Patient privacy versus protecting the patient and the health system from harm: a case study

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ABSTRACT

- A 71-year-old man who presented to hospital with chest pain and a history of cardiovascular disease was repeatedly hospitalised over the course of a month for care that included multiple investigations, intensive care, transfer to and from a metropolitan hospital, discharge, and readmissions for collapse, hemiparesis, and vision change.
- The medical team excluded underlying disease related to his initial chest pain and subsequent neurological symptoms. A search for (undisclosed) prior hospitalisations revealed multiple previous admissions and invasive investigations at hospitals across Australia, resulting in a diagnosis of Munchausen syndrome.
- Assuming that, despite interventions, patients with Munchausen syndrome or somatoform disorders often continue to seek care at other hospitals, we discuss the implications of this patient's behaviour for the health care system, society, and the risk to his own health.
- In our view, this case highlights conflicts between privacy legislation and doctors' mandates to protect the patient from harm, as well as their duty to attend to the financial viability of health services by communicating with other potential health care providers.
- The health care system and similar patients may benefit from efforts to educate doctors about this spectrum of disorders and from considering the implementation of a highly confidential, structured notification system.

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We report an extreme example of the relatively common problem of patients who seek care at multiple institutions or from multiple doctors. The case raises questions about risks to the patient and the staff caring for him, and specifically about patient privacy versus the potential imperative to share information with other health care providers in order to protect the patient from medical consequences of unnecessary care. A summary of some of the complex issues raised by this case is shown in Box 1.

Clinical record

A 71-year-old man, newly arrived in the region, presented to a rural hospital emergency department with a 1-hour history of severe, left-sided chest pain radiating to the neck and shoulder. The patient had no dyspnoea, nausea or diaphoresis. His cardiac risk factors included his sex, age, obesity (body mass index, 32 kg/m^2) and hypertension (blood pressure, 148/90 mmHg). He reported a history of prior transient ischaemic attack. Cardiac enzyme levels and electrocardiograms were normal. The patient was transferred to a metropolitan centre for coronary angiography, which revealed a 30% right coronary artery stenosis with good collateral circulation. After transfer back to the regional hospital, he was prescribed cardiac medications at maximal doses and was discharged. The patient wanted to live in independent retirement housing but his family felt he was "too ill to live alone".

Two weeks later, the man re-presented to the emergency department, again with "severe" chest pain. Diagnostic considerations included aortic dissection, recurrent pulmonary emboli, oesophageal spasm, gastro-oesophageal reflux, and coronary vasospasm. His chest pain was relieved to varying degrees with nitrates, morphine and antacids. Gastroscopy and computed tomography (CT) scans of the chest and abdomen showed only mild gastritis, and treatment with calcium channel blockers (for oesophageal spasm or vasospasm) was ineffective.

The patient had repeated episodes of pain during consultant ward rounds or investigations (for instance, he had a panic-like attack while in the CT scanner). He appeared to the medical and nursing staff to be highly distressed. In the intensive care unit (ICU), the consultant witnessed an episode of chest pain that occurred with elevated blood pressure (184/102 mmHg) and pulse (105 beats/min). Results of repeated examinations and investigations were normal. The dramatic nature of the patient's symptoms generated attention, but his symptoms could be lessened with distraction. Panic disorder and somatisation became the leading possible diagnoses. After being reassured that he had no serious cardiac or gastric illnesses, the patient agreed that anxiety was a factor in his chest pain. Treatment with a serotonin reuptake inhibitor appeared to decrease his "attacks", and he was discharged to live with his relatives.

The day after discharge, the patient presented with chest pain to a local general practitioner, who examined and reassured him. Three days later, his family brought him to the hospital after an unwitnessed "collapse". The patient said that he had fallen and hit his head, stating "I'm sure I've had another stroke. I can't move my left side and my right hand is numb". On physical examination, no bruises or injuries were evident. Neurological examination revealed normal tone, no weakness, and downgoing plantar reflexes. CT and magnetic resonance imaging (MRI) brain scans

1 Issues raised by this case

- Should other health services be notified when patients present repeatedly for care (eg, patients with Munchausen syndrome) and, if so, how?
- How should we deal with ethical concerns that may result from health service notification, such as inappropriate withholding of needed care for genuine medical problems in patients with somatoform disorders?
- How should we deal with medicolegal concerns associated with notification, such as privacy, insurance, and stigmatisation?
- How can we ensure balanced utilisation of services between individual patients and the public in general? ◆

were unremarkable. The next morning, after stating that he had lost vision in one eye, and with examination seemingly confirming blindness to direct confrontation, the consultant asked him to perform finger-to-nose testing with the good eye covered. He was able to do so with only inconsistent past-pointing. Sensory findings were also inconsistent: he reported loss of pain sensation on the right side, but temperature sensation on the right side was reported as "hot". The patient's "stroke" symptoms resolved after reassurance.

Importantly, repeated enquiries regarding his psychiatric history revealed "one episode of depression" for which he had been treated 5 years earlier at a metropolitan hospital. Follow-up of records from a former GP of the patient revealed multiple undisclosed psychiatric hospital admissions and multiple coronary care and ICU admissions across Australia, with at least 10 recent coronary angiograms (including two angiograms in different capital cities within 1 week). After initial denials regarding this history, the patient reluctantly agreed with the need for specialist psychiatric assessment. During psychiatric evaluation, the patient disclosed plans to relocate to another region rather than returning "home" to his relatives.

During this admission, the patient's extended family formally complained to the Health Services Commissioner that the patient was being inappropriately treated and repeatedly discharged without resolution of the life-threatening cardiovascular condition they believed he had. However, privacy issues limited the treating team's ability to speak frankly with the family and deal appropriately with their concerns. The family was informed that further discussions about the patient's care would require his permission, which was not initially granted.

Diagnosis

Clues to the diagnosis of this patient with multiple dramatic presentations over several weeks at one hospital for chest pain, collapse and hemiparesis included his distractibility during chest pain episodes, anatomically inconsistent neurological examination results, and his lack of injuries following a "collapse".

Possible diagnoses included somatoform disorder, Munchausen syndrome (a severe form of factitious disorder), and malingering.[1] Somatoform disorders result from the usually unconscious expression of psychological distress as physical symptoms, with the patient seeking care for multiple physical symptoms.[2] In contrast, patients with factitious disorder consciously pretend to be ill or physically make themselves ill or appear ill (eg, by self-inflicting wounds or self-administering medication). Munchausen syndrome (named for Baron Münchhausen, who fabricated exaggerated stories for amusement), also sometimes called "pseudologia fantastica", occurs in a subgroup of these patients, who feign disease, move from hospital to hospital (often travelling extensively to do so), and submit to repeated procedures for illness they have voluntarily manufactured.[3,4] It is more common in women and health care workers. Malingering involves intentionally faking symptoms for secondary gain, usually in the setting of disability claims or legal battles.[4-6]

Our patient met criteria for Munchausen syndrome by faking symptoms of chest pain ("cardiopathia fantastica") or stroke ("neurologica diabolica")[7] at multiple hospitals and by obtaining repeated medical procedures. Despite deliberately withholding information from the medical team and once taking money from his wife for travel to another hospital, it is arguable whether malingering was a dominant issue, as anxiety and the need for attention appeared to be more significant drivers than secondary gain. Psychiatric consultation confirmed a diagnosis of Munchausen syndrome, with elements of malingering on several occasions (eg, he "once faked chest pain while travelling" to get admitted to hospital for meals and a bed).

2 Practical recommendations regarding the care of patients with factitious or somatoform disorders

- Documentation procedures should include the following:
  - the diagnosis should be clearly documented in the record;
  - a current problem list and summary of investigations conducted (including timing and results) should be available to both general practice and hospital staff; and
  - a protocol for emergency or urgent presentations should be placed at the front of the medical record. Protocols should include specific contact information for primary providers who know the patient's history, and specific plans regarding any medications for anxiety or pain should be clearly documented.
- As patients with factitious and somatoform disorders may also at times present with medical problems unrelated to their underlying disorder, practitioners should be aware of the risk of inappropriate dismissal of a patient's problems in the context of these disorders. A thorough history and physical examination should be conducted for all presentations.
- Patients with such disorders may have fewer urgent presentations if frequent visits are scheduled with a primary provider.
- Doctors should advocate through professional networks for a privacy exemption and notification program (similar to "Project STOP", used by pharmacists to minimise pseudoephedrine diversion[11]) to be used when patients may be at risk of harm from repeated, unnecessary investigations or treatments AND they travel to multiple hospitals and providers for care. ◆

Patient privacy versus risks to the patient and the public interest

Somatoform disorders are common and under-recognised in primary care settings. "Non-organic" episodes may account for about half of all presentations by somatisers and patients with factitious disorder, with half related to other legitimate health issues.[8,9] In a recent Australian study, 18.5% of more than 10000 general practice patients were classified as somatisers.[10] While the prevalence of factitious disorder is likely to be less than 1%, it may be higher in hospitals and specialty clinics (eg, allergy clinics).[7] Concerningly, few patients with factitious disorder seek or follow through with psychiatric care.[4] However, such patients can also develop "organic" illnesses, and the challenge for medical practitioners is to provide appropriate care for patients with diagnoses of somatoform or factitious disorders. Practical recommendations regarding the care of these patients are shown in Box 2.

The patient reported here in particular, and the health system in general, might theoretically benefit from an alert system that would electronically notify hospitals about his condition and the risk of performing repeated invasive investigations. However, if such a system were in place, it is possible that this patient might have organic symptoms that would be ignored or under-investigated because they are assumed to be non-organic. The status quo is that no such system is in place and the patient's privacy is protected, at risk to himself and expense to the health system.

Although sharing of information about patients within a particular hospital or between a hospital and a treating private specialist

or GP is common, the current Medical Practitioners Board of Victoria *Medico-legal guidelines* specify that "relevant medical staff within a hospital" may discuss a case and that "an organisation or practitioner may also use information on their files, to the extent that it is relevant to subsequent treatment".[12] In addition:

> A breach of confidentiality may be justifiable (or even obligatory) . . . if the practitioner reasonably believes that it is necessary to lessen or prevent:
>
> • a serious and imminent threat to an individual's life, health, safety or welfare [or]
>
> • a serious threat to public health, public safety or public welfare[12]

Risks to the patient, doctors and the health system

Cardiac catheterisation, the most risky of the repeated procedures in this case, carries a risk of serious complications of one in 500 to one in 1000.[13] The risks include arrhythmias, cardiac tamponade, local pain, infection or haematoma at the catheter site, serious haemorrhage, hypotension, contrast dye allergy or renal injury (almost 40% in patients with underlying renal disease or diabetes[13]), stroke, and myocardial ischaemia or infarction. Routine risks of unnecessary hospitalisation include those due to repeated phlebotomy, repeated intravenous catheter insertion, exposure to hospital pathogens, and medication errors or side effects (eg, with glyceryl trinitrate and pain medications, including opiates).

The risk of maintaining the status quo (ie, non-notification) to "public welfare" and the health system is mainly financial, but is not insignificant. The cost to the hospital for the episodes detailed in this article alone was $32 250 during 1 month. A conservative estimate of clinical resource consumption by this patient for his repeated emergency and hospital admissions across Australia, with hundreds of ICU and medical bed-days, would include about 30 admissions with CT scans, MRI scans, and angiography at multiple centres, plus outpatient and general practice care. Thus, the cost of care for this patient's Munchausen syndrome might easily have approached $1 million to date. Patients with somatisation, factitious disorders or malingering would consume millions of health care dollars across Australia. Inevitably, the care consumed by these patients delays care or uses resources needed for other patients with genuine medical problems.

The hospital sought a legal opinion regarding notifying other area hospitals about this patient's potential risk of re-attendance, and was advised that the only way to provide such advice would be with the patient's permission (eg, the treating doctors could provide a letter for the patient to take with him). However, given the patient's lack of disclosure, it is likely that he would not give the letter to other hospitals or doctors and that he and the system remain at high risk.

Additionally, the stress placed on the treating team and staff caused by confrontations with the patient's family over provision of "appropriate care" while attempting to protect the patient's privacy, as well as fears relating to the potential medicolegal consequences of the family's complaints to state officials, cannot be underestimated.[14] The team is aware of at least two subsequent non-organic emergency metropolitan hospitalisations (with one cardiac catheterisation) for this patient, despite targeted GP and specialist care. However, he has also had one organic ICU admission for a myocardial infarction.

3 Psychiatric assessment of factitious disorders*

- Should patients suspected of having a factitious disorder be referred to a psychiatrist for assessment? The short answer is yes.
- An assessment by a psychiatrist may help unravel the nature of the condition, regarding whether the presentation is a factitious disorder or malingering. The assessment may also help in identifying the clinical type of factitious disorder under consideration.
- "Wandering" patients (ie, those who travel to present to different health care providers) with factitious disorder are often men with personality impairments and social maladjustment, whereas non-wanderers are often socially conforming women.[16] In a review of published reports of patients with Munchausen syndrome presenting with cardiac symptoms, 93% were men.[17]
- A psychiatric assessment may help in determining comorbid psychiatric conditions and determine possible aetiology. In the case described here, identifying the initial problems that led to this man's wandering helped devise a strategy to increase support for him after discharge.
- An assessment can help in devising appropriate management strategies both when the possibility of factitious disorder is being considered and after it is confirmed. When the diagnosis is being considered, both confrontational and non-confrontational approaches have been tried and reported. In a large case series, confronting patients without being punitive and with an offer of help did not lead to development of negative outcomes such as suicidality or discharge against medical advice.[18]
- Provision of psychological support after discharge from hospital is thought to be associated with good outcomes.[16]

* Commentary by Associate Professor Ravi Bhat, School of Rural Health, University of Melbourne, and Director of Psychiatry, Goulburn Valley Area Mental Health Service, Victoria. ◆

Importantly, because of concerns about "labelling" and stigmatisation of patients, privacy and legal issues, and the social and health consequences related to somatoform spectrum disorders, significant changes to the diagnostic criteria and their usage are being proposed in order to promote better medical care of such patients, specifically by reflecting the impact of external stressors on the expression of stress as physical symptoms.[15]

It may be helpful to consider "Project STOP", a recently implemented program for notification of pseudoephedrine diversion.[11] In this situation, the public is at serious risk from medication diversion and potential misuse or conversion of pseudoephedrine in the manufacture of methamphetamine. Under Project STOP, pharmacists in Australia may request photo identification from a client wanting to purchase a pseudoephedrine-based product; the identification details and the type and quantity of the requested product are then entered into an online database and checked against information submitted by other pharmacies. The pharmacist will be immediately notified if the client has previously purchased any pseudoephedrine-based products within the appropriate threshold period, and can make an informed decision about the sale based on the client's therapeutic history and needs. How does this situation differ from that of patients who are "addicted to" or "misusing" medical services?

This case study illustrates a situation in which a carefully designed, confidential notification program might benefit both high-risk patients and public welfare (health system costs). More generally, assuming that confidentiality and medical care of the

4 Ethical and legal dimensions of factitious disorder*

- Successful doctor–patient relationships depend on trust. The very nature of professional ethical agency confers certain distinct role-related obligations, sensitivities and permissions on professionals. The recipients of professional health care rightly expect health professionals to act in ways that are reflective of the nature and goals of the health care professional's discipline.
- If a doctor acts consistently with the nature and goals of an ethical therapeutic relationship, then we may expect that the doctor has licence to ask personal and intimate questions. In a trusting relationship, the recipients of care will willingly choose to share highly sensitive, personal information with their doctor and will rightly expect their doctor to have the knowledge and technical ability to help them.
- Patients will generally expect ethical health care professionals to show evidence of higher levels of compassion, empathy and trustworthiness in therapeutic relationships than they do in their everyday life relationships.
- In Australian law, medical practitioners and health care workers have a professional obligation of confidence and privacy. In a therapeutic relationship, a patient's partial interests are expected to override the impartial interests of broader health care.
- Although a decision to disclose privately shared health information to a third party without the consent of a competent patient is a serious matter, two relevant defences to a claim of breach of confidence in health care are recognised:
  - a situation of *forced disclosure*, where there is an obligation in law to disclose (eg, reporting infectious diseases); and
  - the *public interest*, where a disclosure is justified in order to protect the public.
- In the case of factitious disorder, there are good reasons to disclose information to a third party. Ideally, a competent patient will consent to such disclosure.
- Disclosure of private information to a third party without the consent of a competent patient is a difficult action to defend. A successful defence would depend on determining if the disclosure is necessary to protect the public, which, in the case of factitious disorder, is a challenging task.

* Commentary by Dr Andrew Crowden, Senior Lecturer in Rural Health and Bioethics, School of Rural Health, University of Melbourne, Victoria. ◆

patient remain central to all doctor–patient relationships, the controversial issue of a national or discoverable portable medical record might increase safe, high-quality care for the patient described here, while reducing high-cost investigations for him and many others like him.

Further comments on the issues raised by this case, particularly in terms of psychiatric assessment of patients and the ethical and legal dimensions of disclosure, are provided by a psychiatrist and a bioethicist in Box 3 and Box 4, respectively.

Competing interests

None identified.

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