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A combined tropical medicine and psychiatry approach to patients with possible delusional infestation

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Background: Delusional infestation (DI) is a well-recognized delusional disorder presenting as the persisting belief of being infested. Combined clinics have been run by dermatology and psychiatry in a small number of centres. In this article we focus on our Liverpool University Hospitals NHS Foundation Trust clinic hosted at the Liverpool School of Tropical Medicine, UK, where we run a specialist clinic for DI.

Methods: We describe the specific set-up and approach of our clinic as a guide for clinicians working in specialties likely to see patients with DI (including tropical medicine, infectious diseases and dermatology) who may either want to set up similar clinics or be better equipped to manage DI patients promptly within existing practice.

Results: We describe the details of the clinic's approach. Between 2018 and 2023, the service saw 208 patients, of which 82.7% could be assessed and 55.7% had DI. The female:male ratio was 2:1.

Conclusion: Interdisciplinary combined clinics with medical and psychiatry consultants working together offer an approach to managing this rare, challenging and high-consequence condition.

Keywords: combined clinics, delusional infestation, infectious diseases, psychiatry, tropical medicine

Introduction

Delusional infestation (DI) is a relatively rare disease characterized by a patient's fixed belief their skin, body or immediate environment is infested by small, living (or less frequently inanimate) pathogens, in the absence of any medical evidence for this.[1] DI is neither a single disease nor a single diagnostic entity. The classic form, primary DI, develops without any known cause or underlying illness and meets criteria of a delusional disorder or somatic type delusional disorder. However, approximately 60% of patients suffer from a variety of secondary forms of DI that are substance related (e.g. cocaine, amphetamines, cannabis, alcohol, dopaminergic medications, antibiotics) or within physical or psychiatric illnesses (e.g. delirium, dementia, depression, schizophrenia, stroke, medical conditions that affect the brain or cause pruritus).[1]

The consequences of untreated DI for both patients and health services are severe.[1] Patients' lives are disrupted by behaviours aimed at eliminating or escaping the infestation, including, for example, thrice-daily showering; daily hot washing of all bedding, towels and clothing; discarding of bedding and mattresses and frequent moving to new accommodations. In addition to the expenses incurred in these behaviours, patients frequently buy unproven remedies via the internet. Examples include tea tree oil, ivermectin and high-strength oregano oil. These behaviours can lead to indebtedness and break-up of relationships. In extreme cases the distress can lead to self-harm, including suicide, or harm to relatives (in cases of DI by proxy).[1] There are rare cases of harm to treating doctors.[1] Health services are also burdened by multiple frustrating care-seeking episodes in primary, secondary and tertiary care as patients continue to seek remedies from different specialties.

Antipsychotic treatment is effective[2,3] and recommended by national guidelines.[4] Amisulpride followed by risperidone is the current recommendation, supported by the most recent evidence.[2] However, engaging patients is difficult, as they do not believe they have a psychiatric illness. Strategies have been proposed to manage these difficulties. Clinicians may actively invite the patient to trust that they have seen multiple other

patients with similar problems before and have successfully treated them. They may also appeal to shared values, such as the aim to reduce symptoms and suffering.[5] Clinicians can focus on associated symptoms such as agitation or anxiety, which can be treated with antipsychotics. In cases that are very difficult to engage, they may point out the fact that the patient has nothing to lose by trying a medication against what they perceive to be their better judgement.[6,7]

Specialist clinics for DI were first set up in Austria in the 1980s.[8] Specialist clinics combine a psychiatrist with either a dermatologist or another specialist who sees patients with DI, such as a physician in tropical medicine. After a period of inaction, some clinics started up again in the 2000s in the UK, Germany, The Netherlands and Russia. DI is also seen within psychodermatology clinics where they exist. Such clinics have been shown to be more successful at engaging patients and thus getting positive outcomes than treatment in primary care, dermatology or tropical medicine alone.[1] Research suggests that the longer DI is left untreated, the worse the outcome,[9] although positive outcomes can be achieved even after a prolonged duration of illness over many years.[10]

In this article we focus on our Liverpool University Hospitals NHS Foundation Trust (LUHFT) clinic hosted at the Liverpool School of Tropical Medicine (LSTM), UK, where we run one of the few specialist clinics for DI that exist internationally.[11] We describe the specific set-up and approach of our clinic as a guide for clinicians working in specialties likely to see patients with DI (including tropical medicine, infectious diseases and dermatology) who may either want to set up similar clinics or be better equipped to manage DI patients promptly within existing practice.

Methods

The service started in 2011 with an initial case series described in 2018.[11] Since then our approach has been developed through intermittent reflective practice discussions (approximately biannually) between the psychiatry and infectious diseases/tropical medicine (ID/TropMed) consultants running the LSTM clinics and with colleagues providing similar services in London, Bruneck, Berlin, Amsterdam and Moscow. Since 2021, one ID/TropMed consultant (TO) has retired and has been replaced in the service by another (MT). In the same time frame, one psychiatry consultant (CK) has moved to a different service and been replaced by another (QJ).

Through the process of biannual reflection and discussion of experiences and outcomes, the consultants running the service have defined the overall objectives of the service as follows: identify and diagnose patients with DI who have no prior engagement with psychiatric services; engage patients with clinicians in order to build a trusting relationship; develop a treatment plan and start effective treatment with an aim to achieve remission; effectively transfer care to appropriate local mental health services, if needed; and develop a treatment plan for those who do not have DI.

The service uses the term 'combined clinics' because each is run by both an ID/TropMed consultant and a consultant psychiatrist. They are not advertised externally as DI clinics to avoid deterring patients.

The key elements of the service can be briefly summarized as follows. A detailed medical, travel and psychiatric history and a physical examination are followed by examination of clinical samples in the LSTM's UK Accreditation Service–accredited Clinical Diagnostic Parasitology Laboratory (https://www.lstmed.ac.uk/CDPL). Submitted samples are examined microscopically for evidence of parasites, urine is tested for drugs of abuse and, depending on the travel history, stool PCR and blood serology may also be examined. This initial stage is a means of developing trust between the patient and clinicians and gaining buy-in to the need for treatment and symptom control. Patients are kept under follow-up until they have engaged sufficiently to allow continued follow-up through their GP or psychiatric services, or they achieve remission.

Results—overall approach

Prior to allocation of a clinic appointment an ID/TropMed medicine consultant and a psychiatry consultant undertake a baseline screening of referral letters (see details in Table 1).

Each initial clinic appointment is allocated 1 h. In this session the consultant pairs aim for a similar approach (see details in Table 2), while recognizing that each patient has individual needs. Some patients are initially uncomfortable with the presence of a psychiatrist, but all of the 208 patients seen between December 2011 and July 2023 have accepted that this is our approach.

The aims of the approach are to assess and diagnose; offer a chaperoned, general clinical examination; reassure the patient that his/her symptoms are taken seriously; build a trusting relationship and try and agree on shared values and purpose (alleviating symptoms, alleviating the patient's suffering, intention to reach a diagnosis).

At the end of the first assessment, the diagnosis of DI is not explicitly discussed even if that is the most likely diagnosis at that stage.[7] Occasionally patients or their relatives ask directly, in which case DI is explained along the following lines as 'a brain disorder in which there has been a change in some brain pathways which determine how some sensations are interpreted'. DI is explained as real to the patient but not to others. However, ideally, even when the diagnosis of DI is clear, a point where the following form of words (or similar) can be used is sought:

- 'It is clear that your symptoms are really distressing and I/we acknowledge and recognize that they are very real and affecting you'.
- 'At the moment it is not completely clear what is causing these symptoms. There are a number of possibilities. One of the possibilities we have considered is a diagnosis of a parasitic infestation. It is worth explaining that any diagnosis is made on the basis of a full assessment, not just on a single blood test or pictures. In your case, a parasitic infection is very unlikely because

Table 1. Actions prior to allocation of a clinic appointment.

1.	The service only accepts National Health Service referrals from health professionals. No direct referrals from patients or family members.
2.	The referral is reviewed by both the ID/Trop Med and psychiatry consultant.
3.	Referral letters that describe unusual, complex and persistent symptoms ascribed to an infecting agent but which have defied diagnosis by one or more clinical disciplines are indicative of DI. If the diagnosis of DI is unlikely, the referral goes back to the on-call tropical medicine physician for a decision on whether to see the patient in an LSTM tropical clinic or refer them elsewhere.
4.	If the diagnosis of DI is likely or confirmed and the patient is already engaged with mental health services, a letter is sent explaining that continued work with the relevant mental health service is the best course of action; our clinic is set up primarily to engage patients with DI who would otherwise not access mental health services.
5.	If the diagnosis of DI is possible and the patient is resident in our catchment area, then a standard letter is sent to the referring physician accepting the referral. Sometimes it is necessary to write to the referring service seeking clarification on some aspects of the presentation or more detailed documentation of previous clinical assessments, including specifically asking if they are already engaged with mental health services.
6.	Once a DI clinic date is confirmed a standard letter is written seeking advance results of recent full blood count (mainly to check for eosinophilia), C-reactive protein (to check for any systemic inflammatory process), B12 and folate (B12 deficiency is a recognized cause of unusual sensations) and electrocardiogram (to check the QTc interval in case antipsychotic medication is indicated).

–From your description of the places you have been and the kind of exposure that you describe, the chance of an infection having taken place is unlikely'.
–From examining you today, we have not found a pattern of abnormalities that fit within our experience of parasitic infections (and ___ has seen many parasitic infections in his/her career)'.
–From the blood tests that were carried out before you came to the clinic, we did not find a pattern of immune response that would fit with a parasitic infection (specifically one kind of blood cell, the eosinophil count, was not raised)'.

- 'Nonetheless, we are keeping an open mind, and we think it makes sense to have the specimens that you brought with you (or will send us) examined in our accredited specialist laboratory, and we can discuss the results of these when we see you at your next appointment'.
- 'Sometimes it is helpful to think of symptoms on a gradient. We all have a threshold for these feelings. Just like when your child comes home from school with head lice and your head immediately starts itching. That is an example of us all having a threshold for such symptoms. Most of the time this threshold protects us from symptoms spiralling out of control. However, some things can destabilize (or lower that threshold) meaning that a trigger can set off a cycle of events and interpretations'.
- 'In our experience, we find that it is helpful to take a pragmatic approach at this stage. We are not completely sure what the diagnosis is, but we have found that giving a small dose of a medicine called amisulpride (sometimes a different antipsychotic is indicated) is helpful while we examine your samples and try to work towards a diagnosis. This is a medicine that often helps the kind of symptoms you describe and the distress they cause. We would like to outline this medicine for you to think about. On the package insert it says it is for schizophrenia, but we must emphasize that we do not think you have schizophrenia. We would be offering you this medicine in a small dose; much lower than the doses used in schizophrenia. As you know, some medicines are used in different doses for different diagnoses; for example, aspirin is used at 75 mg once per day to prevent strokes but at 600 mg every 4–6 h for pain'.

Our practice is in keeping with the National Guidelines on Delusional Infestation, published in 2022 by the British Association of Dermatologists.[4] Whether to offer amisulpride, or another antipsychotic, at the first consultation is a question of judgement, but newest evidence supports this choice.[2] The higher the delusional intensity (patient will not even consider an alternative explanation of symptoms), and the more the patient has invested in his/her own particular explanation of the symptoms, the better it may be to wait for the second consultation to offer antipsychotic medication. Other medications that may be needed to treat the skin or secondary skin infections can always be suggested. Most patients with predominantly dermatological symptoms have already been treated, or have self-treated with topical anti-scabies or lice agents (such as permethrin or malathion) before being seen in the combined clinic.

Follow-up clinic appointments are allocated 30 min. Some patients can be discharged earlier than the standard four follow-up appointments, while others need additional clinic appointments.

The main purposes of follow-up appointments are to review results of investigations and explain the results in detail; review symptoms and, if necessary, offer a chaperoned repeat clinical examination; assess treatment adherence or discuss initiation of treatment; change medication if needed (in case of intolerable side effects or inefficacy) and establish a long-term follow-up

Table 2. At the first clinic appointment.

1.	All patients are asked to produce a urine specimen for toxicology. This is a routine procedure because DI patients have a higher prevalence of illicit drug use than the normal population and illicit drugs can cause symptoms of DI.
2.	All patients are seen by the psychiatrist and the ID/TropMed physician together in the same clinic. This is to normalize the presence of the psychiatrist, who is more difficult to introduce at a later stage. A form of these words is delivered by the tropical medicine physician: 'Hello, my name is ___, I am an infectious diseases and tropical medicine physician, and you are here to see me today. This is ___, who is a psychiatrist. We always run this clinic together because patients with complex problems often have additional difficulties we would like to identify and treat'. If a patient objects to there being a psychiatrist in the room, then we politely decline and say that this is the clinic policy: 'Two brains for complex cases are better than one'.
3.	We allocate 1 h for the first consultation. It is important to be firm with timekeeping and boundaries. This is explained up front: 'We have an hour for the consultation today. In our experience we sometimes don't reach a clear way forward in every consultation, so if you notice me looking at the clock or moving the conversation on faster than you would like, don't worry, we can return to things in a future clinic appointment'. If patients want to show many images or videos on mobile phones they can be reminded of the time constraints and asked to focus on one or two representative images.
4.	Some patients ask if they can record the consultation on their mobile phone. We do not encourage recordings, as they detract from the patient–doctor interaction. If recordings are used to threaten or break confidentiality (e.g. posting on social media), then recourse is to the police whenever necessary.
5.	We offer a chaperoned general clinical examination for all patients. In general, it builds trust, is important for the diagnostic process and gives the patient the feeling of being carefully assessed, which has often been missing in previous consultations elsewhere.
6.	We generally avoid taking blood samples for investigation within the consultation time. Patients need a lot of listening time. This is why we ask for basic investigations to be done in advance. We occasionally arrange additional blood tests in the clinic if relevant to the individual clinical presentation (e.g. thyroid function, autoimmune screening) or travel history (e.g. blood-borne virus screen, serology for certain parasites).
7.	We encourage patients to give us samples for microscopy in the LSTM Clinical Diagnostic Parasitology Laboratory. These are examined primarily as a means of engagement, and to exclude actual infestation. The results build one possible foundation for further discussions of the symptoms and treatment options.
8.	We decide on a case-by-case basis whether to copy letters to patients. Any communication about the patient's condition is ethically complex. The patient may read the letter and be put off coming back to the clinic by the words 'delusional infestation'. On the other hand, it is important to be clear about the diagnosis with the referring physician. We use the principles of the Mental Capacity Act 2005. Gradual disclosure of the diagnosis can be justified in the patient's best interest when the patient lacks the capacity for treatment decisions. If a patient asks directly for a copy of our letter, or a written record of the consultation, we may write a letter addressed to the patient in a more lay language, but also inform the patient that some medical terminology may be included and that it will be copied to the referring doctor and their primary care physician.
9.	Our patients are sometimes unhappy with health professionals in general, and sometimes specifically with our service. Phone, email and social media communications (e.g. X and YouTube) have been used to express this disappointment. Our policy is always to refer patients to LUHFT Patient Liaison and Complaints Services. DI patients do not usually lack insight or capacity into their threatening behaviour (if present) and should be treated as any other member of the public or patient (unless exceptional circumstances apply). If we encounter threatening behaviour in a consultation, we will challenge it, reminding patients of normal expectations of mutually respectful behaviour within all clinical consultations.

management plan, usually with a GP and local psychiatric services.

An innovative image bank has been developed by our Clinical Diagnostic Parasitology Laboratory to support the review of results and explanation of them in detail. This resource serves the purpose of illustrating genuine pathogen images in contrast to common sample results. It shows visually, and at differing magnifications, how epithelial cells or environmental fibres lack internal structures and organs and enables direct comparison to the personal photos or internet searches often brought by patients to clinic appointments.

If a diagnosis of DI has been made, we recommend treatment with an antipsychotic[2–4] (usually amisulpride as a first-line treatment with a target dose of 200 mg twice daily, or half that in the elderly) for 1 y and vigilance for a relapse for 1 y after completion of treatment. We do not keep patients under clinic review for the entire year of treatment, aiming to hand care back to the referring physician, GP or, occasionally, a local Community Mental Health Team (CMHT), after a usual maximum of four clinic appointments. If a patient misses a follow-up appointment, the clinic secretary will try to reach him/her by phone to arrange a new appointment. If they miss two consecutive appointments, they are

Table 3. Possible discharge options.

1. With a diagnosis other than DI (e.g. health anxiety).
2. With a diagnosis of DI and stabilized on treatment:
    a. Details of diagnosis and management plan agreed upon with patient and outlined in the final clinic letter.
    b. Letter to the patient asking their permission for a member of the combined clinic team to contact them a year after discharge to learn how they are.
3. With a diagnosis of DI but patient misses two consecutive appointments or does not attend for follow-up:
    a. Details of diagnosis and management plan agreed upon outlined in a final clinic letter. This may be supplemented by a phone call from the combined clinic psychiatrist to the referring physician if the case is complex.
    b. Letter to the patient regretting that they were unable to attend for follow-up and asking their permission for a member of the combined clinic team to contact them a year after discharge to learn how they are.

discharged from the clinic. See Table 3 for a summary of discharge options.

We record a Clinical Global Impression severity (CGI-S) score[14] from 1 (no illness) to 7 (very severe) for each patient at each consultation (see Box 1). We recently defined the CGI-S specifically for DI patients.[2] The CGI-S score is included in the letter to the referring physician. It allows us to monitor individual patient progress more objectively and can be used to research outcomes.

Box 1: CGI-S score[13]

CGI-S scores (strictly physician scored, takes into account overall disease burden)

1. Normal, not at all ill
2. Borderline mentally ill
3. Mildly ill
4. Moderately ill
5. Markedly ill
6. Severely ill
7. Among the most extremely ill patients

An overview of diagnoses and demographics of patients is presented in Table 4. Outcomes of patients with a diagnosis of DI are reported elsewhere.[1–3,12,13] In brief, about two-thirds of patients with DI who adhere to an antipsychotic treatment plan achieve a response or remission. Amisulpride, followed by risperidone, is the preferred first-choice antipsychotic.[2] Some patients improve without antipsychotics and respond to a cognitive approach to manage their delusional beliefs. Loss to follow-up and poor adherence remain challenges.

Table 4. Diagnoses and demographics of patients attending the service 2011 to August 2023.

Diagnoses/demographics	Values
Total patients attending, N	208
Patients with a diagnosis of DI, n (%)	116 (55.8)
Age of DI patients (years), mean	57.7
Male:female ratio of DI patients	1:2
Patients with non-DI diagnoses, n (%)	54 (26.0)[a]
Patients with no diagnosis of mental health or other, n (%)	2 (1.0)
Patients who cancelled or did not attend follow-up, n (%)	36 (17.3)
Patients deceased during follow-up, %	0
Patients with any laboratory-confirmed insect/parasite, n (%)	1 (0.5)[b]

[a]Of those who did not have DI, half had health anxiety; other diagnoses included depression, generalized anxiety disorder, chronic fatigue syndrome, idiopathic pruritis ani, irritable bowel syndrome and impetigo.
[b]The one confirmed insect was a housefly of no clinical significance.

Discussion

The service currently relies on the experience of individual clinicians and has only been scaled-up from one to two clinician pairs so far. We do not know yet which approach to full transparency and openness in sharing the diagnosis with patients yields the best results. This may be a subject of future research. There is some interest in the use of Cognitive Behavioural Therapy for psychosis, which may be useful for the treatment of DI as well. However, a recent Cochrane review pointed out the lack of generalizable evidence.[13] We would like to see if the offer of non-pharmacological evidence-based treatments may enhance our efficacy rate when it comes to response and remission.

The diagnosis of DI is the most common diagnosis in our clinic, but an open mind towards the diagnosis is vital, as around one-third of our patients have health anxiety, bodily distress (somatization) disorder, depression, substance misuse and others.[11] The psychiatrist on the team can guide treatment in such cases, which may necessitate a GP referral to primary care mental health services, or in some cases liaison with the local CMHT.

Conclusions

Specialist clinics are an effective way of treating patients with DI, with success rates for response or remission in around two-thirds of those who adhere to antipsychotic treatment.[1–3,12] We describe an outline of our clinic that is in line with national guidelines[4] as a guide for clinicians working in specialties likely to see patients with DI (including tropical medicine, infectious diseases and dermatology) who may want to set up similar clinics or be better equipped to manage DI patients promptly within an existing practice.

Authors' contributions: SBS developed the initial concept for the combined clinic (with PL), conducted monthly clinics from 2011 to the present day (with PL), participated in bi-annual reflective clinic development from 2018 to the present day, wrote the first draft of the manuscript, commented on and redrafted sections of all subsequent drafts. MT conducted monthly clinics from 2021 to the present day (with QJ), participated in bi-annual reflective clinic development from 2021 to the present day and commented on and redrafted sections of the first and all subsequent drafts. QJ conducted monthly clinics from 2021 to present day (with MT), participated in bi-annual reflective clinic development from 2021 to the present day and commented on the first and all subsequent drafts. TO conducted monthly clinics from 2011 to 2021 (with CK), participated in bi-annual reflective clinic development from 2018 to 2021 and commented on the pre-final draft of the manuscript. CK conducted monthly clinics from 2011 to 2021 (with TO), participated in bi-annual reflective clinic development from 2018 to 2021 and commented on the pre-final draft of the manuscript. PL developed the initial concept for the combined clinic (with SBS), conducted monthly clinics from 2011 to the present day (with SBS), participated in bi-annual reflective clinic development from 2018 to the present day, wrote the second draft of the manuscript and commented on and redrafted sections of all subsequent drafts. All authors read and agreed on the final manuscript. SBS and PL are guarantors of the article.

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