

Inequality and the Patch

By Julia Adams

Some years ago, there was a little girl with thick glasses with pink frames, often smudged with finger prints and crooked from careless use. She also wore a patch, quite like a pirate's. She wore this patch, not for a costume party for Halloween and not because she particularly admired Captain Hook or felt inspired by Disney's "Pirate's of the Caribbean" ride. She took it off whenever she could. It was uncomfortable. It messed up her hair, rubbed against her sensitive skin, and limited her to the use of one eye. But her mother insisted.

So she hid. She hid herself. She hid the patch. Screaming and tantrums were not an uncommon phenomenon at her house, particularly after she had to wear the patch in her portrait for pre-school. Threatening television privileges was the only way to control her, if only for a little while. Her mother employed every tool she could. She carried the child on her back to ensure she kept the patch on and never left her alone. If any of her other children said one word about the patch, there would be consequences; words she said in such a scary voice that there never had to be.

As such, for as far as memory serves, the girl was not bullied at pre-school for her patch. Most likely, if it had happened, the same screaming skills that so irked her mother would be deployed against a new foe. She just hated the patch with the kind of absolute passion and abandon that belongs to children, who have difficulty maintaining two different emotions at once. Yet, through the power of her mother's persistence and to embrace the cliché, love, she wore the patch. Her time under the tyranny of the patch turned into random childhood anecdote to liven up boring party conversations and it was only later, that she began to question the experience and wonder why.

That little girl was me and this essay is the result of those ponderings, the kind that made everyone uncomfortable, when we're forced to consider how we came to be who we are and realized a great deal of it had nothing to do with our efforts, but the circumstances and people around us.

On the surface, my circumstances were this: I had amblyopia, an eye condition with a treatment that potentially can be bought at a Halloween store. The patch was not a creative punishment designed by my mother. It was cure, a bit of preventive medicine to keep my vision healthy. Like braces or shots, patching is one of those things both parents and children dread but must be done for the child's own good.

My experience with patching and amblyopia follows the general paradigm for what is supposed to happen. This paradigm, itself, follows a simple structure reflective of an old Buddhist axiom: see the problem, seek the cause, find the cure and apply the remedy. The problem was seen by my mother when I was about one or two. She noticed that I had a lazy eye and took me to the eye doctor to find the cause. There, she learned that amblyopia is the result of the brain

Comment [JA1]: I think I may have shot myself in the foot with this intro because it has such a different tone than the rest of the piece. However at the same time, I think it's a nice way to introduce the issue slowly, and creates a sort of "mood whiplash" at the end to make my message more powerful. Would a more scientific, more serious beginning be a better intro to this piece because it would be more representative?

receiving different images from each eye, one weak and one strong. The brain naturally chooses the clearer image, one eye grows to be more dominant, and the other eye grows weaker, the image it sends being repressed.

Luckily, for my mother and me, the cure was already found. She had a choice between atropine drops and the aforementioned patch and to her later chagrin, she chose the less invasive option, the patch. As for applying the remedy, for most children, as little as two hour a day of patching can be effective (Lithander, Sjorstand 111). I had acute amblyopia, as a result, two hours was not satisfactory and I had to do around six hours a day. Despite the severity of my condition, it was cured and patching became a distant memory for me and a convenient way for my mother to make me feel guilty, alongside eight hours of labor.

As my mother explained to me later, there is one catch to this whole process – amblyopia is best resolved before age eight, which is a nice way of saying that it is often permanent if not treated before then. Children with untreated amblyopia lose vision in their weaker eye. Some stop using that weaker eye all together, driving that eye blind and causing damage to their vision as a whole. Still, with treatment, all these negative consequences can be prevented and any child with amblyopia can live a normal life.

There is a difference, however, between simple paradigms and reality, and between potential and actuality. Even though, the problem is seen, the cause has been sought, and the cure has been found, the remedy is not always applied. There are adults who have amblyopia; they are the children who missed the cut-off, whose condition was not resolved in time. So researchers start the process once again, seeing the problem, seeking the cause, finding the cure and applying the remedy.

As a result, there are studies on the best time to screen children; the younger the better. There are studies on whether the patch or atropine drops are most effective. There are studies trying to reverse amblyopia in adults with the latest technology. However, all these studies ignore the true cause, a cause that isn't medical or scientific. There is no cure for, no way to patch away, human nature and inequality.

The most common cause for why amblyopia is not cured is noncompliance with treatment, failure to follow the doctor's orders (Lithander, Sjostrand, 111). Parents play a critical role in ensuring compliance as my own experience shows. There are a number of explanations given as to why families don't comply, the cost of the patch, children's resistance, difficult appointment times and more. These reasons differ according to income and class as outlined in "Barriers to Compliance in Amblyopia Therapy: Parental Perspectives in Low-and-High-income Families" (Leenheer, et al, 6). Lower income families struggle with children's resistance, the cost of the patch and allergic reactions the most (Leenheer, et al, 6). Higher income families complain about short physician contact time and appointment difficulties.

These different reasons reflect how amblyopia treatment, like so many other things, is experienced differently by upper class families and lower class families. Moreover, I have to

wonder if the reason why lower income families are not so concerned with physician contact and appointments is not that their needs are satisfied, but that they don't have adequate health insurance to make appointments and see physicians. However, these difficulties, perhaps other than patch cost, can be surmounted or at least endured. My mother endured what researchers call "child removing patch" certainly. I would say that these "barriers to compliance" are merely explanations for why families do not comply. The reasons are more complicated.

For example, even though most families struggle with compliance, children from the upper and middle classes are more likely to have successful results. "Poverty predicts amblyopic treatment failure", as goes the title of an article from *The American Journal of Ophthalmology* (Hudak, Magoon, 214). In this article, Hudak and Magoon, researchers from Ohio, compare the results for children with amblyopia receiving Medicaid and those with amblyopia, not receiving Medicaid. The results they found are stark: "The likelihood for a good final visual acuity was 26.8% for the group receiving Medicaid and 58.4% for the group not receiving it" (Hudak, Magoon, 214). Even worse, "the likelihood of a poor final visual acuity was 33.8% in the Medicaid group versus 11.5% in the non-Medicaid group" (Hudak, Magoon). In conclusion, poor children were two times less likely to have successful results and three times more likely to have bad results, compared to children who are better off. As such, poverty predicts treatment failure; does it also predict compliance with treatment?

As a matter of fact, "Barriers to Compliance in Amblyopia Therapy: Parental Perspectives in Low-and-High-income Families" also shows that poverty predicts compliance with treatment as well. Researchers found that higher income parents were more consistent and therefore more compliant (Leenheer et. all, 6). 42% of higher income parents were consistent (Leenheer et. all, 6). Only 28% of lower income parents were, however (Leenheer et. all, 6). Moreover, higher income parents were more likely to understand the treatment (Leenheer et. all, 6). In this study, 46% of them did (Leenheer et. all, 6). Shockingly, only 8% of lower income families understood how the patch and atropine drops work (Leenheer et. all, 6). So class, noncompliance and treatment failure for amblyopia are all bound together in a knot.

It's easy to say that the reason for the inequality in success rates for amblyopia is that lower income families do not have the money for patches, drops and doctor's visits. However, those were not the only complaints for lower income family. Also, on the top of their lists of barriers was "child removing patch" (Leenheer et. all, 6). Upper class families did not struggle with this problem as much. If my family had been one of the families studied, would she have responded the same way? As much as my resistance was a problem, she overcame that issue and managed to keep my compliant.

Consequentially, since children's resistance was such an issue, the reason for noncompliance is not necessarily money; it's the symptom of the way money is distributed, class. My family was middle class and educated. My mother understood the treatment; it didn't seem like some strange punishment to her. We had insurance. Therefore, the condition and treatment were explained to us by our family doctor. My mother had the time and energy to devote to ensuring

Comment [JA2]: Tone was a struggle in this piece and this is perhaps one of the most scientific and serious of my paragraphs. Injecting my more conversational tone into this paragraph about poverty and children going half-blind seemed out of place so instead I hoped to transition step by step into it in previous paragraphs. Was that move effective or would it have been a better decision to be more conversational and humorous within this paragraph and the ones similar to it?

my compliance because she was a stay-at-home mom. It is hard to discipline children after a long day at work about anything, let alone about a pirate patch. Not to mention, the patch is to stave off a long-term problem; these families and parents (often young single parents) often have more immediate concerns such as rent. My mother experienced this divide firsthand, when she started teaching in a poor area of Lansing and met children who weren't as lucky as I was and parents full of regret.

Class is created by a society. It is the result of how resources are distributed and how the distribution of resources affects people. Children from lower class families are already disadvantaged and these disadvantages accumulate with amblyopia. The median income for someone with a moderate disability in the U.S.A is 22,000 dollars, 3,000 dollars less than for those without disabilities (Gibson, 3). Following this logic, poor children with amblyopia grow into adults with amblyopia, who then have poor children with amblyopia and the cycle continues. It is easy to talk about how assistance to the poor costs money, a short term setback just like the patch, but there are long term benefits. If compassion is not moving enough, Gibson estimates that 23 billion is lost annually from the income adults with amblyopia could have made and could have paid taxes on (Gibson, 3.) Therefore, government investment in programs that promote awareness, understanding and methods for increasing compliance would not be a deterrent in taxes but a long-term solution to help low income families.

However, as I said earlier, it's not just about money, money in taxes or money spent on public initiatives, because the real world is too complex for such a simple remedy to be effective. As fond as I am of that old Buddhism axiom, I find it more and more insufficient. We see the problem of unequal treatment for amblyopia. We seek the cause and find it to be reflective of poverty, of the great disparity between rich and poor. As such, we try to find a cure but how can we help more children with amblyopia if it's not a medical issue, but a societal one?

Curing inequality is not as easy as making a four-year-old wear a patch. It is too big a problem; yet the costs are too great to ignore it and give up. After all, as a result of greater societal ills, many children are literally doomed to be half-blind for the rest of their lives. Society consequentially must find long term solutions and absorb short term costs to compensate for the consequences of class disparities and even the playing field in amblyopia treatment.

For, after all, we are not children. Children don't think of the future. Children don't appreciate taking a cost now for benefits later. Children don't question the world they live in; any system they are born into is normal. Children don't understand that sometimes the reason for something and the explanation are two different things. Children don't realize that sometimes adults aren't in control, aren't able to do their best, and need help. Children do understand however that the rules of the game need to be fair. As such, as a society we must take measures to compensate for the inequality of amblyopia treatment.

Comment [JA3]: In this paragraph, I sought to unite some disparate "themes" that have been floating around in this paper. The talk about childhood in the beginning, the inequality thread, the Buddhist stuff. Moreover, I wanted to talk about inequality without being preachy yet I still wanted to be strong and convincing. So how do my intentions match my effect/execution? Is there anything more I could do?

Works Cited

Quoted Research

Hudak, Donald T., and Elbert H. Magoon. "Poverty Predicts Treatment Failure." *Journal of American Association for Pediatric Ophthalmology and Strabismus* 1.4 Dec. (1997): 214-15. *Embase*. Web. 13 Feb. 2012.

This journal article details a study comparing the success of treatment for amblyopia in regards to children with Medicaid and those without Medicaid. It uses clear statistics comparing the visual acuity of children before and after the treatment, categorizing them as good, moderate, and bad final outcomes. It does not study compliance with treatment or the severity of the children's initial diagnosis but the statistics largely speak for themselves, notably those I employed in my essay. They tell clearly that those with low income fare worse by a wide margin. This essay was perhaps the most crucial piece of research for me because it provides hard statistical data supporting the main argument of my op-ed column; that poverty affects the treatment of amblyopia negatively. It also underscores my personal experience and makes it less anecdotal by giving me statistics to use. I also feed a little off their statistics at the end.

Gibson, William. "Economic Impact of Blindness From Amblyopia." *Children's Eye Foundation*. Children's Eye Foundation, n.d. Web. 17 Feb 2012.
<<https://docs.google.com/viewer?url=http://www.childreneyefoundation.org/images/uploads/economic%20impact%20of%20blindness%201-7.pdf>>.

In this article, William Gibson stresses the importance and utility of preventing blindness and vision related to and/or caused by amblyopia by doing a cost analysis, essentially suggesting that both individuals and the nation lose income from blindness caused by amblyopia because people with disabilities of any kind make less money.

One of my main critiques for this article is that it is all speculation; there doesn't seem to be any finite statistical data. They estimate the number people with a visual disability. Moreover, it is based on the presumption that people with visual loss due to amblyopia have the same income loss of those with moderate disabilities. "Moderate disability" seems like a very broad term, possibly referring to loss of mobility or hearing, which might have different effects on people's chances and incomes. Despite these flaws, I wanted to show several things in my article which this article supplements: lack of treatment for amblyopia costs society, prevention is cheap compared to the consequences, individuals suffer from a loss of opportunity and income due to amblyopia-related visual disability, and finally, something I would like to touch on in my second draft, that amblyopia-related visual disabilities can help to contribute to the vicious cycle of class in America; People with amblyopia-related vision loss are already more likely to be low class and the economic costs of amblyopia help to keep them there.

Leenheer, Rebeca S., Jennifer A. Dunbar, Jeffrey Colburn, Andrew Edwards, and Carrie Lim. "Barriers to Compliance in Amblyopia Therapy: Parental Perspectives in Low- and-High-income Families." *Journal of American Association for Pediatric Ophthalmology and Strabismus* 13.1 Feb. (2009): 6. Print.

This journal article denotes the different reasons why low income and high income family do not comply with treatment; it looks to see why parents don't patch. It found out that the reasons why families didn't comply differed by income. Its main weakness, at least in terms of my needs, is that it does not address the fact that more of the high income families do in fact comply; class is the elephant in the room. It's hinted at because it mentions huge margins comparing how higher income families were more consistent and understood the treatment better. It helps to provide statistical evidence for my claims as to why families don't comply and the evidence for how higher income families were more consistent and understood the treatment better is also invaluable to my argument about the relationship between amblyopia treatment and class.

Lithander, Joan, and Johan Sjostrand. "Anisometric and strabismic amblyopia in the age group 2 years and above: a prospective study of the results of treatment." *British Journal of Ophthalmology* . 75.2 (1991): 111-116. Web. 19 Feb. 2012. <<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC504127/>>.

This is a report evaluates the results of a study on “the efficacy of optimized treatment in terms of number of cured children, time to achieve cure, and the rate of initial improvement of visual acuity”, which was “evaluated in relation at start of treatment, type and degree of amblyopia and adherence to treatment regimen” (Lithander, Sjostrand 111). This is another article that provided strong evidence and a quote for my argument, though it was more foundational; it proves that the main reason children are not cured of amblyopia is not the severity of their condition or treatment regimen but noncompliance. It's a building block piece of

evidence to my greater thesis that amblyopia is not cured when there is noncompliance and noncompliance is more likely in families with low incomes.

Other Research

Holmes, JM, RW Beck, RT Kraker, et al. "Impact of patching and atropine treatment on the child and family in the amblyopia treatment study." *Archives of Ophthalmology*. 121.11 1625-1932. Web. 17 Feb. 2012.
<<http://ukpmc.ac.uk/abstract/MED/14609923/reload=0;jsessionid=XGe3BjNysK5P4cup8wqO.141>>.

“Although the Amblyopia Treatment Index questionnaire results indicated that both atropine and patching treatments were well tolerated by the child and family, atropine received more favorable scores overall and on all 3 questionnaire subscales,” is the conclusion for this article (1625, Holmes, Beck, Kraker et al.) This study focused greatly on how effective these treatments are and people’s reactions to them. It compares two different treatments, atropine and patching. This is another piece of research that I came across early on, which was not what I was looking for but did reinforce some of my ideas, mainly that amblyopia treatment is effective. It seems to ignore the problem of noncompliance and if that is not a problem, I have to question their sample group and composition. For that reason, I avoided quoting from this article.

Lawson, Richard. *Atlantic Wire*. 15 02 2012: n. page. Web. 18 Feb. 2012.

<<http://www.theatlanticwire.com/entertainment/2012/02/19-kids-and-counting-gets-stranger-sadder/48733/>>.

In this article from *The Atlantic*'s counterpart on the web, Lawson writes about how "19 Kids and Counting", a show about a Quiver-full family, is getting stranger and sadder. It takes notices of the undertones of sexism and paternalism throughout the series, especially in the family's family structure and church groups. It then criticizes the produces for drawing out the mother's pregnancy with their 20th child- it is available on the internet that that child was miscarried, making the current episodes seem pointless and cruel. The content of this article is irrelevant to my purpose. I mainly was looking for inspiration as to what kind of journalistic article I wanted to write. This article is descriptive, persuasive and remains entertaining. It also incorporates a more conversational tone but notes societal issues and occasionally takes a more factual tone. Seeing how Lawson achieved this helped me structure my paper. Moreover, my piece is intended for an "internet" audience. As a result, I looked to Lawson as to how to format my paragraphs (short, no indentation).

Simons, Kurt, and Mark Preslan. "Natural History of Amblyopia Untreating Owing to Lack of Compliance." *British Journal of Ophthalmology*. 83. (1999): 582-587. Print.
<<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1723047/>>.

"Preschool children with amblyopia or its risk factors are at risk of having the current amblyopia deteriorate or of developing amblyopia, if not treated. These results raise questions

about the ethical acceptability of a prospective study of amblyopia treatment at these ages” (Kurt, Prelan, 582). The title of the above article is a bit misleading; the above quote is the main conclusion and it is not reflected well in that title. Therefore, when I first found it, I thought it might be more useful than it ended up being. This article was one of the first I read in pursuit of information that was rather hard to find (statistics on class and income, in relation to the success of amblyopia). I’ve used it as an example of the studies made for amblyopia and it helped me see what kind of research is being most commonly done or at least is most available about amblyopia treatment. This article also emphasizes the saliency of time in amblyopia treatment, if indirectly.