

# The Social Stigma Associated with Head Lice and Its Negative Impact on Mental Health

Brought to you by CIPHER Pharmaceuticals with contributions from Dr. Shirley Gordon, PhD, RN, NBCSN, AHN-BC

## Overview

Head lice infestation is a very common issue among children but is associated with significant undue social stigma from family, community, and school systems.<sup>1,2</sup> For a condition that poses no harm to the child, few words induce as much fear as the word “lice”. Lice do bite and break the skin to feed on blood. They do not cause infection—most common side effect associated with lice is the itching they cause from bites.<sup>3</sup> Scratching associated with head lice can lead to more serious medical issues, including open lesions and secondary infections. Head lice can be problematic in some due to resistance or persistence, but they are associated with no significant morbidity. In fact, evidence shows that the stigmatization due to lice causes far more long-standing damage to the child and their family than lice do.<sup>4</sup>

## Characterizing the Stigma

Stigmatizing characteristics include being identified or labeled as having head lice (the individual feels the stigmas associated with head lice long after successful treatment); presence of live lice or nits; and observable scratching.<sup>1</sup> It has been reported that a link exists between head scratching and social injuries, which

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include shunning, teasing, bullying, physical and social isolation, and forced school absences.

Isolation of a child with head lice is completely unnecessary. As infestations are primarily spread through direct head-to-head contact, responses that include isolation perpetuate social stigmas associated with the condition and can exacerbate the impact on mental health issues.<sup>1</sup>

## **Fear and Shame**

Parents often experience frustration due to time consuming treatment, cleaning, and the cost associated with treatment.<sup>5,6</sup> Once a family member is identified, the American Academy of Pediatrics (AAP) recommends that all household members be checked, all bedding be washed, and hair care items that may have been in contact with anyone who was found to have head lice also be washed.<sup>5</sup>

In addition to a parent’s own fears and concerns about their child’s head lice, other adults may stigmatize the child by isolating the child during lunchtime or disinviting them to playdates and parties, making them feel dirty due to the fear of transmission of head lice to other children. As mentioned previously, head-to-head contact is usually the cause of transmission. Indirect contact through personal belongings, such as combs, brushes, or hats is highly unlikely.<sup>11</sup>

## **Ostracization**

A parent’s fear of their child being ostracized may make them hide the condition from others, which can make it harder to get under control.<sup>1</sup> This type of action can be perpetuated by other members of the family and may include siblings who may fear being teased by the community where parents are left out of social situations and the family is labeled as that “lice family.”

In addition to fear of transmission, people can unknowingly demonstrate behavioral immune system-based responses to lice infestations.<sup>7</sup> Behavioral defenses include psychological responses to cues of infectious pathogens, including behavioral-avoidance. A person detects the presence of pathogens/parasites and engages in behaviors to prevent contact. For example, cues such as a rash or scratching may elicit feelings of disgust and lead to avoidance. Disgust directed toward a person with head lice can be brought on by mass screening for lice in schools, forced absences due to

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head lice, and “no-nit” policies.<sup>8</sup>

These school policies add to the stigma associated with head lice. Many schools still have “no-nit” policies despite the fact that most cases of head lice are acquired outside of the school environment (predominately the home), and to date, no scientific literature exists to support the exclusion of children from school due to head lice infestation. To the contrary, “no-nit” policies increase absenteeism and social stigmas.<sup>1</sup> Only 1 in 10 cases are transmitted in school.<sup>9</sup> Transmission requires active infestation; nits alone do not pose a major risk for transmission. In 2015, the AAP continued to recommend that otherwise healthy children should not be restricted from attending school because of head lice or their nits. In addition, they encourage pediatricians to educate schools and communities that “no-nit” policies are unjust and should be abandoned.<sup>5</sup> Additionally, the National Association of School Nurses (NASN) has also stated evidence-based data support abandoning “no-nit” policies and support allowing students to participate in school sponsored activities when live lice or nits are found.<sup>8</sup>

## The Problem with Misdiagnosis

Misdiagnosis of head lice infestation is common.<sup>10</sup> An active lice infestation is defined as the presence of at least one live louse or nymph on the head and the presence of viable nits. Lice are small and often move away from the light, so diagnosis is often based on the finding of nits attached firmly within ¼ inch of the base of hair shafts.<sup>11</sup> Nits located more than a ¼ inch from the base of the hair shaft, are not considered an infestation. While this may suggest an infestation, it does not confirm it. Use of a fine-tooth lice comb may help proper identification as well as the use of a magnifying glass.<sup>11</sup>

Forms of misdiagnosis include false positives (e.g., nonviable nits, pseudo-nits, hair debris, sand, or persistent itching); false negatives (e.g., asymptomatic cases or ineffective screening); and differential diagnosis (e.g., contact dermatitis, insect bites, or psoriasis).<sup>12-14</sup>

In 2000, researchers at the Laboratory of Public Health Entomology at the Harvard School of Public Health found that healthcare workers, parents, and school officials often misdiagnose, and therefore, inappropriately treat students

head lice.<sup>10</sup> In 555 presumed head lice samples, only 57.5% were correctly identified.

## Impact on Mental Health

Caregiver strain is a basic social psychological problem associated with the caring for a child with lice and is a perceived stress that endures while caring for children with persistent lice infestations.<sup>1</sup> Parents/caregivers experienced stress from the moment their children were diagnosed with head lice, throughout treatment, and long after the head lice infestation had ended. Parents also reported a significant amount of stress associated with observing their child scratching. Parents reported anxiety, fear, desperation, helplessness, anger, and disgust. This stress can lead to hypervigilance and development of an itch-treatment cycle.<sup>1</sup>

Research on prevalence of persistent infestations among US children is limited. It is not known what proportion of children with head lice experience persistent infestation. Persistence is defined as diagnosis of live lice 3 times in 6 weeks that is not susceptible to treatment.<sup>1</sup> As persistence continues, the stigma associated with head lice increases. Additionally, children with persistent head lice face other challenges—education issues due to excessive absences (11 to 37 days); the potential for physical harm due to repeated use, overuse, and misuse of pediculicides; and emotional issues due to the stigma associated with head lice, the fear of transmission, and social isolation.<sup>1</sup>

## Proactive Interventions

Studies have demonstrated that mass screenings in schools for nits have little impact on the incidence of head lice in schools and that they are not cost effective.<sup>5,8</sup> The distribution of “head lice outbreak” letters increases social stigma, embarrassment, and anxiety; puts student’s confidentiality at risk; and encourages the use of prophylactic treatments. The NASN instead suggests that school nurses have an opportunity to implement evidence-based strategies and provide health education to parents and the broader school community. They advocate for a school policy for lice that is more caring and less exclusionary, and help develop intervention strategies that are more student-centered. For example, obtain a complete treatment history and contact tracing by tracking treatment and transmission control methods used, and encouraging the screening of

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all family members and close contacts. Students should be encouraged to maintain social contacts to prevent the feelings of isolation.<sup>2,7</sup>

There is also the opportunity to encourage regular home screening for head lice.<sup>8</sup> We can educate on proper screening techniques and the transmission of head lice in order to decrease the behavioral immune system responses. Strategies can be developed to help reduce caregiver strain and stigmas. These include increasing the understanding of the effects of persistent head lice on the entire family; validating a parent's personal struggle; respectfully offering information on treatment options; supporting treatment attempts, thus shifting the association between head lice and blame to head lice and support; and leveraging communication that continually refers to head lice as a family matter to resolve together, versus individual child phenomena that must be overcome.<sup>1</sup>

### Multifaceted Strategy Needed

Development of evidence-based health policies, including proper identification, treatments and supportive community interaction, will clearly promote a healthy school and home environment and begin the process of dismantling the social stigmas that continue to be associated with head lice. More educational programs directed at parents, but also further education of school nurses and administrators is critical to having all audiences with equal understanding regarding the condition. An empathic-based approach aimed at dismantling stigmas has demonstrated positive results in pilot programs, but the need is now for broader reach in all communities, and enduring activities, if we are to succeed at finally breaking the stigmas of head lice.<sup>1</sup>

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