A person who was known to have severe asthma suffered an acute exacerbation outside of hospital, which led to a cardiorespiratory arrest. The patient was not known to have any other medical conditions and had had no previous contact with the hospital or with the general practitioner that the patient was registered under regarding diagnosis or treatment for any cancer. We knew that the patient was married, with adult children, and had previously lived locally, but, unfortunately, we did not know more about the patient's social circumstances.

TREATMENT

A first responder started basic life support and advanced life support was later carried out by the paramedics. The patient received treatment in accident and emergency department and was then transferred to the intensive therapy unit for full system support and targeted temperature management.

OUTCOME AND FOLLOW-UP

When the patient's partner was contacted, the partner reported that they understood the patient was visiting our hospital for bowel cancer treatment and that the patient had been doing so regularly for several months. However, after extensive searching, no record or evidence of this could be found at any hospital or with the patient's general practitioner.

Unfortunately, due to severe cerebral hypoxia, the patient developed brain stem death and treatment was eventually withdrawn. The consultant in charge arranged to meet with the family when they collected the death certificate to ask if they had any further questions about the treatment received and the contents of the certificate. Death certificates must be completed honestly and fully, and cancer was not

included in part II (Other significant conditions contributing to death but not related to the disease or condition causing it).^{1 2} It was not disclosed to the family that the hospital had been unable to find any record of the patient having had cancer and the family did not ask any specific questions about it. They were, however, informed that the executor has right of access to the medical records, but as far as we know, this was not taken up. The consultant also kept the general practitioner and the trust legal department informed of the situation.

DISCUSSION

Assuming that the story the family believed was not correct, this case raised three issues around confidentiality.

First, what should the medical team tell the partner? The General Medical Council offers clear guidance on the duty of confidentiality and how this duty continues after a patient has died. For a deceased patient, it states that if no advance instruction was given by the patient and a request is made for information, then the medical team should take into account the possible distress and benefit that any information could cause to the patient's partner and family as well as the purpose of the disclosure.¹ The guidance also advises that relevant information about a patient's death should be disclosed if a partner, close relative or friend requests it and if the medical team does not believe the patient would have objected to this.¹

Second, the patient was on the Organ Donor Register, and NHS Blood and Transplant were keen to proceed with the protocol for organ donation due to lack of evidence for the cancer diagnosis. This would have required discussing the organ donation with the family.³ The guidelines for taking organs state that 'any active cancer with evidence of spread outside affected organ (including lymph nodes) within 3 years of donation' is an absolute contraindication for organ donation.⁴ For the family to find this out would only be an internet search away, so it was decided that proceeding with organ donation would undermine confidentiality and organs were not donated.

Third, there is a chance that a child of the patient may seek unnecessary colorectal cancer screening. Current screening recommendations in the UK for patients with one first-degree relative with colorectal cancer are for a colonoscopy to be performed once at 55 years of age.⁵ Using the General Medical Council guidelines,¹ it was decided that since the risk and harm associated with the screening is very low, it did not outweigh the duty to patient confidentiality.

CrossMark

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Learning points

- ▶ The duty of confidentiality continues after a patient has died.¹
- ▶ If a patient has misinformed his or her family of having a condition that is a contraindication to organ donation, proceeding with organ donation would undermine confidentiality.
- ▶ If the medical team does not believe a patient would have agreed to the disclosure, a relative should only be informed about a relevant heritable illness if not doing so may put him or her at risk of death or serious harm, or if the risk is so serious that it outweighs the patient's and public's interest in upholding confidentiality.¹

Competing interests None declared.

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