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Alzheimer's- the Burden that Everyone Faces

Alzheimer's is one of the most heart wrenching and severe diseases for patients. Alzheimer's is one of the most common forms of dementia, in which the rate doubles every decade after the age of 60 ("Memory"). And while many people believe Alzheimer's is primarily a genetic disorder, this is only the case merely five percent of the time (Mayo). Therefore, anyone can be affected by the disease regardless of genetic predisposition. However, this only begins to describe the severity of the debilitating condition at hand. The symptoms of Alzheimer's begin with trouble completing daily tasks, loss of energy, and language difficulties. Yet as the disease progresses, rambling speech becomes more prevalent along with wandering, and forgetting simple information. During the severe stages of the disease, many patients experience extreme mood swings, major confusion, and inability to remember *any* information (Mayo).

While some of the symptoms listed above may be viewed as primarily *physical* conditions, the majority of these symptoms take a severe *mental* toll on patients and anyone else that is directly or indirectly exposed to this disease. These mental difficulties affect three groups of people in particular: observers, patients, and caregivers. *Observers*, who witness the disease from afar in the forms of movies, are generally uncomfortable with the severity of the disease. They are often misled through the happy endings of movies. *Patients* experience the mental and physical symptoms listed above as well as forms of narrative wreckage and difficulty coping due to their inability to tell stories. And *caregivers*- who must care for, interpret, and deal with the patient's conditions- experience their own form of narrative wreckage as well as other mental stressors due to the amount of energy they expend on a daily basis. Due to the mental complexity of Alzheimer's, it is important to remember that Alzheimer's is not only heart-wrenching for observer and patients, but it also takes a heavy and unique toll on caregivers, thus rendering it a disease that effects everyone.

Due to the loss of mental faculties, Alzheimer's is an uncomfortable disease for observers, and this causes Alzheimer's movies to deliberately create happy endings to compensate for this discomfort. One aspect of Alzheimer's disease that makes it particularly uncomfortable to viewers- people who have no connection first or second hand with the disease- is the inability to fully comprehend the disease. To further this, many viewers are actually misled by the portrayal of Alzheimer's in our society. While this disease is a hot topic of many new movies, the movies all chose to end with the climax of what I call the "Alzheimer's plot-" in which the patient- almost always a woman- suddenly remembers her husband or loved one and the bond that they once shared. These movies end with an embrace, strategically placed lights, and happiness, making the movies more enjoyable and providing the necessary relief for viewers. In the 2014 film *Still Alice*, Alice iterates the words "love" after her daughter reads her a book. The movie ends with the pair sitting

close together. As the joyous background musical escalates, the final scene culminates with a flashback of Alice and her daughter on the beach when they were younger. In a comparable fashion, the 2006 movie, *Away from Her*, ends on a similar note. The Alzheimer's patient, Fiona, suddenly realizes that her husband spent months visiting her in her retirement home despite her falling in love with another man. Fiona and her husband share an embrace as the pair rekindle their love.

While the two movies above are only a few examples of "the Alzheimer's plot", it is important to ask: Why choose to end the movie in a happy light at all? Why not end the movie with the continued deterioration of the patient's mental processes, depicting the sad truth of the life of an Alzheimer's patient? This comes back to the previously stated point- the loss of mental capacity in Alzheimer's patients causes an unsettling feeling in the eyes of viewers, most of whom are unexposed to the disease. From the deterioration of the patient's brain to the loosening of familial bonds to the inevitable outcome for the patients, there is only so much that can be done to spin these movies in a less sorrowful way while still retaining important aspects of the disease. Through movies, which epitomize appeal towards lay members of society, it is apparent that Alzheimer's is a difficult disease to process and cope with. In order to deal with this, movies put a positive spin on the disease by ending with a sense of false hope in the form of a happy moment between patients and their loved ones. This resolves some of the confusion and unwanted emotion while ending with the happy message of familial love, something that is more desirable to viewers.

While Alzheimer's is disheartening for everyone, it takes a very significant and unique toll on the patients themselves, due to the narrative wreckage that ensues. Aside from the notorious loss of memory- especially the inability to complete daily tasks and remember people- the underlying struggle for an Alzheimer's patient is the inability for the patient to tell her own narrative. This concept can be further explained through the theories of sociologist Arthur Frank. One of Frank's major claims- if not his most important claim- is that "becoming seriously ill is a call for stories" (53). Essentially, when one gets sick, a method of coping with the illness, expressing oneself, and explaining the situation to others comes through remodeling one's own narrative. However, while the narrative can be powerful and empowering, when in the face of severe illness, patients experience what Ronald Dworkin deems narrative wreckage "which occurs in the face of sudden, life-changing illness" (qtd. in Frank 54). Severe illness changes a person's narrative in forms that could have never be conceived, calling for necessary emphasis on one's own ability to effectively convey feelings and emotions throughout this difficult experience. Narrative wreckage causes a sort of interruption in the person's life story, wherein the person must continue to use storytelling as a method of coping with and rediscovering one's own story.

While the concept of narrative wreckage can be applied to the contraction of many severe diseases, it takes on a slightly different notion with regards to Alzheimer's disease, due to patients' inability to remember the past and present. Frank describes one of his friend's difficulties through his period of narrative wreckage, stating that his "present is not what the past was supposed to lead up to, and the future [was] scarcely thinkable" (55). This quote emphasizes the loss of the patient's sense of self, especially with regards to their future. They feel that they are no longer in control of their future and this causes them to feel even more uncertain about the direction their present is heading. This concept and deterioration of time and certainty is what causes the extreme narrative wreckage. And although Frank's concept of narrative wreckage fits the mold of most illnesses, it cannot be directly applied to Alzheimer's patients. Alzheimer's patients are not only unable to imagine their future, but they are also incapable of remembering their past and comprehending their present. As noted by Dr. Cassandra Germain, a research associate at the Duke University Medical School, the inability to recognize family members and daily tasks happens early on during the Alzheimer's process. And how is an Alzheimer's patient supposed to rebuild her story and properly handle a situation of narrative wreckage while she is unable to even form cohesive ideas? Scafer notes that "the way out of the narrative wreckage is telling stories," which makes it nearly impossible for Alzheimer's patients to get out of this situation (qtd. in Frank 55). Since these patients are incapable of telling these stories, they are almost incapable of getting out of their situation of narrative wreckage. Therefore, there becomes a never-ending inability to tell stories and to convey an emotional message, preventing proper methods of coping as well as methods of communications to loved ones and caregivers. This lack of expression and lack of a proper coping mechanism cause Alzheimer's to take a significant mental toll on the patients.

While the lack of ability to create a personal narrative describes the severity of Alzheimer's for the *patients*, it also describes difficulties *caregivers* face on a regular basis, because of their inability to understand patients' perspectives. As previously stated, telling one's story is important for a plethora of reasons, including providing adequate information to loved ones and others. Frank describes the medical narrative in many ways relating to the patient, but he does not place much emphasis on the narrative of a loved one. With the concept of a self-narrative in mind, a loved one cannot create an adequate narrative for the patient, rendering it nearly impossible to empathize with the patient. This leaves caregivers frustrated and leads them to only hope that they are doing their best to help their loved ones through their illness. In this sense, the caregiver also goes through a state of narrative wreckage in the form of an interruption of daily life tasks through the course of immense physical and mental stress. Although the caregiver does not necessarily go through the loss of memory and other symptoms notorious of Alzheimer's, caregivers are "at elevated risk for developing mental health disorders" due to the immense mental and physical

stress as well as the lack of personal attention with full-fledged focus on the patient (“Mental”). This reemphasizes the struggles faced by caregivers regardless of not having a diagnosed disease. Specifically, there are three ways in which the caregiver is affected by this condition: the immense amount of time and energy that must be spent on the patient, the mental heartaches when the patient can no longer remember them as their relative, and the imminent knowledge that the patient will never recover from her illness.

Aside from difficulty in communication, caregivers also expend immense amounts of money and physical energy in caring for Alzheimer’s patients. This comes in the form of respite care, retirement homes, making decisions for the patient, speaking on behalf of the patient, visiting doctors, and constant monitoring of the patient’s condition. According to *A Place for Mom*, retirement homes can range from \$2600-\$5000 dollars a month, and that does not even account for Alzheimer’s-specialized retirement homes, which cost even more due to the intense amount of nurses’ attention (“Retirement”). Dr. Germain notes that, for families that chose to go the caregiver route, hundreds of dollars are still spent a month for doctor’s visits, special food and needs, travel for other family member visits, etc. Some families may even need to move to better accommodate the debilitating physical condition of the patient. Cost wise, there is no end of the amount of unexpected expenses. And while this should not have an impact on the amount of care given to a patient, it unquestionably impacts the financial stress of the caregiver, who must work out different budgets in order to properly care for the patient. Caregivers must also expend immense amounts of physical energy to properly care for their loved ones. The patients need constant care and supervision, so a caregiver must always be alert during the day and the night. Being alert at all hours requires a strong amount of energy, leaving the caregiver exhausted. One caregiver, Muffett chose to share her story on the *Alzheimer’s Association* website, where she spoke about her caregiver duties that she performed for nine years, from the moment that her mother was diagnosed with Alzheimer’s. After speaking about her own personal heartaches-including her lack of a husband and retirement plans as well as the recent loss of her pets and other family members- she notes that “everything is secondary when you are a caregiver” (“Muffett’s”). This powerful statement depicts the great extent of the patient’s needs as well as what the caregiver must give up in his/her own life in order to properly care for the patient. This implies that caregiving should come on the top of priorities and that it often does so innately.

While the previous examples highlight the *physical* exhaustion faced by the caregivers, it is also important to note their *mental* exhaustion throughout this draining process. One of the more trivial-yet-intense forms of mental drainage comes from the constant decision-making that caregivers must utilize. As stated by Dr. Germain, there are sometimes conflicts between caregivers as to who will have absolute control in the caregiving process. As Muffett also touches upon, it is better

to “establish one caregiver to be the final authority in decisions about caregiving” (“Muffett’s”). And while this is a difficult process, the reasoning behind this can be explained through Dr. Germain’s notion of conflict among authorities. Dr. Germain goes on to mention that there are often times difficult choices dealing with the sedation of retirement home residents as well as other decisions relating to finance and care. Each decision the caregiver makes on behalf of the resident takes a mental toll on the caregiver, who always wonders whether his decision was the best for the patient. This adds to the exorbitant amount of stress, which can be represented through narrative wreckage. Caregivers expend so much of this mental and physical effort to best interpret the needs of their patients but are never sure exactly what to do. This uncertainty makes it difficult to rewrite their own story, which is now dependent on their own interpretations of their patient. Their time and energy often times prevents them from coping in the form of recreating their own narrative, and they must instead focus on best interpreting the needs of their patient.

Caregivers must also deal with the inevitable on a daily basis, which begins with the patient’s inability to remember loved ones. This is one of the most difficult parts of the caregiving process, and one that continues to haunt caregiver as the disease progresses. Dr. Germain points out that this only gets worse over time. She notes that many patients spend most of their disease remembering family members who were with them from earlier time periods, in which the memories are more firmly stored in the patients (Germain). However, there comes times when patients cannot recognize their own children, or as shown in *Away from Her*, their own husbands. This notion further emphasizes the toll that Alzheimer’s can take on familial relationships, deterring the disease into a one-sided relationship where the caregiver continues to give, yet is aware that the patient may not remember who he is. This is one of the worst contributors to the caregiver’s narrative wreckage. Returning to Frank’s previous quote about the toll of narrative wreckage on the past, present, and future of Alzheimer’s patients, this concept can also be applied to caregivers. Although caregivers are able to mentally recall the past, live in the present, and plan for the future, the lack of recognition between patient and caregiver causes them to feel lost and unhappy when nostalgically recollecting the past, and looking to the present and future. This causes interruptions in their story, and continues to play a role in preventing the coping and recovering process.

While the previous point proves truly tragic, possibly the worst realization for caregivers is that Alzheimer’s is a terminal disease. Dr. Germain points out that, “what affects the caregivers and family members is the awareness that there is no cure”. While she goes on to note that professors and other people of high intelligence are often able to conceal the early stage of the disease through their academic endeavors and rationale, in the end, there is nowhere to hide these symptoms, regardless of intellect or speed of disease progression. There is no medicine for Alzheimer’s- something that both the patient and the caregiver are

aware of even at the beginning of their journey. With a tone of sorrow, Muffett also acknowledges this point, stating that, as a caregiver “because this battle cannot be won, you will ultimately fail” (“Muffett’s”). At first, these harsh words seem out of place and pessimistic, but this realization becomes more apparent throughout the course of the Alzheimer’s journey, in which the patient’s mental state continues to deteriorate and lack of an ultimate cure is disheartening. This highlights aspects of the future and the inability of caregivers to reform a positive and healthy narrative, since they are aware of the imminent tragic ending ahead. It is difficult for caregivers to even reshape their narrative when they know the disease will not become better over time. There is fear in reshaping the story, and an innate willingness not to do so in the face of an unhappy ending.

With the knowledge that there is no cure, the question arises: Why be a caregiver if there is no cure for the patients in the first place? If it is a hopeless cause, why waste immense amounts of time and energy through this process? Muffett ends her memoir stating that “the effort is worth it to see that your loved one is comfortable, safe and cared for” (“Muffett’s”). This emphasizes the point that there is a benefit to caring for your loved one. Knowing that you did everything in your power to make a loved one feel better is the underlying motive for why caregivers give up months and years of their time. The knowledge that their loved one is comfortable and that they are doing everything in their power to keep them this way gives them some reason to keep working. And while there is no cure for the disease, helping the patients during the journey is one of the most humble and sincere tasks that a caregiver can take on.

There is no doubt that Alzheimer’s is one of the most uncomfortable, frustrating, and seemingly-hopeless diseases known to mankind. The toll it takes on patients, caregivers, and even observers is inexplicable. And while caregivers are able to help through the journey, Frank points out that the struggle of having a disease is “a responsibility which no one else can finally lift entirely from the shoulders of the one who lives that life” (60). This quote reemphasizes the amount of personal hindrance brought forward by the loss of memory, but also highlights the fact that caregivers do not have the omnipotent power to “lift the burden” from the patients. As educated humans, we seek answers, and Alzheimer’s is one case where the answer has yet to be discovered. While there is still much to be discovered about the disease, it is important to focus on the more controllable aspects of Alzheimer’s that can be applied to each group mentioned. It is important for observers to understand that there is more to the disease than what they witness in a movie. With regards to patients, it is important for others to support them through their narrative wreckage and to continue to provide them with the assistance and coping mechanisms they need. And finally, with regards to caretakers, it is important to acknowledge that they too go through a form of narrative wreckage. Although caregivers spend much of their time and attention on helping their patients, they must also receive support.

And although there is not always a way to lift the burden off of the caregivers, they must be acknowledged for their work. While a cure for Alzheimer's is still in the work, we must strive to educate ourselves on the disease and its unique mental components so that we can properly support and care for everyone through this journey.

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