Improving care for delusional infestation patients: What can dermatologists learn from an entomologist?

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Abstract

Delusional Infestation (DI), represents one of the most difficult patient encounters that dermatology practitioners may experience. It is common for DI patients to doctor shop. Thus, dermatologists are one of several disciplines that may encounter DI patients in their practices. Others include veterinarians, epidemiologists, emergency departments, mental health practitioners, and entomologists. In this article, entomologist, Dr. Gale E. Ridge, with extensive DI experience, was interviewed to find out what an entomologist's perspective has been and what we, the dermatology providers, can learn from that. This is followed by a discussion by the dermatology experts on how the experience of entomologists compares to our experience and what we can learn from them.

Keywords: delusional infestation, delusions of parasitosis, entomology, Morgellons disease, psychocutaneous medicine, psychodermatology

Introduction

One of the most difficult patient encounters for a practicing dermatologist to manage are patients with DI [1]. DI manifests as a fixed false belief of being infested with parasites or experiencing foreign material extruding from the skin. It is common for DI patients to doctor shop, migrating from medical practice to medical practice or expert to expert in search of care. It is good to remember that, as a dermatology provider, we are not alone; other experts such as entomologists, veterinarians, parasitologists, and even emergency room physicians also encounter this specific patient population. Dr. Ridge is an entomologist with The Connecticut Agricultural Experiment Station who runs an Insect Information (Diagnostic) Office. She shares with us, in this short article, the experience of dealing with these patients from an entomologist's perspective.

Dr. Ridge not only has decades of experience with DI (and is a nationally recognized expert on bed bugs), but in 2020, for the first time ever in the authors' knowledge, organized a symposium at the annual meeting of the Entomology Society of America in the US, a most complete panel of experts dealing with DI. This symposium included dermatologists, entomologists, parasitologists, veterinarians, emergency physicians, neuroscientists, and psychiatrists. This session turned out to be very fruitful, and the dermatology authors of this paper learned some things not previously known. For example, there is a tragic situation that thousands of pets are euthanized in the US, because the pet owners developed DI and blamed their pets for their condition. This is a truly tragic case of "DI by proxy" directed at a pet. It can also be directed at children and other family members.

The following is a question and answer format with Dr. Ridge answering the most clinically useful questions. This is followed by discussion by the dermatology experts on how the experience of entomologist's compares to our experience and what we can learn.

Furthermore, given that the authors have no objections to the common request to see an entomologist by DI patients, it is almost imperative to learn what happens during these referrals. The goal of this manuscript is to improve care for DI patients and to improve communication between medical providers and other relevant specialists with the ultimate goal of improving patient care in the DI population. Building a good rapport is sometimes the biggest challenge [2].

Methods

The authors had an opportunity to interview Dr. Ridge and asked her to share, for the benefit of the dermatology audience, how entomologists experience the interaction with DI patients including her recommendations on diagnosis and management. Questions were developed from a key opinion leader in the field of psychodermatology and Dr. Ridge was virtually interviewed on June 21, 2021. Her answers were recorded and then reviewed by her and senior authors to improve content and clarity.

Results

Comparing delusional cases versus non-delusional cases, how has your experience and observations been different?

There are obvious differences with healthy well-adjusted patients compared to those who are suffering from DI. The most striking difference is that DI patients are very vocal and often dominate conversation in proving their point usually with a high level of magical thinking. If one redirects their thinking to other subjects and away from the delusion, conversations become normal two-way exchanges with no indications of mental distress.

How are specimens usually presented to you?

Many DI patients often default to the "fact" that they are educated. "I'm smart" is a statement I often hear. With highly invested patients, this often translates it to "I've been all over the internet and I know what I am talking about" and "I'm coming to you to support my belief system." Therein lies the conflicted dichotomy. On the one hand patients want relief, but on the other hand refute anything said to them that might challenge their belief system. Thus, specimen collecting is all over the map and often accompanied by detailed, copious notes. None of it stands up to scientific standards of sample collecting and can range from material picked up by a lint roller to pillowcases stuffed with detritus. High volume of sample collecting is a DI sign.

How does the patient who has submitted the specimen describe their associated skin condition?

Most patients possess a pathological skin picking disorder that is part of their DI symptomology. For many it is subconscious. I have had patients sit in front of me completely denying they "pick" themselves while they are visibly scratching. It is a repetitive compulsive behavior that many seem quite unaware of. Additionally, in some patients, there develops a disconnect. Over time, as they continue to feel attacked by parasites, there is a fundamental shift in thinking in which patients start to view their skin as an object that is not part of themselves. It is a form of dissociation. The more the patient becomes delusional, the higher the chances they may become dissociated from their skin. The skin has "become something else" for them and is almost objectified.

In many DI patients I've seen, pain thresholds appear to be very high, which may suggest an undiagnosed nervous system disorder as part of the DI complex. The level of dermal harm I have seen, can be alarming (**Figure 1**). A great deal of harm can occur at night while patients sleep through involuntary grooming and scratching. Also, it is not uncommon to have patients describe an elevation of their "parasite" activity late in the day, which indicates a temporal component. This in large part is because patients are becoming tired at the end of the day and their threshold for what they can mentally tolerate has diminished.

How does a patient respond when told that you do not believe they are suffering from a parasite?

DI care requires and responds to one very important element, "time." Before coming to me, if a patient invested time, energy, and money e.g. multiple

resources in the belief of being infested for longer than 6 months, the brain seems to become hardwired to a way of thinking that is very difficult to redirect. The combination of predisposition, confirmation bias, and sunk cost fallacy renders a curable situation almost impossible. A patient who may have had negative experiences with insects in the past has a lower level of tolerance even before the onset of DI. Thus, a direct negative result, even if it is true, will be received as unacceptable. The patient will either dismiss me as manipulated by any other person who was involved in the case or as an imbecile who does not understand them. The patient may respond with pure fury and storm out.
To me, these patients seem addicted to their beliefs and respond as addicts would. The work done by Alcoholics Anonymous bears this out. If I can spend a great deal of time with these patients and win their trust, then often something can be done to help them. With patients presenting with symptoms for less than 6 months, it is far easier to redirect them to appropriate help and usually there is an understanding doctor who can collaborate with the care. This is because many of these patients often have undiagnosed underlying medical conditions and misunderstood symptoms expressed by their skin. They have a symptom, not an infestation, that takes on a delusional aspect if they are allowed to languish. The greater than 6-month cases have often completely alienated their doctors, are casualties of medical failure and oversight, and totally lack trust towards the medical profession. I am often the end of the road for them.

Figure 1. *An example of skin picking behavior manifested by a DI patient.*

As an entomologist, are there any other notable observations you have regarding DI patients which might be of interest or value to practicing dermatologists?

DI patients are fragile in the sense of suffering and are often high functioning. Some are perfectly capable of lying, bending the truth, and manipulating. When working with a suspected DI patient, I have learned to use more than one sense. These include watching body language, listening for ironic laughter, facial expressions that might give away a person's true thoughts, and rehearsed descriptions, indicating I am not the first professional they have seen. Patients have likely been migrating from professional to professional in several disciplines.

I also watch for a readiness to show dermal lesions, magical thinking over implausible pathogen biology such as "one minute they are coming out of the water, the next they're burrowing through the furniture." I listen for telltale language use. The word "they" is very common, as well as repeated short phrases such as "black specs," "white stuff," "they fly through the air," "attacking me," and "biting me".

Some of the red flags I look for are as follows;

Body tension. DI patients are usually very tense.

Overuse of certain words such as "they" and "biting."

Excoriations, particularly on areas of the body that can be easily reached. Injuries on the back are often crescent shape and linear.

Skin injuries are usually circular caused by the fingernails (**Figure 1**).

Usually there's a voluntary quick denial of psychological illness early in an initial interview.

Implausible biology and behavior of perceived parasites.

Confusion or switching parasite behavior descriptions if challenged.

Repeated short phrases such as "they're biting me; I'm being bitten" etc.

Supporting of beliefs using others e. g., folie a deux to push back against challenges.

Verbose and often well-rehearsed narratives.

Patient is either not inclined to volunteer information on medications or drug use or is overly generous with a high level of detail. Often many patients have multiple medical prescriptions, some of which have side effects that can trigger DI, which can, in part, be a consequence of doctor shopping (see No. 22), and/or uncoordinated care.

Admission of self-medication using over the counter drugs.

Severe cases lack eye contact and often look down.

When the topic of the discussion is changed, conversations become a normal two-way exchange.

When focused on the DI, conversations are patient driven and can be patient dominated. It is not unusual to listen to patient explanations for up to half an hour without speaking. Active listening is important. It garners trust and often provides vital information.

The doctor experiencing "the stranger effect" in which patients share too many confidential facts. The patient may be more hesitant to speak with close family members or friends regarding their issues and thus view the doctor/provider as a "stranger" and therefore may feel more comfortable when sharing their story.

Sample sign: a high volume of samples and pictures.

The patient is listening but not hearing.

Paranoia. The sense of being attacked is a common theme.

Increased age and isolation are common. Patients are generally older than 35 years. Highly traumatized patients, those with psychiatric disorders, or drug abusers may present younger.

High use of internet surfing where program algorithms feed patient's information based on their search words. This eventually creates an alternative reality for the patients.

Doctor shopping. In the United States patients often find themselves on their own migrating from medical discipline to medical discipline. In Europe DI patients work with assigned doctors.

As a doctor, one needs to be compassionate, patient, and provide a great deal of time. Time is part of the process of healing. As a professional be aware of anchoring and commission biases. Keep an open mind and avoid "zebra retreat" which is retreating from making a rare diagnosis despite supporting evidence. This is especially important if patients have travelled to a tropical region of the world or have a history of eating raw food. Be absolutely fluent with the biology, behavior, and distribution (range) of dermal parasites and pathogens in your area of the world where you work or consult a someone who possess this knowledge. This is to guard against being misled by often plausible sounding but magical biologies described by patients. Most DI cases are horses (not zebras) but keep an open mind for a "zebra" case where a patient can be ill from a real parasite. It is extremely important to perform a full history of present illness and ask about travel and exposure history. If the dermatologist is not comfortable with endemic infectious disease or micro-organisms and suspects a true infestation, the provider should consider referral to an infectious disease specialist or a parasitologist. One method to improve care is to have a checklist. It is impossible to remember everything and so a checklist is a useful tool with DI patients to secure information that might be overlooked. The checklist might include a list of arthropods endemic to a region where a doctor works, patient travel history, legal and illegal drug use history, and names of family members and

friends with contact information. This method is used in surgery, by pilots and aviation manufacturers, software engineers, and even professional divers to guard against errors when dealing with long complex processes.

Patients are under a great deal of stress and are often "in the heat of battle" when they seek help. Thus, stress and depression are common. It is wise to have a knowledgeable second staff member present, because patients might behave erratically (including being aggressive) and having two professionals present telegraphs your seriousness and concern about the patient's care. It also breaks up the intensity of an encounter. In addition, the presence of a colleague provides the opportunity for the doctor to leave the interview space and take a break while not leaving the patient alone. Additionally, it is helpful to have support staff such as office managers or phone receptionists trained to identify signal language that could indicate a DI patient might be approaching a practice for help. Any casual negative exchanges among support staff which might be overheard should be discouraged. A number of my DI patients have reported this to me and this damages the rapport that is so delicate and may take so long to build.

Discussion

Dr. Gale Ridge's experience is similar to a dermatologist's experience in many ways, but also notably different. It is interesting that she has noticed that many DI patients come across mentally rigid and domineering when communicating their delusional ideation [3]. However, she noticed, when the topic is switched to the topic of anything other than parasites, the conversation immediately becomes normal.

Delusional infestation is a unique type of psychosis and psychiatrists use the term "encapsulated delusion" to refer to this phenomenon [4]. This means that patient is delusional in a very specific way, while the rest of the mental function is essentially intact. This is quite different than many common, chronic psychiatric illnesses, such as schizophrenia, in which there is a more global deficit [5]. For example, a typical schizophrenic patient not only experiences delusions, they also lose social skills, have flat or inappropriate affect, and may even have visual or auditory hallucinations.

Furthermore, Dr. Ridge's observation that DI patients may be psychologically reachable and therefore, more amenable to help, if their DI has the duration of less than six months whereas those with a more than six months' duration of illness become more delusional and unreachable is compatible with the authors' experience. The authors' have experienced that many patients with DI become more rigidly delusional the longer they are suffering from delusions and not being treated with antipsychotic medication.

Dr. Ridge made some comments that were considered novel amongst dermatology providers treating these patients. Specifically, it was not widely known that people who bring in extra-large samples are more than likely to be DI patients. Also, her observation that DI patients appear to have a very high pain threshold, which may allow these patients to seriously ulcerate their own skin, is a new observation. Her reporting that the DI activity may have temporal preference for late afternoon or evening is compatible with dermatological observation that many disagreeable skin sensations tend to be more intolerable at night possibly because patients are less distracted by other activities or possibly also because skin sensations may have diurnal variation in the threshold of perception.

Lastly, in terms of management, the authors felt that her recommendations to have an additional staff member present whenever a DI patient is being interviewed or examined is a useful suggestion for the medical community. It is taxing for many dermatology providers to talk to these patients. Therefore, having two providers present gives each of them an opportunity to "take a break" psychologically and is beneficial. Moreover, because of the possibility that the patient may become emotionally attached to the provider (referred to as the "Stranger Effect"), it is a good to have more than one provider present to make the interaction more

comfortable. Two providers are also beneficial from a medico legal perspective.

Also, Dr. Ridge gave some perspective with regards to the difference between the medical system in Europe as opposed to the USA in how it impacts the care of DI patients. Most specifically, "doctor shopping" where the DI patients typically goes from one specialist to another is not likely to happen in Europe, because DI patients are assigned a primary care physician who organizes the care, including referral to specialists. "Doctor shopping" and the resulting fragmentation of care can make optimal management of DI patients more difficult. Therefore, even though the USA has a completely different and somewhat more fragmented medical system, it may be to the benefit of the patients if one provider, such as the primary care physician, takes charge and helps organize the care for this condition.

Conclusion

The authors hope that this interview with a prominent entomologist, Dr. Gale Ridge, will educate and help dermatology providers interact with and treat patients suffering from DI.

Potential conflicts of interest

The authors declare no conflicts of interest.

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