



Knowing me, knowing you: a qualitative study of the effects on patients of doctors' self-illness disclosures

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ABSTRACT

INTRODUCTION: Very little is known how patients react to learning about their own doctors' illnesses. Doctors can be uncertain if and when such disclosures can be helpful, and in what way, to patients. This paper attempts to bridge this gap by providing an in-depth analysis of one group of patients' experiences with this type of disclosure.

AIM: To understand from patients' perspectives, the effects on them of doctors disclosing their own illnesses, to provide guidance concerning the uses of this disclosure for general practitioners.

METHODS: This qualitative study was an exploration of 13 patients' reactions to receiving such information, using semi-structured interviews and thematic analysis.

RESULTS: The major themes were the emotional dimensions of illness and patienthood, the doctor-patient relationship and patients' concerns about disclosures. Disclosures can have profound effects on patients with both negative and positive consequences.

CONCLUSION: We present suggestions about how to use such disclosures in primary care to minimise potential harms and emphasise potential benefits, based on these patients' perspectives and the current literature.

KEYWORDS: ethics; general practitioners; physician self-disclosure; reflective practice

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Introduction

This study focuses on a specific type of self-disclosure when doctors reveal their own personal illness information directly to their patients. There is very little research specifically exploring patients' perspectives about such disclosures, with only one study, published as an abstract and not widely cited, having this as its focus.¹ Existing guidelines are based on what doctors think are the potential risks and benefits, rather than on research about how patients view self-disclosure.

It is not known how often this type of disclosure occurs. The prevalence of doctors disclosing any

WHAT GAP THIS FILLS

What is already known: Very little is known about patients' perspectives on hearing from their doctor that the latter has been unwell, or even has or had the same illness as the patient. It is uncertain whether, when and why they regard such disclosures as beneficial or harmful.

What this study adds: Doctors' disclosures of their own illnesses can benefit patients by enhancing doctor-patient relationships in several ways, but patients expressed important caveats. This study suggests that general practitioners need to be mindful about these concerns, including the shock some patients experience simply by learning that their doctor has been a patient as well.

personal information during a consultation is 15.4%–34% of all consultations,^{2,3} similar to surgery.⁴ From research with doctor participants, disclosing their own illnesses is thought to reassure patients, improve communication, ease stress, create empathy and increase patient satisfaction.^{4–8} Usually disclosure happens with a specific purpose in mind.⁴ Such disclosures, if concerning healthy behaviours, can help to motivate patients to adopt similar habits⁹ and improve medication adherence.⁵

The Jungian ‘wounded healer’ notion suggests that self-illness disclosures should be beneficial to patients, particularly if that illness has been successfully resolved,¹⁰ yet several studies show doctors are anxious about whether to disclose such information.^{4–6,11,12} There are concerns that inappropriate disclosures cause inappropriate emotional gratification for the doctor,¹³ reduce the focus on the patient,⁶ increased the risk of sexual involvement with patients,¹⁴ reduce the doctor’s privacy,¹⁵ cause medico-legal issues regarding competency,¹⁶ and potentially stigmatise the doctor (particularly with respect to less socially acceptable illnesses such as HIV or mental health issues).⁵ Although general practitioners (GPs) are generally happy to disclose less personal information such as hobbies or interests, only 25% would consider disclosing a physical illness and 12.5% a mental illness.⁴ When analysing illness disclosures using simulations, only 4% were judged by the researchers as being beneficial for patients (the actor-patients’ views were not investigated).¹⁷

The one study that has focused on patients’ perspectives surveyed 357 patients and found 59% of patients knew something about their doctor’s private life, including (but not only) some illness disclosures.¹ Twenty percent reported that disclosures were used to guide them to ‘...accept a procedure or treatment, and 76% of those patients felt it was effective.’ How ‘effective’ was defined – whether positive or coercive – was not stated. Where specific guidelines have been provided,^{18,19} these have been largely based on hypotheses generated from the above research on doctors’ responses and views on self-illness disclosure, not the patients. The current research aimed to address this knowledge gap to help inform GPs about issues they might consider if contemplating such a disclosure.

Methods

We conducted a qualitative study using semi-structured interviews. Ethical approval was obtained from the University of Otago Human Ethics Committee (reference number 018/015). The Committee required their approval of the questions to be asked, although further, spontaneous clarification of respondents’ answers was permissible. The Committee also stipulated that no data were to be collected that could identify the doctor or their diagnosis. To refine the interview technique, LB conducted two simulated interviews with actor-patients following scripted scenarios, which were observed by KH and MW. LB maintained a self-reflective research diary throughout the study. Participants were a convenience sample, with initial recruitment by advertising in local papers and by posters placed in GP practices in Dunedin and Alexandra, as well as posters in Dunedin pharmacies, supermarkets and the Otago university campus. Respondents were sent an information sheet before consent was sought. Demographic data were obtained along with consent. LB undertook the consent process and subsequent interviews using the prompts shown in Table 1.

Inclusion criteria for the study were: age ≥ 18 years, currently enrolled in a local general practice, fluent in English, having had at least one relevant experience, and not current or previous patients of KH or MW.

Enrolled participants were interviewed once for 40–60 min, at a mutually convenient venue. Enrolment continued until data saturation was reached, as indicated by the results of the thematic analysis performed concurrently with data collection.²⁰ Interviews were audio-recorded and professionally transcribed. A debrief within 24 h of each interview was performed with LB and at least one other author to encourage reflection.

The analysis was initially performed by LB. This involved engaging with the data through multiple readings, highlighting initial areas of interest and relevance. A preliminary coding system was constructed from these highlighted areas and they were used as a template for secondary coding, modifying and refining highlighted areas in an iterative process by engaging with the data several times. Codes were

Table 1. Interview questions

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|---|
| 1. How long ago did the disclosure occur? |
| 2. Why was this memorable for you? |
| 3. How did it make you feel at the time? How do you feel about it now? |
| 4. Did it influence the consultation for you? If so, how? |
| 5. Without letting me know why you were seeing the doctor, did it influence any decisions you had to make? If so, how. |
| 6. Looking back, was the disclosure helpful to you in any way? Or was it not helpful? |
| 7. Has the disclosure caused you to think differently about your doctor? Positively or negatively? |
| 8. Do you think it was OK for the doctor to disclose this information to you? |
| 9. Do you think all doctors should be able to do this? |
| 10. Why do you think the doctor disclosed this information to you? |
| 11. Were you told by the doctor that you should keep the information secret? Do you think a patient should keep this type of information secret? |
| 12. Do you think there are any circumstances in which it would ALWAYS be OK for doctors to give health information about themselves to patients? |
| 13. Do you think there are any circumstances in which it would NEVER be OK? |
| 14. Do you think there are any diseases or illnesses which the doctor had had which would ALWAYS be OK for doctors to give health information about themselves to patients? |
| 15. Do you think there are any diseases or illnesses which the doctor had had which it would NEVER be OK? |
| 16. Do you think you would have had a different response to the disclosure if the illness was more or less serious? |
| 17. When do you think it would be appropriate for a doctor to disclose their illness or illness experiences to a patient? |
| 18. Do you think the doctor acted appropriately? |
| 19. Do you think doctors should be encouraged to share their illnesses with patients? |
| 20. When the disclosure occurred, did you think the doctor was acknowledging or dismissing your concerns? |
| 21. Do you think the doctor 'crossed a line' when they disclosed this information to you? |
| 22. Did the disclosure make you feel closer or more distant to your doctor? |
| 23. After the disclosure, did you feel more understood or less understood by your doctor? |
| 24. What do you think about doctors disclosing about their mental illness to patients? |

then organised into overarching themes (metacodes). Both KH and MW independently cross-checked and validated these metacodes, with any discrepancies resolved by mutual discussion. Member validation was obtained when necessary to ensure the analysis aligned with participants' intended meanings. Gender-congruent pseudonyms acceptable to participants were used to anonymise the data. No participant left the study early.

Results

Thirteen patients met inclusion criteria and completed individual interviews. Data saturation occurred at the 12th interview and was confirmed at the 13th. Eight participants self-identified as female and five male. Ages ranged from 18 to 69 years, with a

mean of 44 years (male mean age 52 years, female 38 years). Eleven participants (84.6%) identified as New Zealand European, one as Chinese (7.7%) and one as both New Zealand European and Māori (7.7%).

The elapsed time between the interview and when the illness disclosure had occurred ranged from ~3 months to 6 years (mean 2.5 years). Disclosures were associated with high emotional salience; participants could easily recall their experiences despite sometimes quite lengthy passages of time. All disclosures involved the doctor revealing that they had had the same illness or illness experience as the patient. Three major themes were identified: the emotional dimensions of illness and patienthood, the doctor–patient relationship, and patient concerns.

Emotional dimensions of illness and patienthood

The disclosures happened at times of increased emotional need or vulnerability for these patients. They believed that disclosures occurred when the doctor thought this would be helpful for the patient in some way:

‘I think she could probably tell that I was pretty, sort of, I wouldn’t say depressed about it. But that my injury had been making me feel very, sort of melancholy, about the state of my body ... I think she wanted to tell me about her own injury so that I could, yeah, relate to it.’ [Tara]

Participants thought disclosures were used to convey empathy for their situation, to intend to give emotional support and reassurance, and to reduce the likelihood of patients feeling stigmatised by their illness:

‘I suppose during the conversation and his self-disclosure, he was to a certain extent normalising the situation ... and not making it such an issue and everything.’ [Russell]

Disclosures could help participants’ understanding of their illnesses and feel better understood by their doctor; this was recognised as therapy in itself. Disclosures could communicate that their doctor had some idea of the impact of the illness for the patient and could relieve patients’ burden in having to provide more details. Successful resolution of the illness for the doctor provided hope and reassurance that the same would happen for them:

‘I felt that the doctor understood me a lot more, given that I knew that he had the same diagnosis and I thought he actually knows what I’m going through here, and he can understand and pre-scribe more appropriately who knows?’ [Lydia]

Not all disclosures resulted in an emotionally positive outcome. Although, still believing that his doctor was acting with the best of intentions, Adam’s experience made him feel:

‘... pretty embarrassed ... because he basically said that my concerns over my health weren’t that important and that he’d been through similar concerns, and it was no big deal to have them.’

Doctor–patient relationships

Surprise and even shock was expressed that doctors were not immune from illness, but this still could result in a positive outcome:

‘... you always think your doctors are perfect and ... they’ve got all their crap together ... at first, I was a little bit surprised ... and then, at the same time, I felt like a little bit closer to her, like she seemed more human to me.’ [Renee]

Disclosures could stimulate patients to think about the whole nature of the practice of medicine:

‘... I thought, ‘Gosh, that’s quite unusual’ ... I’m very aware that the old guard of stoic, middle-age men is going, and we’re getting a new breed of people who are more in tune with their own experience, and seemingly more empathetic towards their clients.’ [Russell]

By having experienced the same illness as the patient, a doctor could appear more qualified and respected by a patient and their advice more validated. Disclosures about shared mental illnesses could be seen as especially beneficial for doctor–patient relationships due to enhanced emotional rapport. Disclosures could deepen patients’ trust and confidence in their doctor’s clinical ability:

‘... because this particular GP told me she has it, it gave me confidence in her recommendations and that she really did know what she is talking about.’ [Lisa]

‘There is some weight behind it. There’s now weight behind what the doctor is telling you.’ [Lee]

This could result in practical outcomes such as improved treatment adherence.

For Adam, who had not experienced a positive emotional reaction to his doctor’s disclosure, its effect on the doctor–patient relationship was devastating:

‘Actually, I wondered about the trust that we had afterwards, and I felt as if I had gone from 100% trust of my doctor, down to 50% ... [even though] [they had been my family doctor for all my life.]’

Adam changed his doctor after this event because of this reaction.

Patient concerns

Patients were asked their thoughts about disclosures in general. Anxieties could arise even if the experience was viewed highly positively. Patients could feel a weighty sense of responsibility for their doctor:

'I don't really want to be burdened with someone else's health issues if they are that serious.'
[Tegan]

The acceptability of disclosure could be (but was not always) related to the type of illness involved; views concerning mental illness were mixed. Some patients were surprised that doctors suffered in this way: '...you wouldn't think they'd have mental health problems...' (Stephen). Disclosure could result in a loss of confidence in the doctor:

'...it sounds bad because they're going through their own issues, but you kind of want someone stable and not having a past with it [mental health issues] ...' [Kristie]

Patients were concerned that doctors who shared their illness, whether mental or physical, might not recognise significant and important differences between the patient's illness experience and their own, but assume that they were identical. Views varied as to whether disclosures should occur only when patients and doctors previously knew each other. While this could be thought preferable, it could also be viewed as unimportant. Some participants were grateful that the disclosure could occur while they were still developing rapport with their doctor, as disclosure enhanced its development.

Patients were concerned about doctors excessively focusing on the disclosure, depriving patients of the time and opportunity to talk about themselves, especially as they paid for the consultation (although none had had this actual experience). There were also concerns about disclosures biasing the consultation towards gratifying the doctor's needs over those of the patient. Key determinants as to whether disclosures were acceptable were the relevance to the patient's need(s), the length of time taken up by the disclosure and the focus remaining on the patient.

Patients recognised that disclosures were potentially risky for doctors and discussed whether the

patient had a duty to keep the disclosure confidential, concluding no such duty existed:

'No, if the doctor wants to keep it a secret then the doctor should keep it secret. Why put that onto a patient?' [Lydia]

Generally, patients would keep the information confidential out of respect to the doctor, but as a choice, not as a perceived and obligatory ethical behaviour.

Discussion

Beach *et al.* described self-illness disclosures as a form of 'reassurance disclosure' to help patients feel better about themselves or to give them hope; this was also found in our study.² Both positive and negative experiences occurred. Patients found these disclosures highly meaningful, memorable and impactful.

Simply learning that doctors can be patients themselves can be very challenging for patients. For some patients, this set up role incongruities and dissonances with how patients thought doctors should behave. Such challenges did not necessarily mean a negative experience occurred. Having processed their surprise, patients could then go on to appreciate the disclosure, and recognising that their doctor was also a human being. The reasons for this shock or surprise were beyond the scope of this study, but are an interesting area for future research. Doctors with mental illnesses were considered particularly challenging, even though patients recognised disclosures may be even more needed and useful in that situation.

Similarly, to Klitzman and Weiss, we found that disclosures can elicit patient responses beyond emotional soothing.⁵ Patients found their experiences of disclosure highly meaningful and emotionally charged. Other ways of creating empathy, compassion and reassurance might be more appropriate and safer for both doctor and patient.¹⁷ Zerubavel and Wright have argued that disclosures in the context of psychotherapist–client relationships pose multiple risks, especially if specific details are included.¹⁰ Yet, the power of disclosure for our participants arose from knowing that the doctor has suffered *the same* illness, or illness experience, as themselves. This suggests the closer the one-on-one

identification with the doctor, the greater the ability to provide emotional sustenance and enhance the patient–doctor relationship. This aspect requires further research. Concerns raised by others¹⁹ that patients became overly inquisitive, inappropriate or progressively invasive of boundaries were not substantiated in our findings, although self-reporting by patients may not be the ideal mechanism to explore this.

A selection bias may be present in this study, as patients who did not have emotional reactions could be less likely to respond to advertising and participate. As this was a qualitative study, nothing can be said about frequency. There was little ethnic diversity in participants, which may have limited the findings. The strengths of this study are the choice of methodology, which is appropriate for previously poorly explored areas, allowing hypothesis-generation for future research. The reflective activities of debriefing and diarying enhanced researcher sensitivity to the data, and multiple triangulation occurred between the researchers and participants, thus improving validity.

We suggest disclosures need to be used with prudence. Our research concurs with others' recommendations (based on theoretical considerations) regarding disclosure;¹⁸ that doctors consider other less problematic ways of communicating empathy, avoid assuming the patient's experience is identical and keep any disclosure short and focused on the patient. Our results suggest that disclosures do not necessarily require a previously established doctor–patient relationship; positive experiences could occur early in this relationship, and negative ones after years of being with a doctor. In our study, only disclosures that related closely to the patient's current illness, or illness experience, were wanted by patients and perceived as useful by them; hence, we would suggest that only this type of disclosure is ethically acceptable (this needs further research).

This study demonstrated that doctor disclosure could produce an association with strong feelings in the participants. Therefore, we suggest great caution in using it with patients who are emotionally vulnerable, highly dependent or who have poorly defined boundaries. Used inappropriately, doctor disclosure can be emotionally devastating

to patients. Doctors need to be mindful that there is no ethical or legal duty for patients to maintain confidentiality after the disclosure, effectively placing the information in the public domain. Patients may recognise this issue and choose to keep the information private, but are under no obligation to do so. Finally, we suggest that doctors should be mindful that it can be a genuine surprise, even a shock, to patients that doctors can become ill. Notwithstanding, self-illness disclosure can be a powerful tool creating deep emotional rapport and enhancing doctor–patient relationships in a unique and positive way. Patients may have a range of responses to these disclosures, but the greatest power may lie in hearing from their GP (in Lydia's words) that 'I, too, suffer.'

Competing interests

The authors declare no competing interests with this research.

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