Confidentiality in Munchausen’s syndrome

INVITED COMMENTARY ON... NEUROPATHICA DIABOLICA†

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This commentary questions whether the usual ethical and legal requirements for maintaining confidentiality of individuals who fabricate illness should be breached in order to prevent further harm to themselves as well as cost to society. A case report of an individual with Munchausen’s syndrome submitted for publication in Advances in Psychiatric Treatment provoked considerable Editorial discussion regarding the absence of written informed consent from the individual described. It is hoped that this commentary will widen the debate regarding the requirement for confidentiality in the exceptional circumstances of patients with Munchausen’s syndrome.

Case studies have always formed an important part of medical education. The somewhat dry written descriptions of the clinical features of a disorder are brought alive when illustrated using the experiences of a real person. Case conferences inform continuing professional development (continuing medical education), and individual case reports can also play a role in research, where a single case can refute a previous hypothesis (e.g. in Popperian terms, the black swan that refutes the hypothesis that all swans are white).

As the majority of patients with Munchausen’s syndrome (chronic factitious disorder) discharge themselves from hospital and disappear from follow-up, obtaining written informed consent to write up a case for publication is seldom possible. This was the case for Bourke & Turner (2008, this issue). Their first submission of their article to APT included the case details of someone presenting with significant medical symptoms that were later discovered to have been fictitious. The authors used their account to illustrate the features of the neuropathica diabolica subtype of Munchausen’s syndrome. In addition, they commented on novel aspects of the case not previously described in the literature.

This first version of the text caused a flurry of concerned emails, not only between the authors and the APT Editor but also between the Editors of APT and of the British Journal of Psychiatry, about the ethical and legal issues of reporting such a case without the written informed consent of the patient. The discussion widened to include members of the Royal College of Psychiatrists’ Publications Management Board and the College’s Committee on Publication Ethics. One outcome of these discussions is that I have been asked to write this commentary in order to widen the debate. As well as considering the specific educational aspect of informed consent for a published case report, there are also issues pertaining to whether the clinical management of individuals with Munchausen’s syndrome should include breaching their confidentiality.

The clinical argument for a breach

With regard to clinical management, one can argue that it is in both the public’s and the individual’s interest to publicise the case as widely as possible. As pointed out by Bourke & Turner, one of the key features of Munchausen’s syndrome is ‘peregrination’, i.e. the patient re-presents with similar clinical features to another hospital, where extensive investigations are repeated and treatments instigated for

† See pp. 276–282, this issue.
the non-existent pathology or injury. Not only is there considerable wastage of professional time, but there is also the huge economic cost of unnecessary hospitalisation and treatment, as Bourke & Turner discuss. The public clearly has an interest in trying to prevent such misuses of the healthcare system. In addition, in this case the patient was given treatment known to be associated with a risk of serious complications, for what later transpired to be a non-existent neurological disorder. So he could have been seriously harmed by his actions.

Bourke & Turner mention the unofficial ‘black-listing’ system, that consists of passing on information between accident and emergency departments. However, as they point out, such details can only be limited. People with Munchausen’s syndrome frequently have many aliases, and can easily change their appearance and their story, rendering such an informal system insufficient to prevent repeated admissions. Hence, each hospital team has to find out for themselves by slowly piecing together the evidence as it is revealed. In the vignette described, it took the team a month to determine that the serious illness was fabricated.

One could also consider that maintaining the confidentiality of patients with Munchausen’s only exacerbates the behaviour by facilitating their movement between hospitals with anonymity. Indeed, what is needed to reduce harm to the patient is a much more widespread and detailed system of publicity. This would make it harder for the patients to continue their peregrinations, as well as allowing appropriate treatment for their psychopathology (as opposed to any fabricated illness) to be instigated. However, this would mean that individuals with Munchausen’s syndrome would be treated very differently from the majority of patients.

UK guidelines on confidentiality

With regard to breaching confidentiality, both the law and the General Medical Council (GMC) are very clear. All personal information must be kept confidential unless there is a justifiable cause for revealing it. On the matter of public disclosure the GMC states that:

‘Personal information may be disclosed in the public interest, without the patient’s consent, and in exceptional cases …, where the benefits to an individual or to society of the disclosure outweigh the public and the patient’s interest in keeping the information confidential’ (www.gmc-uk.org/guidance/current/library/confidentiality.asp).

The website goes on to say that the ‘public interest’ can only be decided by the courts, but that the GMC may also ‘require you to justify your actions if a complaint is made’. It would take action through the courts or an approach by a national body such as the College or even the National Institute for Health and Clinical Excellence to propose any change in the law.

Certainly, as regards the vignette in Bourke & Turner’s article, the unusual circumstances of the case described in detail in their first draft would have made it highly likely that the patient would be recognised both by himself and others. Confidentiality would certainly have been breached. The fact that the patient’s complaints are fictitious does not alter the legal requirement to maintain confidentiality.

Thus, concern about possible litigation was what caused the exchange of emails and debate at the College. However, in this case who would be legally liable? Certainly the authors, but also the Editors and Editorial Board members who agreed to publish the report, and possibly even the Officers of the College, who might be considered to be ultimately responsible for the Journal’s content. So in the end, the authors were asked to redraft the case history and change any identifying details so that the patient could not be unequivocally recognised.

A question of best interests

This decision begs the question of the future role of published case studies where the patient is either unable or unwilling to give consent. Would this case have made more of an educational impact if there had been more explicit (and identifiable) details about the patient?

Also, as regards the clinical management of Munchausen’s syndrome, although it is rare, the problems caused and the costs of the aberrant behaviour are exceptional. So should we be considering treating such individuals as special cases whose rights to confidentiality should be breached in order to prevent them further harming themselves and also to provide more opportunities for long-term treatment?

Declaration of interest

None.

References