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Scratching the Surface: An Autoethnography to Begin to Understand and Address Illness Experience in Lice Infestation

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Scratching the Surface: An Autoethnography to Begin to Understand and Address Illness Experience in Lice Infestation

Abstract

Though pediculosis, more commonly known as lice, is extremely common and has nothing to do with hygiene, misconceptions persist. Lice, constructed as a highly contagious illness, is more of a nuisance, with most contagion resulting from head-to-head contact, and 3% resulting from environmental causes; still, the condition tends to be associated with negative behavior like uncleanliness and neglect. There is very little study of it in the U.S. save for some “no nit policy” studies and almost none on the psychological or communicative impact on those affected. Through the analysis of pediculosis in my children, I detail an autoethnography of lice illness experience. Analysis suggests implications for the condition’s relationship to stigma, shame, misconceptions, victim blaming, and secrecy, as well as issues related to seeking social support, finding contradictory health information, special services costs, and giving over to health experts, particularly regarding framing. Stories thoughtfully examined and shared may aid in mitigating harmful frames and misconceptions as well as provide directions for helpful research. An examination of experience is a start in exploring this context from a communication perspective.

Keywords

lice, autoethnography, health communication, framing, stigma

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Scratching the Surface: An Autoethnography to Begin to Understand and Address Illness Experience in Lice Infestation

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Though pediculosis, more commonly known as lice, is extremely common and has nothing to do with hygiene, misconceptions persist. Lice, constructed as a highly contagious illness, is more of a nuisance, with most contagion resulting from head-to-head contact, and 3% resulting from environmental causes; still, the condition tends to be associated with negative behavior like uncleanliness and neglect. There is very little study of it in the U.S. save for some “no nit policy” studies and almost none on the psychological or communicative impact on those affected. Through the analysis of pediculosis in my children, I detail an autoethnography of lice illness experience. Analysis suggests implications for the condition’s relationship to stigma, shame, misconceptions, victim blaming, and secrecy, as well as issues related to seeking social support, finding contradictory health information, special services costs, and giving over to health experts, particularly regarding framing. Stories thoughtfully examined and shared may aid in mitigating harmful frames and misconceptions as well as provide directions for helpful research. An examination of experience is a start in exploring this context from a communication perspective.

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Introduction

During a recent spring, I received an unexpected call that would begin a peculiar and stressful health journey. My mother-in-law had taken my oldest, then eight-year-old, daughter to have her hair cut. And, the stylist, saw some, well, visitors, in her hair. She called to let me know. My feelings centered on disbelief, shame, guilt, and blame (“Why hadn’t I seen this? How did we get this? We’re so clean!”). My only previous experience with lice, or pediculosis, was in second grade, when I recall a boy in my grade had it and we were all checked by teachers with pencils separating strands of hair.

One dilemma often felt when faced with a stigmatized condition (Sontag, 1978) is whether to share that experience to receive support and to allow others to use preventative measures. An even less common decision would be for an academic to share her experience with such a condition in the interest of helping herself and others learn more about healthful ways of discussing and treating it. This autoethnography of pediculosis experience results from my decisions in both areas. The resulting analysis has led to implications for health communication messaging in the lice context, and possibly other health areas, regarding framing and stigma.

Pediculosis

Lice is constructed as a highly contagious illness, but is not, with most contagion from head-to-head contact, with only about 3% stemming from environmental causes. The condition

is fraught with misconceptions, often associated with negative behavior like uncleanliness and neglect (Annells & Smith, 2004; Centers for Disease Control, 2020).

Pediculosis is common in the United States, with an estimated 9 to 16 million reported cases of lice amongst elementary school children each year (Centers for Disease Control, 2020). In children between ages 3 and 11 and their families, it is more common than the common cold. In the U.S., there is very little study of it save for some “no nit policy” studies and a handful on the psychological effects of those affected (Annells & Smith, 2004; Gordon, 2007; Hurst et al., 2020; Mumcuoglu et al., 2006). There are a few exploratory studies outside of the U.S., examining stigma and social implications of pediculosis (Campos Nogueira et al., 2021; Neuberg et al., 2022; Parison et al., 2013). A search of the literature, however, did not yield any studies on communication or autoethnographic approaches in lice contexts.

Framing and Stigma

Framing and stigma offer two lenses through which lice may be viewed. Stigma is a kind of social rejection stemming from a comparison to the “normal other,” and in the case of health, rising from negative associations of attributes of a condition (Goffman, 1963; Sontag, 1978). Related, there is self-stigma, or perceived stigma, when rejection is internalized, and individuals believe negative associated stereotypes (Link, 1987; Link et al., 1989). Lice is a stigmatized condition, often framed as an emergency or crisis, given its association with neglect, uncleanliness, and imminent transmission. Framing is placement of a concept, or in this case, an illness, within a field of meaning; how something is conceptualized or presented (termed “the frame”) influences how information is processed and how meaning is formed (Goffman, 1974).

The way a condition is framed may help to construct stigma and its effects on individuals, families, caregivers, and institutions (Bateson, 1972; Goffman, 1963; Meyer et al., 2020; Sontag, 1978); further, stories thoughtfully examined and shared may aid in mitigating harmful frames and misconceptions (Charon, 2006), as well as provide directions for helpful research. An examination of my own experience via autoethnography is a start in exploring this context from a communication perspective, and the following research question is advanced here: What implications for how lice is communicated, particularly through the lens of framing and its relationship to stigma, may be garnered from close examination of an experience with this health context?

Method

Autoethnography is an analysis of researchers’ personal experiences (Ellis, 1999; Ellis et al., 2011; Holman-Jones, 2005; Porter, 2004; Spry, 2001). It is a qualitative research method in which a researcher examines unique life experiences considering social and cultural institutions as well as extant research, concepts, and theory (Jones et al., 2013, Tillman, 2009). Ellis (1991) suggests that the method allows researchers to “observe” themselves “observing,” reflexively examining the many layers of experience (p. 670). It requires that researchers reappraise experience and connect to larger phenomena, creating new meaning (Raab, 2013; Sell-Smith & Lax, 2013).

“I systematically storied and explored my lived experience” with lice (Tillman, 2009, p. 100) through data collection, data analysis, and then synthesis and interpretation. Data consisted of journal entries from the time period in which the illness occurred (all entries written over that spring and summer, from the first notice of lice during that fateful haircut, to our clearance as “lice free”), electronic calendar entries from that same time period, sessions of writing notes about the experience from memory, and later, having family members read the

journal entries and notes. In addition, I interviewed family members about their experiences to help with recall of timelines and details (something akin to interactive interviewing; Ellis et al., 1997). Also, as I read autoethnographies, I wrote down any triggered memories sparked for analysis; for instance, as I read some of Tillman's (2009) discussion of her eating disorder experiences and autoethnography project, it gave me pause to reconsider specific dialogue I wanted to reflect upon. Data were gathered over a three-month period. I should note that I thought of a few health communications concepts that highlighted our experiences during the time of lice infestation but did not consider analyzing the journal entries or undertaking any other data collection or a research project until several years later.

I then began an open coding process, allowing concepts that stood out to emerge, reading the data and reflecting upon it, noting themes that seemed to emerge on the data itself (electronic files) and creating memos of initial and subsequent patterns of meaning. Frames and stigma began to stand out in initial writing, so then exploring my notes and journal entries from those vantage points was undertaken, attaching specific frames to the data. I read the journal entries from the lice experience as well as the calendar entries, reflections, notes, and interview data and labeled passages with particular frames that seemed to stand out, such as "the lice makes my daughter untouchable," and noted when I saw elements of stigma (self-stigma, perceived stigma, etc.). Upon rereading my initial notations, I found overlap. Frames began to overlap and seemingly the chronic versus crisis frames seemed to evolve as a framework for the story. I then recoded according to chronic and crisis, noting specific illustrative passages which became the later mini-sections of the desired and offered frames detailed in the results section. Stigma emerged as a concept useful in outlining these specific events and memories of the experience to connect them to larger health phenomena. I also looked to specific quotes I recalled from memory or from my journal during the illness experience that illustrated the frames and illuminated concepts within them. For example, I found a quote from my initial journal entries from our family doctor, "please don't do that here," when we brought our daughter to a well child visit, mistakenly believing the lice was gone and then examining her hair and nearly flicking lice onto surfaces in the examination room.

I then refined themes of crisis and chronic illness frames as well as stigma, and refined reflections in the draft writing of the resulting manuscript, connecting my family's story to cultural and social concepts, gathering references as needed. For instance, as I found the themes of illness frames and stigma to be helpful lenses to examine the experience, I read more thoroughly on these topics and noted these sources near accompanying coding on the data. For instance, for elements of stigma noted in the journal entries, memos, and interviews, I would note specific pages from Sontag (1976) that would explicate the analysis further. Though various autoethnographic procedures exist, the one employed here is essentially a layered account where the researcher's observations and experiences are discussed and measured against theory and literature, posing analysis and observations into potential explorations in larger settings (Ellis, 1991; Rambo, 2005; Ronai, 1992). In the present study, I analyzed my own personal experience with pediculosis in the form of examination and analysis of journal entries, reflection, and memos.

Analysis

A Spring and Summer of Lice

On the phone with my mother-in-law, I leapt into problem-solving mode. I was with my youngest daughter (then three years old) at home. My husband was teaching late, so I asked my in-laws to stay with my daughters while I went to a drugstore to buy the standard chemical

over the counter (OTC) shampoo kit, the only thing I could think of at first. I sort of looked around as I placed the kit on the counter, as if the cashier might not notice what I was buying and associate that purchase with me as its consumer. Upon my return, we worked it through everyone's hair and then came the fine combing and combing and combing of very long, very thick dark hair, and crying and crying, ensued. My three-year-old was not happy about the combing of the chemical shampoo through her hair; my oldest tolerated it to a point and then was in tears like her sister. I then washed all linens and stuffed toys, sprayed the house with some spray that came with the chemical shampoo for this purpose, vacuumed, and isolated other Luvvies and toys in the garage. I hadn't been through this with my kids before. This process was repeated daily until it looked like the lice was eradicated from everyone's hair, and there was quarantine and more quarantine (we were oddly somewhat prepared for 2020).

Between quarantines, there was a process of thinking the lice was gone, sending the children out to a camp, and, once, a well-child doctor's visit, when we were that told the lice was still there, though we were positive it was gone; these discoveries were met with crisis responses of fearful, immediate incredulity (such as, "How could you bring her here?"). There were more OTC shampoos, olive oil, mayonnaise, and then more checks, and then going out and thinking the ordeal was over. There was thinking it was gone and then finding out it sadly was not, coupled with irritability and loneliness in the isolation of our family, and feelings of remorse and guilt and shame and anxiety again. Sentences circulating our house during that time included: "Is that lint or dandruff or nit," "Keep away from your sister," "Don't touch that blanket—it needs to be sanitized," and "Minnie has to go in the dryer before you can snuggle her again!" Our panic was amplified by our isolation, the framing of the situation as a crisis, and the fear and anxiety of not wanting to begin the cycle again.

Any bit of lint, thread, or any signs of itching or scratching of any heads in our household signaled potential lice; the residual illness lurked in our home and hypervigilance with treatment and cleaning and observation became central. There was no certain source or cause of the illness, so victim blaming ensued (e.g., "What did I do? Why didn't I catch it sooner? Why couldn't I get rid of it?"; Ryan, 1971). In the absence of a particular cause or with limited understanding of a condition, the patient (or guardian of the patient), is often looked to for cause or blame (Sontag, 1978). Stigma is tied to this kind of blaming as well as fear in that in othering the victim or patient, one is distancing oneself from the "type of person" who would be afflicted with the condition (duPre, 2020; Sontag, 1978).

Treatment is tedious and painstaking, difficult, and stressful, as is the decision of whether lice is present in the first place and if it is gone and if it is going away. And who to tell? You have some big dilemmas, moral dilemmas. If you remain silent, you run the risk of spreading lice further by not allowing those exposed to take measures. But they may not have been exposed (head-to-head contact may not have happened). So, if all the confession is for naught, you have embarrassment, stigma, this mark of uncleanness, and this "scarlet L" left there. You can help, maybe even offer, or give support to others with your confession and story and get help, but you must decide if the potential stigma is worth it.

I found myself on the verge of tears when our youngest would not sit still for the in-office treatment at a pediatric office specializing in lice treatment and we would have to alternatively purchase the home treatment for her. It was the end, the solution, the end to the endless race we were running for so long in the supposedly leisurely pace of summer. We received the welcome we certainly could not obtain elsewhere. In our preventive (in our minds) shower caps, I thought the burden was on someone else now, and that was shattered. I was back to our sense of non-control, as our methods seemed not to work, mitigating any sense of self-efficacy for treating these bugs ourselves. The solution and transfer of burden and control was obliterated, and I finally lost control of my emotions in that moment; the relief patients may feel in finding a diagnosis and treatment that is then found ineffective or not feasible may

obliterate any sense of self-efficacy and control garnered from that sense of control and relief once held (duPre, 2020). Ultimately, we were given a very expensive treatment and home-based instructions for shampooing and combing and simpler cleaning solutions; we were fortunate to be able to afford this; healthcare costs are a significant burden for many American families (Centers for Medicare and Medicaid Services, 2022), even with insurance, and lice treatment was in fact not covered by our plan A check-up at this same office two weeks later deemed us all lice free.

I have concluded that many issues surrounding communication in a pediculosis context point to framing, “a spatial and temporal bounding of a set of interactive messages” (Bateson, 1972). There were certain frames offered throughout my family’s life experience that could be transformed to allow for more productive, healthful communication, and reduction of stigma, in this setting.

Frame Offered

A frame of a crisis of disease, where health is seen as purely organic/biological/biomedical, was offered in the ideas and communication surrounding lice during our experience. In this frame, there was a dire situation, high risk of contagion, and necessary secrecy due to stigma; isolation was necessitated by the supposed quick and inevitable spread of this condition to others. There is a hazy cause of this condition due to misinformation and blaming of those affected ensues; little information can lead to panic and a seeking of cause often turns to the patient in healthcare contexts. Othering of the patient may make the condition seem less likely to happen to those yet unaffected (duPre, 2020; Sontag, 1978).

Panic with No Source/Cause, Victim Blaming - “Why didn’t I see it?”

When I first heard about the lice, I was initially quite panicked and began to question and blame myself: “Was it in our home now? Clean the hair and the home! It’s spreading! The tiny nits were growing and spreading and was I to blame?” I was not aware of the major source of spread, head-to-head contact, and that lice could only crawl, but could not fly. The risk of transmission is not inevitable, and the cause is quite simple, but I received messages over and over of a crisis-based and victim-blaming reaction (e.g., a nurse who shook her head at us and administered chemical lice spray in an exam room after we left a doctor’s appointment and thought that the lice was no longer present in our children’s hair.)

Stigma and Secrecy - “Should we tell the camp director?”

Our experience included weeks of cleaning, home and store remedies, and self-quarantine, as well as the anxiety of determining if the illness was still present or not. There was stressful decision-making regarding whether to tell people we had potentially, unknowingly exposed lice to others, and thus expose our family to potential stigma. We sent our youngest daughter to camp one morning during this time, when we thought she was lice free, but was not, with potential exposure to others. We told the camp director, and an email was sent out quickly without much thought, resulting in cancellations from campers and likely our anonymity compromised.

Anxiety - “Don’t do that here.” and “Should we send her?”

There were decisions to be made based on various kinds of advice, medical information, stress, and anxiety over decision making and consequences. Should we send her to school or to camp? Are we at fault if we think the condition is healed and it is not and then it is spread to other children? As my child’s doctor found the lice I thought was gone, I felt horrified and guilty, and, as I inspected my daughter’s hair, she thought I was removing a nit, and chided, “Don’t do that here.” She did not want the crisis to extend to her office. This experience further enhanced my anxiety, my self-blame, and the residual illness we were experiencing with every tiny speck of something on our families’ heads.

Residual Illness, Misconceptions - “Is that lint or a bug?”

There was much information online and from others: olive oil and mayonnaise as home remedies, washing and combing out very distressed children with very thick hair, spraying chemicals on stuffed lovies and furniture, and constant washing, drying, and vacuuming. There was also advice to keep children and families at home, to avoid spreading the condition to others. And every minor imperfection in the hair, every scratch of the head from a family member was an indication that the whole ordeal of isolation, worry, and chemicals was potentially beginning again.

Giving Over to Experts/Affordability and Access - “You will have the tools you need to succeed.” and in Tears, “Please, please...try the treatment on her”

After feeling helpless, after weeks of anxiety and uncertainty, we found a facility founded by a nurse practitioner, about an hour’s drive from our home that specialized in treating lice. We felt much weight lift off our shoulders to give our illness over to experts, given its largely biomedical and crisis frame, though treatment was quite costly. As noted, when my youngest daughter would not sit through a vacuum-type hair treatment, I broke down in tears.

Frame Needed

A more productive frame for lice may be as a chronic, everyday condition, with health as holistic. There is of course a biomedical aspect, with a clear cause of a common condition, but given its low risk it may be framed as an everyday manageable condition in otherwise overall healthy individuals. In this frame, when we have pediculosis, we are still healthy normal human beings with a condition that is quite common and can only spread through head-to-head contact. The condition is detached from a frame of crisis and myths that perpetuate stigma such as neglect and uncleanliness.

Problem-Solving - “We will go to this place and have it checked in a few weeks. Okay...”

We felt like we should handle our dirty crisis ourselves; it was a health emergency but a private one. Do we want our children to be known as the children that had lice? After trying to handle it ourselves, we found that we needed help; expert help was the endpoint and did eradicate the illness. This approach now includes sharing our struggle and what we learned with others and seeking help focused on treating the condition versus anxiety, guilt, and shame over the illness; the change was healing and ended a stressful time.

Seeking Support/Sharing Knowledge Against Spread - “We can ask the school nurse.”

Should we ask the school nurse? Should we tell her teacher? The answer is undoubtedly, “yes.” A culture of sharing and education, problem-solving and understanding, would mitigate stigma, framing the condition as common and manageable, with its true cause, and facilitate less spread and lesser shame. School nurses can be an expert source of help in diagnosis and shared medical decision making if there is trust and a frame of chronic, everyday condition. We did contact a school nurse, but were very conflicted about doing so, given that this decision would involve revealing our children’s condition and bringing the children to the school with this condition.

Self-Efficacy - “We don’t need to wash the stuffed Minnie Mouse every day?!”

Understanding that head-to-head contact was the major cause helped a great deal. The cause and solution seemed more tangible and accessible. Once we had decided to visit the experts and received helpful information (such as that running items through a dryer, rather than washing and drying items, is quite effective, and much less time consuming), and a plan we mutually agreed upon, our stress lifted. The lice treatment facility emphasized the common nature of the condition and its solution and framed that solution as a negotiation of a team effort. A nurse there let us know that we “would have the tools we need to succeed.”

Correcting Contradictory Information - “This is dandruff versus lice—see how it flicks away easily...” and “The dryer kills the little buggers.”

Lice is seen as a crisis and something dirty and contagious. It is contagious, but nearly entirely through head-to-head contact. Lice can jump but do not fly. Nits stick to the hair and are very, very tiny and can thus be differentiated from dandruff and other flotsam and jetsam that are easily “flicked” from the hair. As noted, running towels and sheets and stuffed toys through a dryer kills nits much better than washing and drying. There is misinformation online and interpersonally and crisis framing coupled with this can lead to unnecessary added stress in experiencing this condition.

Confidence with Self-Care/Affordability and Access- “We could pay this, but can everyone?”

The affordability of specific pediculosis medical intervention is problematic and is not covered by most insurance. Expert help that is more affordable, such as a pediatrician or school nurse, in diagnosis and helping with decision-making is important, and can alleviate anxiety. However, the act of seeking that help comes with revealing a stigmatizing condition and possible guilt in wrongful self-diagnosis or inadvertent spread of the condition to others. Policies that strictly keep children home from school can also be problematic, given parents’ need to work and the cost of childcare.

Discussion and Conclusion

In the pediculosis context, there must be consideration for how the condition is framed; framing transformation is needed (Snow & Benford, 1988) from one of crisis to one of chronic condition, with a holistic view of health. There is a clear biomedical cause (head-to-head contact) for this low risk, common condition with manageable (though potentially costly) treatment in otherwise healthy children and families. Recognition of the cause mitigates stigma and increases the likelihood that individuals will seek support, have greater self-efficacy, share

information, and engage in problem solving, rather than feel shame, anxiety, spread illness, and/or engage in victim blaming and secrecy.

This work supports others investigating stigma reduction by matching frames and worldviews. Message strategies addressing categorical and dimensional worldviews with both biomedical (in the case of lice, biomedical cause of head-to-head contact) and more holistic or biopsychosocial (a chronic, common, low risk condition in otherwise healthy, normal individuals) frames may combat stigma. The element of framing conditions as low risk (in the case of lice, chronic not crisis, support not secrecy, self-efficacy, and information, not fear and blaming) may also aid in mitigating stigma, as conditions of lower risk are less likely to aid in social rejection (Goffman, 1963; Meyer et al., 2020).

It is worthwhile to note that individual experience may not convey unbiased, broadly applicable results; other stories may yield alternative conclusions. Future work may expand and elaborate upon the findings presented here, testing ideas in larger samples and in other settings. However, individual stories offer dimension and clarity to what could be a one-dimensional, often unshared health condition such as pediculosis.

Custer (2013) describes autoethnography as a transformative method that may be viewed through several lenses, noting that the process changes time, requires vulnerability, honesty and creativity, celebrates subjectivity, eliminates boundaries, and offers therapeutic benefits. As I reflect on this analysis, I have found it helpful to consider the method through these aspects or lenses (Custer, 2014), as well as to examine my past training and assumptions about the method and research more generally.

Looking to experience can allow a reshaping, reframing, and reappraisal of experience that may benefit future experience individually, but also benefit understanding of larger more widespread phenomena more generally in the larger environment of health communication, and more specifically, in the lice context. One is close to the truth if writing honestly, trying to capture experience accurately, and then distill the experience into conceptual elements that may impact the larger societal—health in this case—issue. Stories foster empathy and understanding of human experience for readers and empathy between writer/researcher and larger concepts and experiences written about from individual perspectives. Further, the autoethnographic style of writing can draw in a reader to understand concepts through stories, a natural piece of the human condition. Through this method, we may bring an individual experience into the larger world, to bear what was learned into the larger culture; isn't this what we hope to do in all research conveyed in the concept of generalizable knowledge? The method seeks to remove the boundary between our experiences to share ones with others.

Subjectivity can be taught as something to avoid in research, but perhaps it isn't always best to do so; knowledge of the self, awareness of biases and intimate knowledge of your story and how it affects others, and how it might mesh into the larger societal story, is important. Subjectivity and closeness to a research topic or participant may be quite important in capturing concepts accurately; Patti (2015) cites the importance of rapport and empathy with an interviewee to capture his or her experience truthfully. This kind of closeness may be necessary to write about an experience to “escape dominion” (Charon, 2006) by it, through reframing experience into learning, into something that may benefit others.

Most surprising in this endeavor was my recall of my past experiences in qualitative methods training and the realization that I did still hold some small fragment of that disparaging opinion, largely surrounding the idea of subjectivity. I had a professor in my doctoral program who exhorted that if we were to do an autoethnography for a class project we would automatically fail, as it was too subjective to garner analysis and did not qualify as research. However, as I've learned from this project and colleagues in the field, subjectivity and objectivity can be thought of as tools in a toolbox as well, much like other advice from my training. Methods are data gathering tools and should fit the question. Noting that you are

qualitative or quantitative is like being half of a researcher. Perhaps that same sort of case could be made for being always subjective or always objective. There is benefit from being close to your story to recall it, close to your interviewee to establish real rapport and capture the true essence of your discussion, the topic at hand. There is also benefit from reflecting in a more distant way on your story as text to connect it to the larger world of experience, and learning not just about one's own experience, but transforming the experience of others in the larger phenomena of illness and communication.

Frame transformation can be facilitated through more research in this area, as well as through writing and sharing experiences, with narratives used in education/training of healthcare providers, school children and teachers, as well as parent and patient training and sharing via interpersonal contact and social media. Education and sharing of stories, what Goffman (1963) may term "educating the normals," may be helpful in reducing social rejection and demystifying lice; keeping the unknown in the background and continuing to frame the condition as a crisis rather perpetuates myths and stigma.

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