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WORKING GROUPS INSTILL CONFIDENCE IN ASSISTING SUSPECTED DELUSIONAL INFESTATION INDIVIDUALS

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Abstract Collaborators across the US southern region trained nonhealthcare professionals to guide individuals with suspected delusional infestation (DI) to healthcare providers. Delusional infestation is a false belief that arthropods, other parasites, or items are infesting a person, home, vehicle or other environment, regardless of lacking evidence. Based on the success and template of a Tennessee DI working group, the Southern Region Delusional Infestation Working Group, comprised of 35 professionals from 12 of 13 US southern states, created publications (*Unknown Skin Irritations: A General Guide*, *Extension Agent Protocol for Unknown Skin Irritations and Suspected DI Cases*, and *A Guide to Arthropods Associated with Delusional Infestations*) and delivered presentations on DI. At least 29 DI presentations with before and after training evaluations have been given in 10 states to more than 688 Extension agents, pest management professionals, entomologists, or other professionals. Substantial increases in knowledge, skills and abilities were recorded from participants. Post-training test responses indicated that 90% of participants understood or fully understood the condition of delusional infestation and their responsibility in assisting those suspected of having this condition, which was an increase of 37% compared to pre-training responses. The most significant impact of these trainings is that 82% are extremely confident or confident that they can safely assist individuals with delusional infestation, representing a 44% increase in their confidence after training. Our next step is to create networks between these nonhealthcare professionals and the medical community to encourage individuals to seek medical care to resolve their condition.

Key words Delusory parasitosis, delusional parasitosis, Ekbom syndrome, training, nonhealthcare professionals

INTRODUCTION

Previously referred to as delusional parasitosis (DP), among other terms, delusional infestation (DI) occurs when individuals "hold a fixed belief that they are infected with organisms such as unicellular parasites, bacteria, viruses and worms; or infested with insects; or infiltrated by organic and nonorganic fibres, threads, 'stealth viruses' or other forms of inanimate particles known or unknown by medical science" (Bewley et al. 2010). Individuals with this condition often approach professionals who have entomological expertise (Extension agents, pest management professionals, and entomologists at universities and government agencies) to identify the insects and other parasites they assume are on or have invaded their body. DI was considered rare, but the rarity is now questioned (Freudenmann and Lepping 2009). Nearly three-quarters of Tennessee Extension agents and pest management professionals responding to an online survey indicated that in the past year, they had worked with a potential DI individual (Peña et al. 2023). These nonmedical professionals spend more time and have more interactions with suspect DI individuals than with inquiries of a general nature. They become frustrated

because of the time spent on DI situations, and the lack of training and other resources needed to guide these DI individuals to a healthcare provider. Two working groups formed in succession created the needed resources identified in the survey. The University of Tennessee One Health Initiative Delusional Parasitosis Working Group (UT OHI DP WG), composed of 28 (entomologists, pest management professionals, Extension agents, veterinarians, a psychiatrist and a psychologist), created three publications: (1) *Unknown Skin Irritations, (2) A Checklist of Potential Causes of Itchy Tingly or Irritated Skin Suspected as Caused by Arthropods, and (3) Extension Agents' Protocol for Working with Unknown Skin Irritations or Suspected Delusional Infestation Situations.* We leveraged the success of the UT OHI DP WG to obtain funding from the Southern IPM Center to use the UT approach as a model for the US southern region. The Southern Region Delusional Infestation Working Group (SRDIWG), composed of 35 similar professionals from 12 states, modified the UT publications and created three publications: *Unknown Skin Irritations: A General Guide, Guide to Arthropods Associated with Delusional Infestations,* and *Extension Agent Protocol for Unknown Skin Irritations.* A summary of each product and the differences between each working group's publications can be found in Table 1. The SRDIWG took extra steps to create and deliver a presentation. In this paper we document the change in knowledge and intended practice resulting from the delusional infestation training.

Table 1. Materials developed by working groups to address delusional infestation.

Material	***Title of*** **and uniqueness of materials produced by the University of Tennessee One Health Initiative Delusional Parasitosis Working Group (UT OHI DP WG)**	***Title of*** **and uniqueness of materials produced by the Southern Region Delusional Infestation Working Group (SRDIWG)**
Factsheet on DI	*Unknown Skin Irritations.* Discusses arthropod causes of skin irritation, the need to identify a pest before applying pesticides, the danger of misapplying pesticides, environmental and medical causes of skin irritation, the signs and symptoms of DI, physiological causes of DI, and action to take	*Unknown Skin Irritations: A General Guide.* Combines and simplifies the UT publications (1) *Unknown Skin Irritations* and *(2) A Checklist of Potential Causes of Itchy Tingly or Irritated Skin Suspected As Caused By Arthropods.*
Checklist for Unknown Skin Irritations	*A Checklist of Potential Causes of Itchy, Tingly or Irritated Skin Suspected As Caused By Arthropods.*	

	Contains three checklists – 1. Checklist of arthropods for use by Extension agents or entomologists. Checklists 2 (environmental factors) and 3 (medical causes) are for use in consultation with a healthcare provider.	
A Guide to Arthropods Associated with DI		*Guide to Arthropods Associated with* *Delusional Infestations.* 36 pages of written descriptions and color photos of arthropods associated with samples from individuals suspected of experiencing delusional infestation.
Protocols for Extension Professionals	*Extension Agents' Protocol for Working With Unknown Skin Irritations or Suspected* *Delusional Infestation Situations.*	*Extension Agent Protocol* *for Unknown Skin Irritations.*
Handbook		*Manual for Extension Agents Working with Suspected Delusional Infestation (DI).* Includes all of the materials developed by the two working groups and a chapter on DI treatment. In prep.
PowerPoint Presentation for Extension Agents and Pest Management Professionals		*How to Respond to Delusional Infestation Individuals.* We provided a slide presentation and allowed the presenter to tailor it to their audience.

MATERIALS AND METHODS

Presentations The SRDIWG presentation was based on the working group's publications. Each presenter was allowed to modify the presentation for their state and audience (Extension agent vs. pest management professional) and was required to cover the information in the before and after training evaluations (Table 2). As of 26 January 2025, 29 presentations with before and after training evaluations were given to at least 688 individuals in 10 states.

Data analysis Pearson chi-squared tests compared the before and after training responses (IBM SPSS Statistics 2021).

Table 2. Questions and possible responses to before and after delusional infestation training evaluations.

1. Indicate the best description of your occupation
Agricultural Extension Agent, Family and Consumer Science Extension Agent, 4H Extension Agent, Pest Management Professional, Other

2. How many years have you been in this or a similar position?
1 year, 2 – 5 years, 6 – 10 years, 10 – 20 years, >20 years

3. In what state are you attending this training?
Alabama, Arkansas, Florida, Georgia, Kentucky, Louisiana, Mississippi, North Carolina, South Carolina, Tennessee, Texas, Virginia

4. I _____ the condition of Delusional Infestation and my responsibility as an Extension agent or pest management professional in assisting those suspected as having this condition.
Fully understand, understand, somewhat understand, don't understand at all, am unaware of

5. Delusional infestation is also referred to as
Delusory parasitosis, Delusional parasitosis, Ekbom syndrome, All of the above

6. Delusional infestation is a neuropsychiatric condition that results in the mistaken belief without medical or entomological evidence that a person, pet, or property is infested with insects, mites, parasites, or other irritants.
True, False, Don't know

7. When no arthropods are found in the sample submission for an unknown skin irritation, agents/PMPs should tell the client they have delusional infestation.
True, False, Don't know

8. How confident are you that you can safely assist individuals with delusional infestation?
Extremely confident, Somewhat confident, Neutral, Somewhat not confident, Extremely not confident

9. What would you recommend to improve this training?

RESULTS AND DISCUSSION

Working with a suspected delusional infestation individual can be trying for an experienced professional but can be overwhelming for newcomers. Many nonhealthcare professionals attending our DI training were reasonably new to their field; 39% had 5 years or less experience, so the training was extremely timely.

After training, 89.5% of attendees indicated they understood or fully understood the condition of DI and their responsibility as an Extension agent or pest management professional in assisting those suspected of having this condition, which was a 37% increase from before their training and a significant change ($\chi2= 194.8$; df=1; $Pr < 0.001$). We collapsed categories by combining *fully understand* with *understand* and then combining *somewhat understand*, *don't understand at all* and *unaware of*, and compared the two groups. By the conclusion of the training, 99.6% of attendees indicated correctly that *Delusional Infestation is a neuropsychiatric condition that results in the mistaken belief without medical or entomological evidence that a person, pet, or property is infested with insects, mites, parasites, or other irritants*. This was an 8.6% increase from before training ($\chi2= 47.1$; df=2; $Pr < 0.001$).

We told the attendees about how their behaviors and actions could affect the success of referring someone to a healthcare provider. We explicitly stated several times that attendees should NOT tell the individual they had DI because they lacked healthcare credentials. Also, doing so could diminish the rapport they had worked hard to establish. Meeting participants were asked to be sensitive, understanding, and respectful when working with these individuals. Suspected DI individuals should be educated on the inappropriate use of pesticides and other chemicals and that pesticides should not be applied without identifying a pest. Attendees were advised to be careful that their actions did not reinforce the delusion. For instance, pest management professionals were warned to refrain from making placebo treatments because the client would assume that pests were present, and specimen submission should be accepted once, maybe twice, but no further; otherwise, the individual could assume pests were present. On the other hand, they were also cautioned not to jump to conclusions and were given an example of how this had nearly occurred.

After training, only 85% of the attendees responded FALSE to the statement, *When no arthropods are found in the sample submission for an unknown skin irritation, agents/PMPs should tell the client they have a delusional infestation.* While this was nearly a 15% increase from before training and a significant change ($\chi2= 63.8$; df=2; $Pr < 0.001$), we were perplexed it wasn't higher. A closer examination of the data revealed that nearly the same percentage of attendees had chosen TRUE for this response before (11.6%) and after (11.5%) training, indicating attitudes are sometimes difficult to change.

The most crucial impact we had on the audiences was increasing their confidence level. We collapsed the confident categories from five (Table 2) to two by combining extremely confident and somewhat confident (=confident) and then combining neutral, somewhat not confident and extremely not confident (=not confident). After training, 82.4% of attendees were confident they could safely assist individuals with a delusional infestation, a 44% increase from before training ($\chi2= 245.0$; df=1; $Pr < 0.001$).

CONCLUSIONS

We report the success of two working groups to increase the understanding of the neuropsychiatric condition of delusional infestation. The trained nonhealthcare professionals now have a step-by-step process for working with these individuals, can distribute materials to

increase knowledge of the possible causes of unknown skin irritations to these individuals and are confident in their ability to work with them safely. The next steps will be to create a local network between identifiers of potential arthropods (entomologists, Extension agents, and pest management professionals) and the medical community (primary care providers, dermatologists, psychiatrists and psychologists) which, we believe, is necessary to assist suspected DI individuals to remission. The model for creating this local US network will be shared to increase adoption throughout the region.

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