

The Impact of Head Lice Related Stigma



Shirley C. Gordon, PhD, RN, NCSN, BC-AHN

Professor and Assistant Dean Graduate Practice Programs

Director, Head Lice Treatment and Prevention Project

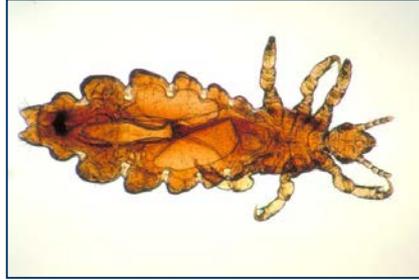
Florida Atlantic University

Christine E. Lynn College of Nursing



Dedicated to Caring: advancing the science, practicing the art, studying its meaning and living it day-to-day.

Today's Objectives



- ❖ Explore the impact of head lice related stigma on students, families, schools and communities.
- ❖ Identify strategies to reduce head lice related stigma

Head Lice Exemplar

- ❖ Carol, a young mother with 3 girls ages 2, 3 and 6 years old arrived at a head lice treatment facility after her daughter Sophie (age 6) was sent home again from school for an active head lice infestation.
- ❖ Carol appears anxious and states *“I am so upset! I have tried everything on the shelf and no matter what I do the lice keep coming back. I told Sophie to keep away from other children. Sophie has missed 4 days of school this week and she was not invited to her best friends slumber party! “*
- ❖ Sophie is turned away from her mother. Her eyes fill with tears as she looks up at the facility staff.

Social Stigma^{1,2}

❖ Primary

- Stigma faced by persons with an undesirable characteristic or health condition
- “Spoiled social identity”

❖ Courtesy

- Stigma faced by unaffected persons due to association with a person who bears a stigma
- May impact entire family

Understanding Stigma

- ❖ Major concern: **Fear of Head Lice Transmission**
- ❖ Under what conditions are head lice transmitted?
- ❖ What methods are currently used to avoid head lice transmission?
- ❖ What is the impact of head lice and control methods on school systems, children, families and communities?

Fear of Transmission: Role of Disgust¹⁻²

- ❖ Transmission occurs: child: child, child: adult, adult: adult
- ❖ Disgust: Emotional response
 - Drives Transmission Fear
 - Part of a behavioral immune system¹
 - Detect presence of pathogens/parasites and engage in behaviors to prevent contact
- ❖ Elicits contamination-avoidance mechanism³
 - Useful in explaining school based policies and social reactions

¹ Schaller, M; Park, J.H. (2011). “ The behavioral immune System (and why it matters)”. Current Direction in Psychological Science 20 (2) :99-103.

² Jesse Bering (2013) That’s Disgusting. Scientific America October 17, 2013

Behavioral Immune System¹

- ❖ Disgust directed outward → toward those responsible ¹
 - Identifying and avoiding persons with head lice
 - School based screening
 - Forced school absences
 - No nit policies
 - Shaming , bullying, teasing
- ❖ Interventions which target pathogen transmission or beliefs about transmission can interrupt behavioral responses ¹



¹ Schaller, M; Park, J.H. (2011). “ The behavioral immune System (and why it matters)”. Current Direction in Psychological Science **20** (2) :99-103.

Under What Conditions are Head Transmitted?

- ❖ Only 1 in 10 transmissions occur at school¹
- ❖ Common outbreak times
 - Start of the school year
 - After winter vacation
 - After spring break
- ❖ Whenever children are in the community for extended periods of time

-
- ❖ **Active infestations are necessary for transmission to occur**
 - ❖ **Eggs/nits alone do not present a major transmission risk**

Definition and Diagnosis of Active Head Lice Infestation

- ❖ Presence of at least 1 live louse or nymph on the head¹ or presence of live lice, viable nits^{1,2}
- ❖ Entire head must be examined
- ❖ Lice move fast and avoid light¹
- ❖ Blend in with hair and skin
- ❖ Prefer warm moist locations¹
 - Nape of neck, behind ears
 - Crown of the head
- ❖ Misdiagnosis is common¹



Types of Misdiagnosis¹⁻³

False positives

- ❖ Pseudo-nits
- ❖ Nonviable nits
- ❖ Hair debris
- ❖ Sand
- ❖ Persistent itching

False negatives

- ❖ Asymptomatic cases
- ❖ Ineffective screening methods
 - Inexperienced screeners

Differential diagnosis

- ❖ Contact or seborrheic dermatitis
- ❖ Insect bites
- ❖ Psoriasis
- ❖ Piedra

References: 1. AAP. Pediculosis capitis (head lice). In: *Red Book*. Pickering LK, ed. 29th ed. Elk Grove Village, IL, AAP, 2012, 543-546.
2. Meinking T, et al. Infestations. In: Schachner LA, Hansen RC, eds. *Pediatric Dermatology*. 4th ed. Mosby Elsevier;2011:1535-1583.
3. Lice (pediculosis). In: Paller AS, Mancini AJ, eds. *Hurwitz Clinical Pediatric Dermatology*. 4th ed. New York, Elsevier Saunders, 2011:424-427.

Typical Transmission Control Measures

- ❖ Isolation of children with head lice in school setting and within families and communities
- ❖ No nit policies
 - Forced school absences
 - “Dear Parent” letters
- ❖ School based head lice screening programs
 - Individual child
 - Classrooms
 - Whole schools
- ❖ Parental education

Persistent Cases of Head Lice

- ❖ Persistent cases of head lice create a transmission challenge.
- ❖ Caregivers treat approximately 5 times before seeking assistance

Persistent Head Lice Infestations¹

- ❖ Of the children who develop head lice, only a small number will develop persistent infestations
 - 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. Its prevalence likely varies across geographic areas and population groups
- ❖ Persistence is defined as **diagnosis of live lice 3x in 6 weeks— not susceptible to treatment**
- ❖ As persistence increases – stigma increases
- ❖ Children with persistent head lice may be placed at risk:
 - **Educationally**, due to excessive absences from school (11–37 days)
 - **Physically**, from over use and misuse of chemical products
 - **Emotionally**, from stigma, fear of transmission, and social isolation

Causes of Persistent Cases¹⁻²

- ❖ 1. Failure to treat
 - Misdiagnosis
 - Caregiver neglect and/or limited access treatments
- ❖ 2. Treatment failure:
 - Failure to follow manufacturers' instructions, not using enough product, or not leaving product on long enough
 - Resistant head lice (the actual prevalence of resistance is unknown and can be regional)
 - Auto-re-infestation by not completely killing and/or removing viable eggs
- ❖ 3. Re-infestation resulting from contact with persons with active infestations
 - Family members - Community members – Schools -Camps

Grounded Theory Study of Families Experiencing Persistent Head Lice¹

- ❖ Problem: Caregiver Strain
 - Parents experienced stress from the moment their child was diagnosed with head lice, throughout treatment attempts, and long after the infestation had ended
- ❖ Caregiver Strain denotes the enduring nature of the perceived stress of caring for children with persistent head lice
- ❖ Stress associated with caring for children with persistent head lice was as persistent as the lice

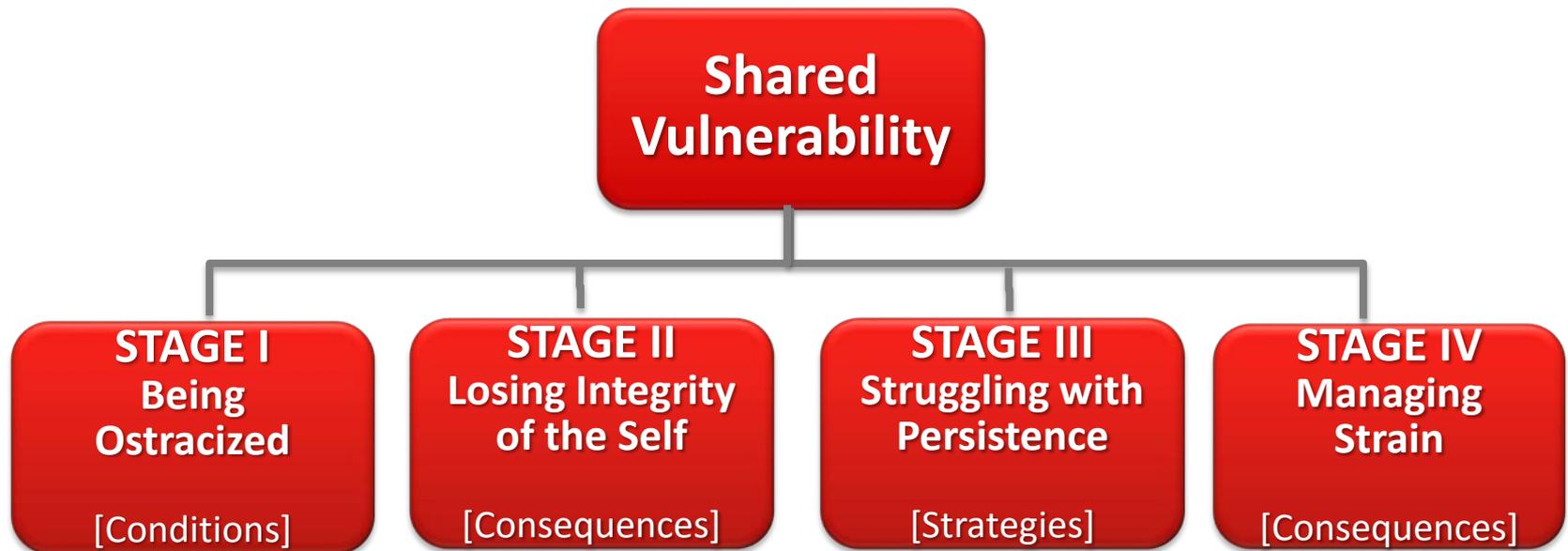
“You can’t imagine how stressful this is– it takes over your whole life!”

Characteristics of Children Affected¹

- ❖ Number of children in the home
 - Range of 1–6
 - Median of 3 children
- ❖ 50% receiving free/reduced lunch
- ❖ “Forced absences” from school for lice
 - Range of 0–37 days
 - Mean of 11 days
- ❖ 65% spent time in more than 1 home
- ❖ 30% of children slept in bed with others
 - Number of persons in a bed
 - Range of 2–4 persons
 - Median of 3 persons

Process of Shared Vulnerability¹

- ❖ Participants described suffering the same openness to injury as their child with persistent head lice
- ❖ They were also susceptible to becoming infested with head lice themselves



Caregiver Response to Stigma

- ❖ Participants had a tendency to exaggerate the seriousness of head lice and negatively evaluate their ability to successfully treat the infestation.
- ❖ *“Head lice is a dirty, nasty disease. I mean is there anything worse, more disgusting?”*
- ❖ *“I’ve been trying to get rid of these things for 4 years! No matter what – they keep coming back. You start to believe you will never win.”*
- ❖ An exaggerated negative mental mindset resulted in higher levels of perceived caregiver strain and increased vigilance

Stigmatizing Characteristics

- ❖ Being identified (labeled) as having head lice
 - ❖ Individual child and entire families
 - ❖ Feelings of stigma associated with head lice persisted long after successful treatment¹
- ❖ Presence of live lice
- ❖ Presence of nits (viable and nonviable)
- ❖ Observable scratching

Itching is the Hallmark Symptom of Head Lice Infestation

- ❖ Scratching/itching can lead to open lesions and secondary bacterial infection¹
- ❖ Some treatments may irritate and cause an itching or burning sensation on the scalp²



Gordon SC. Dermatology Nursing, 2010;22(4):18-20

Caregiver Response to Observable Scratching

- ❖ Itching → observable scratching is a stigmatizing attribute
- ❖ Participants reported a link between head scratching and social injuries:
 - Shunning, teasing , bullying, physical & social isolation, forced school absences,
- ❖ Some participants kept children home until all itching resolved
 - Average missed school days 11
 - Range 37 days

❖ Parents reported a significant stress response when observing their child scratching . Including feelings of:

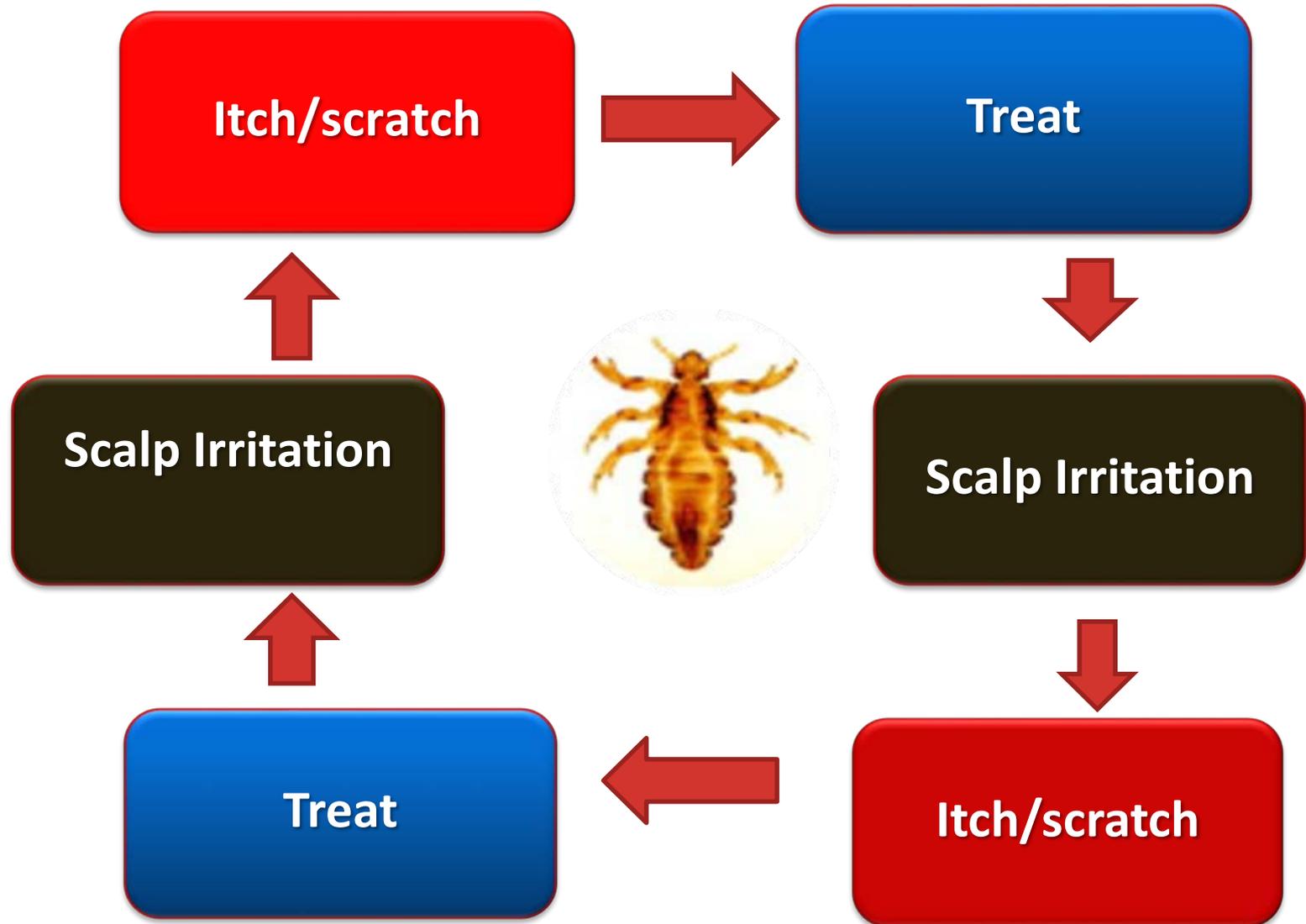
- Anxiety Fear Desperation
- Helplessness Anger Disgust



❖ Caregiver stress response leads to:

- 1. Hyper- vigilance for visible signs of itching**
- 2. Development of an itch-treatment cycle**

Itch – Treatment - Cycle

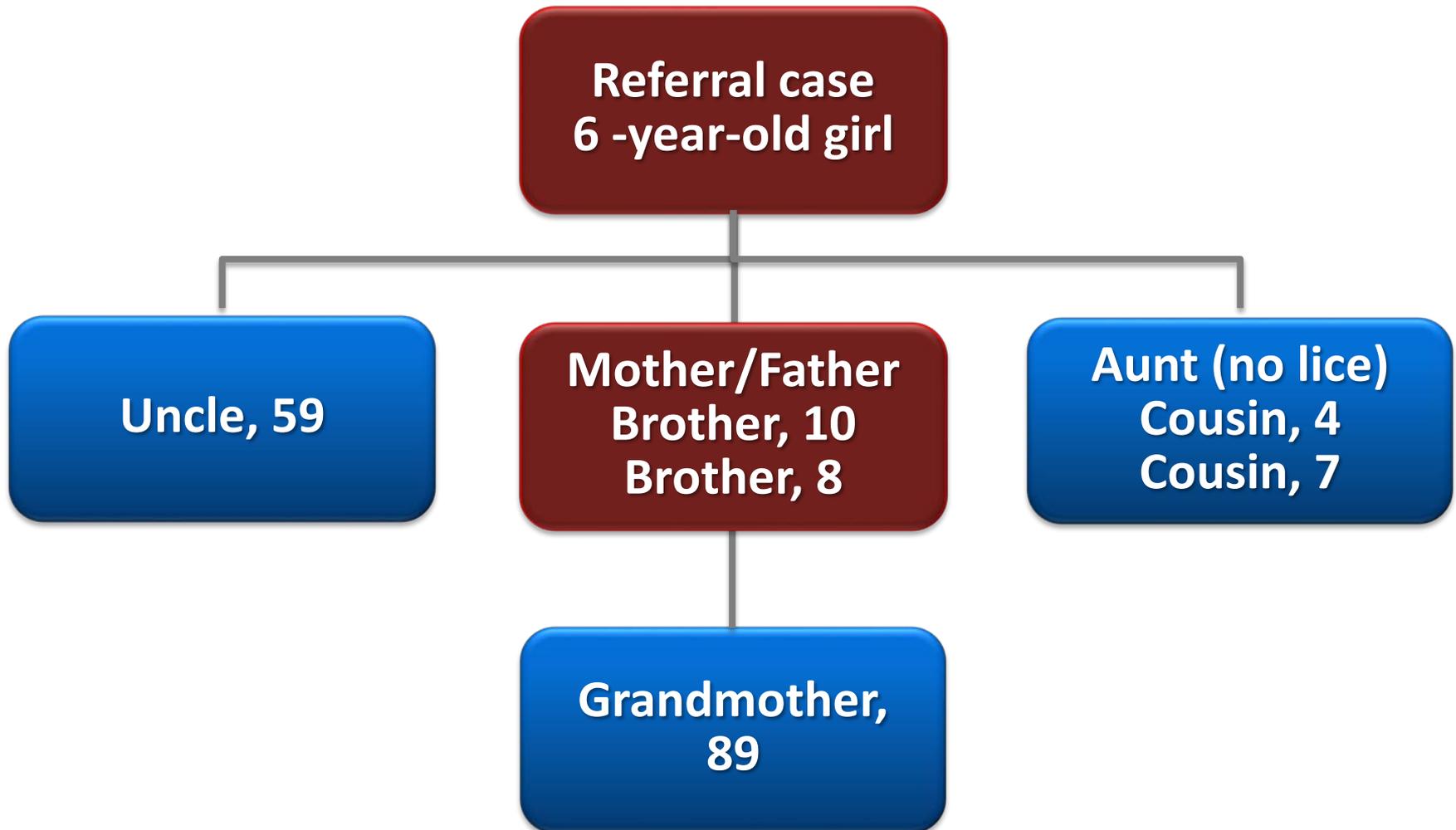


Implications/Conclusions

- ❖ Avoid the use of the “Dear Parent” letter
 - Encourages prophylactic treatments
 - Searching for and avoiding **“the child”** with head lice
- ❖ Obtain a complete treatment and social history
 - Type and use of treatment product(s)
 - Transmission control methods used
 - Encourage social networks – diminish social isolation
- ❖ Conduct contact tracing
 - Encourage screening all family members and close contacts (extended family, neighbors, close friends)

Importance of Contact Tracing

(9/10 family members: 4 homes, 3 cities, 2 counties)



Implications/Conclusions

- ❖ Encourage regular home screening for head lice
 - Teach **caregivers and older children** screening techniques
 - Educate caregivers about head lice transmission to decrease negative behavioral immune system responses
- ❖ Strategies to reduce caregiver strain and stigma
 - ↑ understanding of potential effects of persistent head lice on the family as a whole
 - Validating parents' personal struggle, respectfully offering information on treatment options and support treatment attempts
 - Shift from blaming → supporting
 - Advocate for the adoption of school head lice policies that are less exclusionary
 - Head lice as a family vs. individual child phenomena

❖ Questions?



[CDC.gov/headlice](https://www.cdc.gov/headlice)

❖ sgordon@fau.edu