CLINICAL MANAGEMENT RECOMMENDATIONS

Best Practices for Management of Delusions of Parasitosis

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INTRODUCTION

Delusions of parasitosis (DOP), also known as delusional infestation and the eponym Morgellons disease, is a condition where a patient has a fixed false belief that he or she is infested with parasites. Patients may also complain about foreign material, such as fibers, extruding from their skin. Clinical encounters with patients suffering from DOP can cause unease and even resentment for dermatologists whose expertise lies in identifying objective evidence of skin disease. Dermatologists are usually treated deferentially by their patients and can become uncomfortable when put in a situation where they have to deliberately revolve around the patient’s thinking. This issue is exacerbated by the fact that few dermatology residency training programs offer formal training in psychodermatology, no official psychodermatology fellowship exists and there is a paucity of resources for the practicing dermatologist such as specialized clinics for these patients¹. This creates a situation where a dermatologist consciously or subconsciously may feel aversion for having to deal with patients who insist that their specific ideation is a reality.

Furthermore, providers in the United States are now under the system of “value-based reimbursement,” meaning that physicians’ overall reimbursements are determined in large part by patient satisfaction scores. In this system, physicians may be penalized financially if their satisfaction score is below the 50th percentile compared to their peers. The total patient satisfaction score is based on the input from patients who are motivated enough to spend their time and energy rating their dermatology providers. It is well known that DOP patients who are angry at their dermatology providers will be motivated to make sure that their dissatisfaction with their provider is well known, potentially causing patient satisfaction scores to plummet. Therefore, even if a dermatology provider is not particularly interested in psychodermatology, it is prudent to learn a few tips regarding how to handle these patients. This, at a minimum, could help dermatologists from being globally penalized financially from these encounters. Dermatologists can, with training, diagnose DOP, build rapport and therapeutically treat DOP patients.

DIAGNOSIS OF DOP

The evaluation of patients with suspected DOP begins with a careful skin examination to exclude a true infestation or neurologic
disease as the cause for the reported symptoms. Every patient that presents with DOP or is referred for this condition should be assumed to have a bond fide skin condition until proven otherwise. Patients should undergo a full body skin exam along with possibly bacterial/fungal or viral culture and KOH preparations, if indicated, of any suspected areas of infestation. At the very least, these procedures help the patient feel cared for and mitigate negative feelings the patient may have towards the provider. Thus, a diagnosis of DOP can only be considered after true dermatoses are ruled out following a thorough history and physical examination.

Patients determined to have DOP are categorized according to whether they have a spontaneous disorder, i.e., primary DOP, or secondary DOP consequent to conditions that include illicit substance abuse or withdrawal, organic brain syndrome, schizophrenia, hyperthyroidism, and vitamin B12 deficiency, among others. Primary DOP is commonly seen in older, post-menopausal women while for secondary DOP, the age range varies. Primary DOP may have to be treated by the dermatologist (as primary cases are uniformly resistant to seeing any mental health professionals), while secondary cases are best co-managed by a psychiatrist and a dermatologist. It is important to realize that both primary and secondary DOP patients generally end up in the dermatologist’s office because they believe they have a skin problem and simultaneously can be aversive to any inkling of mental health or psychiatry. The following laboratory tests may be considered in aiding to elucidate a secondary cause of DOP and to establish a patient’s general health status, especially if the patient is starting a systemic medication: Complete blood count with differential, serum electrolytes, liver function tests, thyroid function tests, serum calcium, serum glucose, serum creatinine, blood urea nitrogen, vitamin B12, urinalysis, toxicology screen, HIV, hepatitis C and RPR for syphilis. Still, the three most useful tests in elucidating etiology are thyroid function tests, Vitamin B12 level and toxicology screen. Although, further data are needed, there is some evidence that DOP symptomology may in part be caused by dysregulation of the dopamine transporter system (DAT) as age-related loss of striatal DAT is much more prominent in older woman and, as mentioned above, primary cases of DOP are seen mostly in older woman.

Building a strong rapport with these patients is one of the most important principles of effective management. There is a high likelihood that the patient has had several negative encounters with other physicians before their visit with you. These patients may already feel quite skeptical or even hostile towards you, even before you meet them. As such, first impressions count. Building a strong rapport with these patients is one of the most important principles of effective management. There is a high likelihood that the patient has had several negative encounters with other physicians before their visit with you. These patients may already feel quite skeptical or even hostile towards you, even before you meet them. As such, first impressions count. Before entering the room to meet a patient with a chief complaint of “parasites coming out of my skin”, take a few moments outside of the door to make sure you are in an open and positive mindset. If an adequate rapport is not established, then it does not matter if you can prescribe appropriate or effective treatment, because the patient is unlikely to accept any of your advice or fill their prescriptions.

It is also important to avoid the diagnosis of “delusions of parasitosis” as either a diagnostic billing code or for the purposes of documentation. Instead, we most often use the ICD diagnosis of “formication” or “(cutaneous) dysesthesia.” Moreover, we deliberately avoid using terms that are
offensive to the patient, such as “psychosis,” “crazy,” “psychogenic,” or “delusional” in our notes. Medical records can now be accessed on demand by patients in many states without having to put a request in with medical records or their providers. Using such terminology for documentation, coding and diagnosis risks undermining therapeutic rapport, which takes much effort to build with DOP patients. With regard to the need to communicate to other clinicians when the patient is truly delusional and may even have bizarre delusions, a good way to communicate effectively in the medical record without using offensive terms is to use verbatim quotes of the patient’s ideation (especially the most bizarre aspects), which any reasonable practitioner can recognize as delusional. Furthermore, we do not refer to our clinic as “psychodermatology clinic” or our patients as “psychodermatology patients.”

Patients may bring in a wide variety of samples such as bundles of dirty paper towels, plastic containers with floating material inside them, random trash, debris, or anything else that one can imagine. If this is the case, we do not dismiss the samples as this could damage rapport. However, we also do not try to put them on our microscope. Instead, the patient should be thanked for bringing in the specimens, but nicely told that each specimen needs to be prepared in a very specific way as the specimens cannot adequately be analyzed without examining them under a microscope. Patients should be given a few glass microscope slides (with a warning to not break them in their pocket) and told that the most critical step of slide preparation is to use “absolutely clear”, transparent, tape to fix the specimen on the slide and not to use the matted tape, which does not allow detail to be seen. This method helps to reduce the amount of material that DOP patients tend to bring to the office while helping to further build trust and rapport.

Sometimes, patients may appear as if they are only interested in getting validation that their skin problem is caused by a parasite. The best way to handle a patient with this disposition is to shift their focus from etiology to therapy by helping them acknowledge how miserable this condition is and how much it is distressing them. Their problem can be referred to as a “mysterious condition” for which no one knows the etiology, which is technically true because an exact etiology for this disease has not been delineated. Rather than focusing on etiology, you can inform the patient that there is a medication which usually works very well for this condition if they are willing to be pragmatic and try it on a “trial and error” basis. At the end of the day, the patient will usually appreciate the fact that there is a chance to treat and possibly even cure their condition, and if therapy and recovery is emphasized, rather than the etiology, the patient will likely be willing to accept treatment. On the other hand, if they still insist on investigation, the patient can be referred to an infectious disease specialist, entomologist or parasitologist with the reassurance that if these providers cannot help the patient, they are always welcome back for follow up.

As stressed above, it is well known that DOP patients can be reluctant to accept anything that has a psychiatric indication or is linked to mental health in anyway. Luckily, there is one medication, namely pimozide (Orap®), which works very well for the treatment of delusions of parasitosis. Not only is pimozide efficacious, but it is uniquely acceptable to these patients due to...
Figure 1. Trapezoid dosing regimen for pimozide and risperidone

The fact it has no official U.S. Food and Drug Administration (FDA) psychiatric indication: it is only indicated in the U.S. for Tourette’s syndrome, which is a neurological disorder. Therefore, patients who refuse all psychiatric medications are much more willing to try pimozide for this reason.

The dosing strategy resembles a trapezoid (Figure 1). Pimozide is usually started with a very low dose of 0.5 mg to 1 mg per day. Then the dose is increased by no more than 0.5 mg increments every 2-4 weeks until an efficacious dose is achieved. This dose is continued for 3-4 months before any further titrations are made. There is no absolute maximum dose however, most patients show good clinical response by the time the dose of 3 mg per day is reached. Patient usually do not have recurrences if the medication is tapered slowly but if the patient experiences a recurrence, the same trapezoid dosing method can be used to treat these symptoms effectively. Common side effects include sedation or increased energy. If sedation occurs, have the patient take the medication at night. If the patient experiences increased energy from the medication, they should be instructed to take it in the morning. Rare side effects include stiffness and restlessness (akathisia). The same dosing strategy can be used for risperidone, an atypical antipsychotic agent which can also be used to treat DOP.

CONCLUSION

Many dermatology providers may find it challenging seeing a patient with DOP. However, these patients are most often reachable when approached in a deliberate, sympathetic and systematic manner as outlined here. Understanding the rapport-building techniques and guidance on the use of pharmacotherapy presented here, DOP is
often treatable and sometimes even curable. With a certain knowledge base and skill set, these patients could become some of the most grateful seen in your practice.

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