ORIGINAL ARTICLE

MJS PUBLISHING

ActaDV Acta Dermato-Venereologica ActaDV Advances in dermatology and venereology

# Ethical and Communicative Challenges in Informing Patients with Delusional Infestation: Insights from Moral Case Deliberation

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**Delusional infestation is a rare psychiatric condition where patients falsely believe they are infested by organisms, often accompanied by physical symptoms such as pruritus. Communicating the diagnosis and initiating treatment present significant challenges, as healthcare providers must balance honesty, sensitivity, and trust to avoid damaging the therapeutic relationship. This qualitative study explored ethical and communicative dilemmas through interviews and moral case deliberations with 11 multidisciplinary experts. Three themes emerged: the importance of building trust in the doctor–patient relationship, employing sensitive communication strategies, and enhancing multidisciplinary collaboration. Effective approaches include avoiding stigmatizing terminology, focusing on symptom management, and centralizing care in psychodermatology clinics. These findings provide recommendations to improve care outcomes and highlight the need for guidelines on communication strategies in the management of patients with delusional infestation.**

*Key words:* delusional infestation; ethical approach; patient communication; psychodermatology.

Submitted Mar 31, 2025. Accepted after revision May 5, 2025

Published May 27, 2025. DOI: 10.2340/actadv.v105.43511

Acta Derm Venereol 2025; 105: adv43511.

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## SIGNIFICANCE

This article contributes to the ethical and communication challenges of conveying information to patients with delusional infestation. By addressing the difficulties faced by healthcare providers, it aims to enhance patient outcomes, foster trust, and provide guidance for best practices in the management of delusional infestation.

Delusional infestation (DI) is a rare psychiatric condition characterized by the persistent false belief that the body is infested with living or non-living organisms, such as insects or fibres. This belief is often accompanied by symptoms such as pruritus or formication, driving patients to take harmful actions, such as using toxic cleaning agents or hiring pest control services. The condition significantly impacts patients' quality of life, leading to social isolation and impaired daily functioning (1). Patients with DI frequently seek help from dermatologists or other healthcare providers, expecting confirmation of a physical cause for their symptoms, almost always unaware of the psychological nature of their condition (2).

While antipsychotic medications are effective treatments, communicating the diagnosis and initiating therapy present substantial challenges (3). Negative patient reactions to the diagnosis and the resulting strain on the doctor–patient relationship often complicate this process (3–5). Such communication difficulties can delay diagnosis and treatment, even though early intervention is critical for improving prognosis and enhancing recovery (6, 7).

Recent survey findings among doctors underscore these challenges: more than half of respondents expressed reluctance to disclose the diagnosis directly to patients, and only 20% explicitly communicated the diagnosis (8). This hesitancy reflects the complexity of balancing honesty with the potential risk of damaging trust and therapeutic relationships.

The current study aimed to identify the ethical and communicative challenges healthcare providers face when informing patients with DI of their diagnosis and initiating treatment. It sought to explore values and strategies that facilitate effective communication, such as minimizing resistance and fostering acceptance of appropriate care. By translating these insights into recommendations, the study aimed to improve care outcomes for patients with DI and support healthcare providers in managing this complex condition.

## MATERIALS AND METHODS

### *Study design*

To explore the challenges faced by healthcare professionals, a qualitative study design was employed utilizing semi-structured interviews and focus groups.

### *Participants*

A purposive sampling strategy was employed, meaning that participants were deliberately selected based on their

expertise or involvement in the care of patients with DI. This approach ensured the inclusion of 11 professionals from various disciplines, providing a comprehensive perspective on the challenges of DI patient care. The study was conducted at Amsterdam UMC (**Table I**).

### *Data collection*

Semi-structured interviews were conducted to investigate the challenges faced by physicians when conveying information to patients with DI. A topic list was developed focusing on participants' experiences and the specific difficulties they encountered in caring for patients with DI. The insights from these interviews formed the basis for the cases discussed during focus-group meetings. In the focus groups, moral case deliberation (MCD) was used, a structured approach in clinical ethics support that promotes systematic reflection on moral questions (12). The dilemmas centred on the tension between 2 approaches: (A) transparently informing the patient about the diagnosis and treatment or (B) not fully disclosing the diagnosis, either by aligning with the patient's beliefs or stating that the diagnosis was uncertain to allow more time to build trust (9, 10). To enrich the findings, additional interviews were conducted with legal and ethical experts. These experts reflected on the MCD sessions and provided recommendations to address identified challenges. Data were collected between December 2022 and March 2023. Interviews lasted 30 to 60 min, while focus-group sessions lasted 2 h. All sessions were audio-recorded and transcribed for analysis.

### *Data analysis*

A thematic analysis, a method for identifying recurring themes and patterns in qualitative data, was conducted to identify patterns and themes within the data (13).

**Table I. Group-level characteristics**

| Participant No./Sex | Discipline | Frequency of involvement with DI patient | MCD 1 ($n=10$) | MCD 2 ($n=8$) |
|---|---|---|---|---|
| Interviewed before MCD | | | | |
| 1/M | Dermatologist | One day in 2 weeks | Yes | Yes |
| 2/M | Dermatologist | One day in 2 weeks | Yes | Yes |
| 3/M | Dermatologist | Monthly | Yes | Yes |
| 4/F | Psychiatrist | One day in 2 weeks | Yes | Yes |
| 5/M | Psychiatrist | Few cases in his whole career | Yes | Yes |
| 6/F | Parasitologist | Weekly | Yes | No |
| 7/M | General practitioner | None | Yes | Yes |
| Interviewed after MCD | | | | |
| 8/F | Legal expert | None | Yes | Yes |
| 9/M | Ethicist | None | Yes | No |
| Not interviewed | | | | |
| 10/F | Physician and philosophy student | None | Yes | Yes |
| 11/F | Ethicist and complaints officer | None | Yes | Yes |

N: sample size; MCD: moral case deliberations.

The transcripts of the audio recordings were coded by 2 researchers (VS and YV) using MAXQDA version 2020 (https://www.maxqda.com/blogpost/free-update-maxqda-2020-1), qualitative data analysis software. To ensure consistency, the researchers compared and discussed their codes to verify that similar themes were identified. Data saturation was reached when no new themes or insights emerged, indicating that the data sufficiently captured the range of experiences and challenges discussed. The study results were reported according to the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist (11), ensuring methodological rigor and transparency.

## RESULTS

The study identified 3 main themes related to the moral dilemma of informing patients with DI:

- Doctor–patient relationship.
- Communication.
- Organization of care.

### *Doctor–patient relationship*

In the doctor–patient relationship, time emerged as an important factor. Building trust and a strong relationship takes time, but, due to time constraints, healthcare providers sometimes withhold information to address the diagnosis later. However, this can negatively affect the patient's prognosis. A psychiatrist said: "The biggest problem is that the patient wanders for too long … and as a result, the delusional disorder lasts much longer, and they become more entrenched in their delusion. The earlier you treat, the more favourable the prognosis, in my opinion."

Healthcare providers face an ethical dilemma when balancing transparency with the therapeutic relationship. Some practitioners prioritize trust over full transparency to foster future communication. A GP noted: "I prioritize trust over full transparency. This allows me to build a platform for future discussions." In this regard an ethicist highlighted proportionality: "Not fully informing may be justified depending on the disease burden and the lack of insight." A legal expert stressed the risks of withholding: "Our priority is to inform patients thoroughly and provide answers. Saying 'I don't know' can harm by creating uncertainty.

Honesty and respect are interlinked." A dermatologist shared: "Respect means I share my professional opinion while valuing the patient's perspective." However, respect must be balanced with sensitivity to stigma. A psychiatrist warned: "Certain terms like 'psychosis' carry emotional weight. Empathizing with patients' distress requires explicit effort.

Not fully informing patients is perceived as potentially undermining their autonomy. According to a psychia-

trist, transparency is considered essential to respecting autonomy, as it empowers patients to make informed decisions. However, healthcare providers also face the risk that full disclosure may lead to treatment refusal, leaving the patient without any care. Autonomy is interpreted by most healthcare providers as the ability to lead a normal life while addressing the patient's suffering. The legal expert adds: "Sometimes it is necessary to limit autonomy to achieve a better situation in the future."

### *Communication*

According to the respondents, the manner in which communication with patients is conducted, as well as the language used, is of great importance. Effective communication strategies were identified. First, the term delusional disorder is often avoided as patients then often end the treatment relationship immediately. The psychiatrist adds: "The patient has only heard the word 'delusion' and concludes that you don't believe them." During the moral case deliberation, a dermatologist stated: "By initially withholding information to buy time, you can become gradually more transparent – framing the symptoms in terms of stressors rather than psychiatric diagnoses." Another dermatologist added: "We often describe it as an overfocus where patients fixate on certain beliefs, intensifying their perception." Second, linking symptoms to objective findings also proved effective. Another dermatologist said: "The itchiness persists despite negative tests. Shouldn't we explore other possibilities, like stress?" All experts agreed with using the burden of disease as a hook to introduce treatment: "We can explore ways to address the consequences of this condition, such as utilizing certain medications commonly used in psychiatry. These medications, known as antipsychotics, can be prescribed in low doses to help alleviate the intensity of symptoms and improve your overall quality of life." Finally, agreeing to disagree was another strategy. A psychiatrist explained: "Let's agree we don't see eye to eye but focus on what I can do to help you." This approach shifts the conversation from diagnosis to improving quality of life and reducing suffering. To support clinical practice, **Table II** summarizes practical language strategies for managing interactions with DI patients, focusing on empathy, shared goals, and non-stigmatizing language.

### *Organization of care*

Collaborative care, involving dermatologists, psychiatrists, psychologists, and general practitioners, was seen as crucial. Often the dermatologist takes the lead, which aligns with patient expectations. For example, prescribing medication through dermatologists often builds more trust than when done by psychiatrists. The importance of clear communication between disciplines was emphasized, particularly in referral letters. As one dermatologist noted: "If a referral letter says 'unspecified skin infection', while the diagnosis is actually clear, the GP might assume it isn't delusional. Transparency in correspondence is therefore crucial."

Specialized psychodermatology clinics have been recognized as essential for facilitating multidisciplinary care and providing tailored treatment for patients with DI. Nevertheless, the scarcity of such clinics significantly restricts access to comprehensive care. Furthermore, the limited expertise in psychodermatology among healthcare professionals presents challenges in delivering appropriate treatment and promoting effective interdisciplinary collaboration.. A psychiatrist highlighted this issue, stating: "There are not many psychiatrists, even in the Netherlands, who find this subject interesting and have specialized in it. So far, I have few colleagues to whom I can refer in this regard." Respondents emphasized the urgent need for clear protocols and guidelines to enhance collaboration and ensure optimal care for patients with DI.

**Table II. Practical language strategies for empathic and effective communication in delusional infestation**

| Situation | Example phrases |
|---|---|
| Validating the patient's experience | "I can see that what you're experiencing is very real and distressing for you."<br>"I take your symptoms seriously, even if we don't yet have a clear explanation."<br>"It's clear that this is affecting your life, and I want to help reduce that burden." |
| Avoiding the word "delusion" | "Sometimes the body and brain process signals in a way that can be confusing."<br>"Sometimes the brain can send or amplify signals that feel very real, even though there's no physical cause in the body itself."<br>"The word 'delusion' isn't helpful here, I prefer to talk about what you're feeling and how we can manage that." |
| Offering alternative explanatory models | "It seems like your brain is focusing more on certain sensations, making them feel stronger."<br>"We sometimes describe this as an 'overfocus' or heightened sensitivity."<br>"Even in the absence of infection, the nervous system can become overactive, that's something we can try to calm." |
| Introducing treatment without naming the diagnosis | "We can begin by addressing the symptoms and see how your body responds."<br>"Let's focus on making you feel better first, sometimes that gives us more clarity too."<br>"We can look at ways to reduce the itching and discomfort while continuing to explore what's going on." |
| Introducing antipsychotic medication | "This medication is sometimes used for people who experience persistent skin sensations."<br>"It's originally designed for other purposes, but in low doses it helps reduce these kinds of nerve signals."<br>"Some patients have found that this medication helps them sleep better and feel calmer overall." |
| Managing disagreement about the cause | "We may have different ideas about what's causing this, and that's okay, I still want to help."<br>"You don't need to accept my explanation for us to work on reducing your symptoms."<br>"Let's agree that we have a shared goal: that you suffer less from this." |
| Maintaining trust and support | "You don't have to agree with my view, what matters is that we find a way forward that works for you."<br>"I respect your experience and I want to help you feel better."<br>"I won't try to convince you of anything, I just want to offer something that might help."<br>"The fact that we're talking openly is already a great step." |

## DISCUSSION

This study aimed to identify the ethical and communicative challenges faced by healthcare providers when informing patients with DI of their diagnosis and initiating treatment. By analysing interviews and MCDs, the study explored key dilemmas and effective strategies to support communication while minimizing resistance and fostering acceptance. The findings highlight 3 key areas: building trust in the doctor–patient relationship, employing sensitive and effective communication strategies, and enhancing multidisciplinary collaboration to provide comprehensive care.

The first theme highlights the critical importance of establishing a trusted doctor–patient relationship and maintaining open communication. While these principles are fundamental to all areas of medicine, they hold particular relevance in the care of patients with delusional infestation (DI). These patients often exhibit a heightened mistrust of healthcare providers and strong resistance to explanations involving psychiatric diagnoses. In this context, the therapeutic relationship serves as a foundation for overcoming these barriers and fostering collaboration. Time plays a crucial role in this process, as it allows for the gradual development of trust, which is essential in managing the complexities of DI. This finding aligns with existing literature highlighting the importance of a solid relationship built on respect, empathy, and active listening (12, 13). Such a relationship promotes honest dialogue, respects patient autonomy, and ultimately improves health outcomes (3, 14). This relationship-centred approach not only enhances patient engagement but also lays the groundwork for successful treatment outcomes.

The second theme delves into communication strategies used by physicians to inform DI patients, balancing the need for honesty with the risks of alienating the patient. Some physicians avoid explicitly naming the diagnosis, opting instead for an explanatory model centred on an overfocus of the brain (15, 16). While this approach minimizes immediate resistance, it raises ethical questions concerning transparency and patient autonomy. Another approach involves agreeing to disagree regarding the name of the diagnosis and focusing on addressing the burden of the disease, potentially through the use of antipsychotics (3, 14). Actively involving patients in the diagnostic process not only rules out other causes but also validates their concerns, fostering trust and collaboration. Given the stigma associated with DI, healthcare providers must choose their words carefully. For instance, avoiding terms like "delusional" can prevent defensiveness, while emphasizing symptom management helps redirect the conversation constructively. These strategies highlight the critical role of sensitivity and adaptability in communicating with patients affected by DI.

Söderfeldt argues that using an inaccurate explanatory model undermines patient autonomy by misrepresenting their condition (16). However, the present study advocates for a care ethics perspective, which views autonomy not as isolated independence but as inherently relational. Autonomy flourishes in the context of meaningful relationships, as people rely on others to help shape their understanding of life and health (17). Respecting autonomy, therefore, goes beyond merely providing information and allowing the patient to choose. It involves a collaborative effort to identify care strategies that best address the patient's needs. Care is a dynamic process of mutual cooperation and shared responsibilities. In the context of informed consent, explicitly naming the diagnosis may not always be necessary. Instead, attentiveness to the patient's unique concerns and priorities can lead to treatment approaches that are both acceptable and effective (18). For instance, framing discussions around symptom management rather than diagnostic labels can help foster trust and avoid unnecessary resistance.

Multidisciplinary collaboration plays a vital role in psychodermatology care, ensuring a comprehensive approach tailored to patients' needs (19). Establishing strong collaboration with psychiatrists, psychologists, and general practitioners enhances continuity of care; however, the heavy workload of GPs may limit their capacity for active involvement. To address this, specialized psychodermatology clinics play a pivotal role by offering coordinated expertise and serving as a central hub for care (19). Clear communication among healthcare providers is equally important. While withholding the explicit diagnosis in correspondence can sometimes protect patient trust or prevent complaints, it may also result in ambiguity and hinder effective collaboration. Striking a balance – by ensuring that critical information is shared transparently without compromising the therapeutic relationship – is vital for optimal care delivery. By centralizing care within psychodermatology clinics, multidisciplinary teams can provide the necessary guidance and support to both patients and referring clinicians.

While this study underscores the significance of multidisciplinary psychodermatology clinics, it is acknowledged that such facilities are not readily accessible to the majority of practising dermatologists. Nonetheless, many of the communication strategies and ethical considerations informed by expert input are applicable to routine clinical practice. Rather than prescribing rigid guidelines, this study presents a reflective framework and practical communication techniques that clinicians can adapt to their specific contexts. An overview of these key strategies is provided in **Table III**. Acknowledging that the ethical and communicative challenges associated with delusional infestation are familiar to many practitioners, our objective is to support their daily practice with concrete insights and language strategies that maintain trust, reduce conflict, and promote treatment acceptance, even in resource-limited settings.

**Table III. Practical strategies for managing delusional infestation in daily practice**

| Challenge | Suggested strategy |
|---|---|
| Resistance to psychiatric explanation | Use non-stigmatizing terminology: describe symptoms as a result of "overfocus" or "heightened perception" rather than "delusion"<br>Avoid psychiatric labels in the early stages<br>Take time to align with the patient's perspective by acknowledging the emotional and social impact of their condition, such as isolation from family and friends, being housebound, or other limitations in daily functioning and quality of life |
| Fear of losing patient trust | Prioritize the therapeutic alliance<br>Delay diagnostic labelling if needed and focus on symptom validation first |
| Disagreement about the diagnosis | Use a collaborative approach: "We may see things differently, but I want to help you feel better"<br>Focus the conversation on shared treatment goals |
| Introducing antipsychotic treatment | Frame medication in dermatological terms: "This can help calm the skin and reduce the itching" rather than "this is an antipsychotic"<br>Focus on effect, not psychiatric indication |
| Time pressure in regular consultations | Break communication into phases: initial focus on symptoms and relief, follow-up for gradual disclosure and care planning |
| Lack of access to multidisciplinary care | Collaborate informally via phone/email with psychiatrists or psychologists<br>Use clear, consistent language in referral letters to align expectations. |
| Legal or ethical uncertainty | Respect relational autonomy: support patients in making informed decisions by aligning with their values, not just by providing information<br>Balance beneficence and autonomy case-by-case |
| Clinician discomfort or frustration | Acknowledge emotional burden and complexity<br>Consider ethics consultation or peer supervision<br>Recognize limits while maintaining empathy |

### *Strengths and limitations*

The current study offers significant insights into the communication strategies for patients with delusional infestation (DI), supported by methodological strengths such as expert diversity, analyst triangulation, and moral case deliberation. It advances the understanding of effective communication with DI patients and identifies areas for future research.

However, limitations should be acknowledged. The sample selection was biased, mainly consisting of colleagues from 1 researcher's network, potentially leading to overrepresentation of similar views. The absence of patients in the sample limits external validity. The use of moral case deliberation as a data collection method in the focus groups is relatively new; the structured method leaves little room for issues other than those addressed in the case.

Future research should include a more diverse participant sample – ideally including patients – and explore alternative focus-group formats to enhance validity and reliability. However, in cases involving DI, direct patient participation may require careful consideration due to limited insight and the potential risk of disrupting the reflective process.

### *Conclusion*

This study elucidates the ethical and communicative challenges encountered by physicians when informing patients about DI. Establishing a robust doctor–patient relationship, allocating time to build trust, and employing sensitive communication are crucial for overcoming resistance and fostering cooperation. While terms such as "delusion" may provoke defensiveness, employing alternative explanatory models and concentrating on symptom relief can preserve trust without compromising care. Although multidisciplinary psychodermatology clinics provide optimal care, they are not widely accessible. Consequently, this study offers practical communication strategies applicable to everyday practice. These strategies include avoiding stigmatizing language, utilizing the burden of symptoms as an entry point for discussion, and adopting a stepwise or "agree to disagree" approach when patients resist psychiatric framing. Importantly, this study does not aim to prescribe what clinicians must or should do. Instead, it offers ethically grounded reflections and practical suggestions that can support clinical decision-making in the context of DI. The insights are based on the experiences and reasoning of a diverse group of professionals and are meant to inform, not to dictate, clinical practice. Ultimately, the findings support a relational and pragmatic approach to autonomy and care, helping clinicians navigate the tension between honesty and empathy. By applying these techniques, even in resource-limited settings, healthcare professionals may improve patient engagement, reduce conflict, and facilitate better outcomes.

## ACKNOWLEDGEMENTS

The authors would like to express their gratitude to A.H.P.W. Mulders (general practitioner), R. Waalboer-Spuij and M.T.W. Gaastra (dermatologists), G. van Brussel (psychiatrist), and C. Ploem (health lawyer) for their valuable input and thoughtful reflections during the interviews and moral case deliberations.

*The authors have no conflicts of interest to declare.*

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