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Invisible Illness & Stigmas

 “It is like having a bad phone charging cord. You plug it in expecting to wake up with a full battery. But the cable didn’t connect properly so you wake up with 20 percent or less. No matter how much you try to rest, or ‘plug the phone back in to charge it’, it doesn’t always work, or you only get another 5 percent after hours of rest/‘charging’. You never know how much battery power you will have at any given moment, and even when you try you cannot fully charge when you need or want to. You just have to take what you get and use the power wisely” (Priscilla, G) This is one personal and captivating story of several which portrays the deep pain and suffering attributed with invisible illness. Invisible illness is when disabilities are not immediately apparent, and they can be tremendously detrimental to one’s health and ability to function. Some invisible illnesses are easily diagnosed by a blood test while others are not. These are referred to as medical mysteries. This can be incredibly frustrating to people who are suffering because we, as humans, value reassurance. It can become exceedingly challenging to live a happy life when you are unsure of what is happening to your body, and why. I wish to thoroughly examine Crohn’s disease, lung cancer, and obesity and further my research by observing the stigmas that are associated with them. Why are there certain stigmas attached to some invisible illnesses but not to others?

 A stigma is “an attribute that is deeply discrediting”, often contravening social norms, and perceived by others as being undesirable” (Dibley, Norton, & Whitehead). Crohn’s disease is known to carry a heavy stigma along with it. This chronic illness is characterized by symptoms of “diarrhea, urgency, and vomiting occurring in a relapsing and remitting pattern”. It is common that there is temporary loss of bowel control leading to fecal incontinence, which can potentially lead to stigmatization through infringement of social hygiene rules. The Heideggerian study, a phenomenological study aimed to examine the stigma associated with Crohn’s Disease, was performed in order to capture people’s personal experiences with the disease and their experiences feeling stigmatized. 40 members of a national Crohn’s Disease charity were recruited, and participants either did or did not experience fecal incontinence, and they either did or did not feel stigmatized. Individual interviews with each participant were conducted, and there were eight relational themes and three constitutive patterns present in the results. The study proved that stigma attached to Crohn’s disease is very complex and changes according to social setting. There were several stigmas reported, such as kinship stigma, which is directed at the person by someone “with whom they have a close biological or intimate bond” with. It was also found that certain characteristics of childhood experiences contributed to stigma reduction and stigma resistance. To conclude this study, it was decided that Crohn’s disease stigma occurs regardless of status which can negatively affect the experience associated with the disease. It is important to understand that “time, experience, and suitable support enhance stigma resilience”. Crohn’s Disease nurses can most effectively help patients achieve stigma resilience by instilling a sense of control, building support networks, and becoming increasingly competent in taking care of themselves in whatever condition.

 Stephanie Sendaula and Kiere Parrot explored what it is like to live with a chronic illness like lupus, multiple sclerosis, and Crohn’s disease and also explained that there is a common misconception that illness is an unfortunate, but rare experience. For the majority of people with chronic illnesses, symptoms are extremely challenging to dissipate and involve managing unpredictable symptoms quite often (Sendauala & Kiere). However, most of these people choose to not speak out about their illness and chronic conditions due to fear of stigmatization. The National Academy of Medicine estimates that “40% of Americans live with chronic illness, and approximately 50 million have an autoimmune disease” according to the American Autoimmune Related Diseases Association. Unfortunately, it has been proven that women are far more likely to have multiple chronic conditions, and throughout history there has been a pattern of doctors dismissing the concerns of their patients which consequently increases the stigma surrounding invisible illness. It is fair to state that people suffering from invisible illness can struggle greatly with expressing their identity and feeling comfortable enough to speak out about their chronic illness. In 2003, advocate Chrstine Miserandino developed the “spoon theory” which was a way to communicate about chronic illness, specifically focusing on how much energy one has on any given day. Since then, the spoon theory has transformed into a common self-identifier for people affected with invisible illness. It is great that this theory was constructed and has become as successful as it is now; however, it is important to acknowledge that someone had to create an actual theory to enable people suffering from chronic illness to communicate with one another about their experiences. This group of authors each describe how there is ultimately a major lack of communication among people in and out of the invisible illness medical community, due to the stigmas associated with the disease. Crohn’s disease is unique within itself because it is affiliated with fecal incontinence which is a very private matter that is not often openly talked about. After researching this disease and its symptoms, I believe that this is the stem of the majority of stigmatization of Crohn’s. Outsiders get “grossed out” by this disease simply because it touches on a topic that society has taught us to not openly speak about. As a result, people with Crohn’s hesitate to be open about their symptoms and experiences because it will make them stand out against every other “normal” person in society. One very positive outcome of social media is it has allowed for people to openly post and document their experiences with invisible illness, which breaks the silence slowly but powerfully. Some notable Instagram accounts of people battling Crohn’s disease are “uncoverostomy”, “girlinhealing”, and “marywiththegreenhair” (Welch, Ashley). Each day, these people are pushing the boundaries of silence which are consequently a result of invisible illness, and they are especially bringing light to Crohn’s disease.

 My second topic of research is lung cancer. Prior to researching this disease, I was completely unaware that there was so much stigma stemming from it. There are two forms of lung cancer: non-small cell lung cancer and small cell lung cancer. Lung cancer is the “second most diagnosed and the most lethal cancer among men and women in the United States” (Steffen, Gan, Smith, Edelman). In 2017, more than 22,000 new lung cancer cases were expected along with 155,000 deaths (Siegel, Miller, & Jemal). Symptoms include cough (often with blood), chest pain, wheezing, and weight loss. Treatments vary but may include surgery, chemotherapy, radiation therapy, targeted drug therapy, and immunotherapy (MayoClinic). Cancer researchists Gregory Gan and Martin Edelman, performed a study which observed about fifty lung cancer patients (39 non-small-cell stages and 11 limited and extensive small cell) and had these patients complete a baseline questionnaire and 21 daily diaries. These diaries assessed hope, stigma, physical symptoms, treatment factors, and functioning. The results were as followed: Patients who reported more daily hope reported higher social and role functioning in same and next day models. On the days that patients reported more hope than their usual average, they had higher social, role, and physical functioning; however, this did not carry into the next day. On treatment days, patients reported lower social and role functioning. On days that patients reported more stigma than usual, they reported lower social and role functioning. In conclusion, hope is associated with functioning in lung cancer patients. The takeaway message of this study was hope and stigma may be appropriate intervention targets to support daily social and role functioning during lung cancer treatment.

 Authors Hamann, Ostroff, Marks, Gerber, Schiller, and Lee each wrote about another study that took place examining how key stigma-related themes provide a blueprint for item development through a thematic analysis of semi-structured interviews and focus groups with lung cancer patients. Participants were recruited from two outpatient oncology clinics and included 42 lung cancer patients who participated in individual interviews and five focus groups. These participants were never smokers, long-term quitters, recent quitters, and current smokers. Each of the interviews promoted theme development and a conceptual model of lung cancer stigma, and the focus groups concentrated on feedback on the conceptual model. The results of this experiment were very fascinating; there was both perceived (felt) stigma and internalized (self) stigma emerging from the patients. The discussions of the perceived stigma were pervasive, whereas the people who experience internalized stigma were more commonly endorsed by current and recently quit smokers (Hamann, Ostroff, Marks, Gerber, Schiller, & Lee). The results imply that there is a widespread acknowledgement of stigma surrounding lung cancer patients, but that it occurs in varying degrees of internalized stigma and associated consequences. Another study to investigate stigmas and emotions associated with lung disease was performed by the Genetech, Project Implicit, the LUNGeveity organizations. This study evaluated 1800 people by providing them with a 10-minute online test. This test was designed to see if they had a subconscious bias towards people with lung cancer. The main question being targeted was: “What are your first thoughts and how do you really feel when you hear that someone has lung cancer?” It was found that three fourths of those who participated had a negative bias towards people with lunch cancer. 67% of people felt shame, 74% felt stigma, and 75% of people felt hopelessness. The most evident stigma that is associated with lung cancer is that this disease is self-inflicted, often caused by smoking. It can be predicted that the hopelessness of people living with lung cancer is coming from the low survival rates. Lung cancer has an overwhelming “you did this to yourself” stigma which can be a cause as to why so many lung cancer patients feel depressed. It is a definitive fact that chances of developing lung cancer are tremendously higher (roughly 23 times higher in male smokers compared to non-smokers). However, it is still unfortunate that this is the main stigma associated with lung cancer, as it can ultimately push patients who have lung cancer to feel even more depressed.

 The final topic that falls under invisible illness may not be considered an actual invisible illness because it is extremely visual. Obesity is an ambiguous term in itself, because numerous people consider themselves to be obese or overweight, when they are not. According to Medical News Today, a person is obese when they have a BMI between 25 and 29.9. Studies show that if current trends continue, more than 50% of the US population will have obesity in the next 20 years (Brewis, A.). Severe obesity appears to be increasing in prevalence faster than overweight obesity, and illness associated with obesity such as diabetes, cardiovascular disease, steatohepatitis, and sleep apnea is also increasing in prevalence and severity. Obesity has become so prominent that it is known as a major health crisis that threatens to overwhelm our health care system, shorten life expectancy, and reduce quality of life for millions of people. Obesity is caused and affected by many different factors, like genetics, personal behaviors, family habits, school and community programs, state and federal policy, and environmental factors. Obesity can be so severe that it inevitably affects every organ in one’s body and it can be extremely challenging for doctors to treat. As obesity rates increase, social stigmatization of obesity also increases. Many obese people claim to feel incredibly judged and looked down upon for their appearance by others. Therefore, obese people can sometimes experience psychosocial stress from feeling stigmatized, and the structural effects of discrimination also have a significant impact on their emotions. It has been proven that women and young girls are especially more prone to stigmatization in connection to obesity, and the increase of social media use has become a main cause of this. Ironically, people who are obese and are experiencing stigmatization feel the desire to progress their obesity even more. People do this by continuing to live an unhealthy lifestyle by eating poorly, not dieting, and not giving their bodies the important nutrients they need. Several obese people have also admitted to being bullied due to the way their bodies look and for being obese. There is a common stigma associated with obesity that is not always true. As I mentioned before, obesity has many causes and some of them are not necessarily one’s choice, or simply because they are eating poorly. Some people struggle with obesity their whole life because it was in their genes. In this case, it is unfortunate that there is such a strong stigma surrounding obesity with the assumption that all obese people bring it on themselves.

 There is one article that describes the importance of teaching pregnant women how not to become obese, without creating a stigma surrounding obesity. I found this article to be very interesting, because I viewed the title to be a bit contradictory. The management of obesity in pregnancy is rated of great importance in several doctors’ health agendas and it is identified as one of the biggest current issues facing midwifery **(**Olander, & Scamell). Some unsettling evidence is that student nurses not only hold negative discriminatory attitudes towards obese patients, but they also tend to see obesity as a lack of self-control. There was a recent survey study using established stigma questionnaires which found that there were unacceptable levels of weight bias in student dieticians, doctors, nurses, and nutritionists. Fillingham’s review of training for caring of patient’s with obesity concluded that training quality if low for nurses and midwives when treating patients with obesity. There is a demanding need for a more sensitive approach to obesity management and care when it comes to nurses and midwives taking care of pregnant women. Olander and Scamell believe that raising awareness of the stigmatization associated with obesity among pregnant women is critically important and that the effect of stigmatization is too consequential to continue without changing. Their proposition is that the way obesity management is taught to nurses and midwives is not acceptable and it is improved, pregnant women would be positively effected and their experiences would improve. Teaching students about obesity and obesity management revolves around four themes: The reductionism of the medicalization of obesity, the translation of epidemiological risk into woman centered care, the implicit and explicit stigma underpinning obesity management, and the insensitivity of the language of obesity management. The hope is that if each of these themes are enacted upon, the massive stigmatization associated with obesity would be reduced and health professionals would be properly trained to provide supportive care to people with obesity (American Academy of Pediatrics).

 Invisible illness is clearly a very an eminent topic of discussion. Unfortunately, it is not talked about enough and there are too many stigmas attached to invisible illnesses. It is worthy to note what type of stigma is attached to each invisible illness and why, so we can work away from these stigmas in the future. Every author and article I used to support my research brought a unique perspective to the medical world and invisible illness. Ultimately, each author complimented each other with their facts and beliefs, while explaining the harmful effects of stigmatization for individuals living with invisible illness. I want the readers of this essay to walk away with a better grasp of invisible illness and all of the damage that comes from stigmatization. I propose that schools and parents begin to talk about invisible illnesses more to their students and children, so younger people of our generations become more accustomed to these topics. If there is more self-awareness surrounding these topics, there will not be nearly as many stigmas associated with them.

Works Cited

A. Fillingham, S. Peters, A. Chisholm, J. Hart. Early training in tackling patient obesity: a systematic review of nurse education

Nurse Educ. Today, 34 (2014), pp. 396-404

American Academy of Pediatrics, publisher. (2018). *Obesity : Stigma, trends, and interventions / American Academy of Pediatrics.*

Brewis, A. (2014). Stigma and the perpetuation of obesity. Social Science & Medicine, 118(C), 152-158.

Hamann, H., Ostroff, J., Marks, E., Gerber, D., Schiller, J., & Lee, S. (2014). Stigma among patients with lung cancer: A patient‐reported measurement model. Psycho‐Oncology, 23(1), 81-92.

Millions of Women are Living With "Invisible Illnesses": Here's What That Means. (n.d.). Retrieved from https://www.health.com/condition/autoimmune-disease/invisible-illness

Olander, & Scamell. (2016). Teaching students about maternal obesity without creating obesity stigma. Nurse Education Today, 42, 59-61.

P604. Stigma in Inflammatory Bowel Disease. (2015). Journal of Crohn’s and Colitis, 9(Suppl1), S382.

Sendaula, Stephanie, & Parrott, Kiera. (2018). LIVING WELL WITH ILLNESS. Library Journal, 143(18), 36.

16 Metaphors for Chronic Illness to Use When the Spoon Theory Doesn't Fit. (2019, June 05). Retrieved from <https://themighty.com/2018/08/chronic-illness-energy-metaphors-spoon-theory/>

Steffen, L., Vowles, K., Smith, B., Gan, G., Edelman, M., & Freedland, Kenneth E. (2018). Daily Diary Study of Hope, Stigma, and Functioning in Lung Cancer Patients. Health Psychology, 37(3), 218-227.

Welch, A. (2018, July 24). Inspiring Crohn's Accounts to Follow Now on Instagram. Retrieved from <https://www.everydayhealth.com/crohns-disease/living-with/inspiring-crohns-accounts-follow-now-on-instagram/>