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**CASE AND COMMMENTARY**

## How Should Physicians Use Their Authority to Name a Stigmatizing Diagnosis and Respond to a Patient's Experience?


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**Abstract**

Patients with delusional infestation are unlikely to agree to take the mainstay of treatment—antipsychotic medication. While stressing the general importance of truth telling in medicine, we suggest that, in some cases of delusional infestation, patients' lack of decision-making capacity will—provided a series of criteria are met—justify briefly withholding their diagnosis. We acknowledge this action as a kind of deception with ethical pitfalls and discuss those related to prescribing antipsychotic medication without frank disclosure. We recommend full disclosure of a delusional infestation diagnosis when the patient is recovered, despite this action's potential to exacerbate stigma.


### Case

Ms M presents to Dr P's family medicine clinic for assessment of severe pruritus (itch) that she has been experiencing for the past 4 years. She first noted the itch in association with small bumps on her ankles and wrists. She was diagnosed with bed bugs and had her apartment cleaned and fumigated. The bumps went away, but the itching persisted. She became concerned that the infestation had returned and ultimately moved out of her apartment and into a new building. She sold all her belongings, including her bed and books, gave away her cat, and bought new furniture 3 years ago. She continues to note severe itching of her arms, legs, and back since that time. She had her new apartment fumigated 3 more times. She discusses with Dr P that, recently, she thinks she has been able to see the bugs—they are hatching eggs and she can pull them out. She brings the "eggs" with her in plastic bags for Dr P to review. She has found topical permethrin to be helpful in the past.

Dr P examines her skin and notes scabbed-over bumps from repeated manipulation of the skin. He sees no signs of an infestation. He reviews the contents of her bag and notes that it is consistent with simple keratin. Dr P suspects the source of Ms M's symptoms and experiences to be delusional infestation, and he wonders how he should respond in a way that is respectful and truthful.

## Commentary

Delusional infestation is a condition in which patients believe themselves to be infected by parasites.[1] It is one subtype of what the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-5*) terms *delusional disorder*, in which patients exhibit few signs of mental illness beyond one unfounded pathological conviction.[2] Like Ms M, patients with delusional infestation commonly present to their physicians with amorphous debris as evidence of parasites or eggs.[3] This clinical feature—the matchbox sign—was named after the vessel patients often used to transport the debris.[4]

Dr P's suspicions that Ms M could be suffering from delusional infestation are entirely justified. However, confirmation of this diagnosis would require ruling out anxiety, depression, or any other possible comorbid mental illness and excluding medical or neurological conditions that cause itching, which could be mistaken for, or lead a patient to develop, delusional infestation.[5]

It is vital that, while establishing a diagnosis, the physician both establish and maintain rapport with the patient. The main task early on is to explore the patient's experience while gently inquiring whether her symptoms could be accounted for by something other than bugs. In doing so, the physician gauges the patient's level of insight and the extent to which she might be willing to consider her symptoms as psychologically based. Prematurely labeling Ms M's experience as delusional infestation could be experienced by Ms M as invalidating and might lead her to abandon further contact not only with Dr P but with all health professionals. A general practitioner or dermatologist might, understandably, feel out of his or her depth in diagnosing and managing cases of delusional infestation but also recognize that these patients might be reluctant to consider seeing a psychiatrist. Even without formal psychiatric referral, however, local psychiatric services might be able to provide useful advice.[5]

In this article, we discuss a physician's ethical predicament when diagnosing and managing a patient with delusional infestation while withholding the name of the disease. Physicians sometimes use *benevolent deception* to justify withholding information from patients. We suggest that withholding a diagnosis is a form of deception and that it is probably ethically objectionable without further justification. Therefore, we propose criteria we believe should be satisfied in order to make withholding a diagnosis ethically acceptable. Lastly, we clarify that when patients regain insight with treatment, they should be informed of their diagnosis, despite the risk of stigmatization associated with labeling the illness.

### Managing Without Naming

Delusional infestation is a psychotic illness, and hence antipsychotics are the recognized mainstay treatment and, in most circumstances, the only practicable way to assist patients with this disorder.[6] Although formerly the antipsychotic pimozide was preferred

in delusional infestation, evidence of its differential effectiveness is weak and its side effect profile is poor.[6,7] As a result, newer antipsychotics are usually used in contemporary practice.[7]

Prescribing any sort of antipsychotic to patients with delusional infestation presents a challenge. They will typically come to the consultation without insight, certain they are infested and, understandably, will have no interest in taking antipsychotics. In some cases, with cautiously delivered education and decision-making support, it will be possible to enable patients to reach points at which they, first, understand how antipsychotics could help them and, second, consent to treatment. However, in cases of delusional infestation in which patients do not have insight into their conditions, best efforts at support might still fail to secure patients' consent. Recognizing this reality, some have suggested that the best option for motivating adherence to medication is to deceive patients about the nature of their illness or the mechanism of action of the proposed medication.[5,8,9] Several authors too easily justify such actions with terms such as *benevolent deception*.[10,11] For example, Zomer et al. advise the following:

> We tell the patients that some people are more sensitive to stimuli on their skin than others, and that the drug (pimozide) increases the threshold to these stimuli. Their belief with regard to infestation is not challenged. It is of no use attempting to convince patients that they are not infested by parasites, because their conviction is unshakeable.[12]

In our opinion, this type of advice models an unreflective use of the term *benevolent deception* that gives too broad a license to physicians to lie to patients based only on their perception of patients' best interests. We reject this approach while acknowledging that it might, in many cases, be reasonable (temporarily) to lie to patients and to prescribe antipsychotics without explicitly acknowledging the condition for which they are prescribed. In this context, lying has broader meaning than simply imparting false information; it means deliberately withholding information that a clinician knows a patient would see as relevant—in this case, the fact that the medication being proposed is used to treat delusions, not itches. If physicians are going to lie, it is important to own this and reflect carefully on their reasons for managing patients' care in a way that is, generally and usually, rightly condemned. We argue that clinicians are justified in (temporarily) lying to patients with delusional infestation only in circumstances in which they believe all of the following apply:

1. As a result of a patient's delusions and associated lack of insight, he or she is incapable of making an informed decision. That is, despite a physician's best efforts to provide decision-making support, the patient cannot understand or cannot use and weigh information that would be relevant to consenting to or refusing antipsychotics.
2. Harm would likely come to a patient for whom antipsychotics are not prescribed.

3. A patient who lacked insight would probably not take an antipsychotic if it were recommended.[13]
4. Typical means of compelling treatment to which a patient has not consented—by using a hold or involuntary commitment justified by statute, for example—are either (*a*) unavailable because harm from which a patient requires protection is insufficiently severe or immediate or (*b*) inappropriate because legally sanctioned coercion itself would cause a patient harm that might be avoided by withholding information.

We argue that when these criteria are met, physicians are justified in prescribing antipsychotics while not labeling them as such to a patient. Instead they may say, in truth, that their intention is to relieve a patient's symptoms. Note that physicians are not relieved of an obligation to fully disclose possible side effects, and these must be truthfully conveyed.

Physicians are well advised to avoid blatant lies, such as "This is not an antipsychotic." In our experience—rightly or wrongly—patients usually find blatant lies more morally objectionable than other forms of deceit, and the distinction between a blatant lie and a benevolent deception could become important later on—for example, after a physician reveals a diagnosis and is trying to maintain rapport. Also, of course, some lies are easily uncovered by a simple internet search. With these concerns in mind, we usually declare that the prescribed medication is used as an antipsychotic but that we hope it will relieve the patient's symptoms nevertheless.

If possible, it is important to engage family and friends to reinforce treatment aims and to better understand the effects that delusional infestations can have on people around the patient. If the patient's children are being significantly affected or if there is immediate concern for a patient's safety, using a hold or involuntary commitment could still be necessary.

**Revealing the Lie**

When a patient like Ms M has been treated, has recovered, and has regained insight and decision-making capacity, she will no longer satisfy the first criterion in the above list. If Ms M is like many patients with delusional infestation, she will need to continue antipsychotics after the psychosis has resolved.[7] At this point, the clinician is obligated to reveal the diagnosis, the rationale for the treatment chosen, and that treatment commenced without the rationale being fully explained. This last revelation is best combined with an apology and an explanation that demonstrates the reasoning outlined in this article. With the resolution of the psychosis, the patient will be competent either to consent to continue the antipsychotic or to refuse to continue it. Competent informed refusals must be respected no matter how foolish they might appear, though, of course,

the clinician should continue to try to persuade the patient to continue with a treatment that *ex hypothesis* has been effective.

Revelation of a diagnosis to a now-recovered patient still risks being perceived by the patient as stigmatizing. Sadly, the public continues to hold stereotypes of people with psychosis as dangerous, unpredictable, incompetent, and responsible for their condition.[14] There is also risk that patients like Ms M might agree with, identify with, and internalize these beliefs, leading to self-stigma, which itself can cause lowered self-esteem and self-efficacy and demoralization.[15,16] To decrease the likelihood of adverse consequences, Dr P should not only reveal Ms M's diagnosis but also explore her understanding and beliefs regarding her diagnosis. As he does so, he should provide Ms M with information about her illness to combat any myths, and, if he identifies any self-stigmatizing beliefs, he should gently but firmly challenge them. Some patients may benefit from referral for further psychological therapy.

**Conclusion**

Delusional infestation provides rare examples of cases in which physicians are justified in temporarily withholding a diagnosis from their patients. However, physicians should embark on this kind of deceit only if certain criteria are met. When the patient recovers, the diagnosis should be revealed, as should the physician's understanding of the patient's illness, but these revelations should be approached skilfully and cautiously to avoid damaging the patient-clinician relationship and possibly amplifying stigma.

## References


1. Von Ekbom KA. Der präesenile dermatozoenwahn [The pre-senile delusion of infestation]. *Acta Psychiatr Neurol Scand*. 1938;13(3):277-259.
2. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders*. 5th ed. Washington, DC: American Psychiatric Association Publishing; 2013.
3. Lyell A. Delusions of parasitosis. *Br J Dermatol*. 1983;108(4):485-499.
4. The matchbox sign [editorial]. *Lancet*. 1983;2(8344):261.
5. Lepping P, Huber M, Freudenmann RW. How to approach delusional infestation. *BMJ*. 2015;350:h1328. doi:10.1136/bmj.h1328.
6. Lepping P, Russell I, Freudenmann RW. Antipsychotic treatment of primary delusional parasitosis. *Br J Psychiatry*. 2007;191:198-205.
7. Al-Imam AML. A systematic literature review on delusional parasitosis. *J Derm Dermatologic Surg*. 2016;20(1):5-14.
8. Vulink NC. Delusional infestation: state of the art. *Acta Derm Venereol*. 2016;96(217):58-63.
9. Heller MM, Wong JW, Lee ES, et al. Delusional infestations: clinical presentation, diagnosis and treatment. *Int J Dermatol*. 2013;52(7):775-783.

10. Elin JS. Lying and deception: the solution to a dilemma in medical ethics. *Westminst Inst Rev*. 1981;1(2):3-6. Quoted by: Mappes TA, Zembaty JS, eds. *Biomedical Ethics*. 3rd ed. New York, NY: McGraw Hill; 1991:81-87.
11. Jackson J. Telling the truth. *J Med Ethics*. 1991;17(1):5-9.
12. Zomer SF, De Wit RF, Van Bronswijk JE, Nabarro G, Van Vloten WA. Delusions of parasitosis. A psychiatric disorder to be treated by dermatologists? An analysis of 33 patients. *Br J Dermatol*. 1998;138(6):1030-1032.
13. Ryan CJ, De Moore G, Patfield M. Becoming none but tradesmen: lies, deception and psychotic patients. *J Med Ethics*. 1995;21(2):72-76.
14. Angermeyer MC, Matschinger H. The stereotype of schizophrenia and its impact on discrimination against people with schizophrenia: results from a representative survey in Germany. *Schizophr Bull*. 2004;30(4):1049-1061.
15. Corrigan PW, Watson AC, Barr L. The self-stigma of mental illness: implications for self-esteem and self-efficacy. *J Soc Clin Psychol*. 2006;25(8):875-884.
16. Cavelti M, Kvrgic S, Beck EM, Rüsch N, Vauth R. Self-stigma and its relationship with insight, demoralization, and clinical outcome among people with schizophrenia spectrum disorders. *Compr Psychiatry*. 2012;53(5):468-479.

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