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*University of Mississippi*

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**TO CARE WHEN THERE IS NO CURE: CHRONIC ILLNESS AND MEDICINE**

By:

Skylar Nash

A thesis submitted to the faculty of the University of Mississippi in partial fulfillment of the requirements of the Sally McDonnell Barksdale Honors College.

Oxford

April 2021

Approved by

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## ABSTRACT

Skylar Nash:

To Care When There is No Cure: Chronic Illness and Medicine

(Under the direction of Dr. Sarah Moses)

Millions of people worldwide are suffering from chronic illness at this very moment. Just in the United States, a little less than half of the entire population has been diagnosed with a chronic illness, and a large portion of those patients have been diagnosed with multiple chronic diseases. Those stricken by incurable illness are forced to face and manage their unique illness experience along with the side-effects of the disease itself. For this subset of the population, everyday normal activity can become relatively impossible to work through. There are financial, psychological, social, and physical obstacles to overcome every day that happen to seem just that much worse when placed in conjunction with a long-term ailment.

The world of Western medicine today, despite its ever-advancing ways, still fails to provide a proper systematic care plan for these individuals' personal and intricate needs. Studies have shown promising treatment plans, such as integration and practice facilitation; however, few studies have been performed in regards to these treatment approaches, and the positive results have yet to be fully implemented in a way that suggests their utilization across the country. The goal of this original research is to explore how the current healthcare system, specifically in the United States, approaches chronic.

This research was gathered through research studies, notable books by reputable writers in the area, an interview, and first-hand shadowing experience. Through these outlets, it was found that while there is a greater recognition of the problem today, there is still little knowledge

regarding the proper way in which to care for the chronically ill. The system fails to approach the topic in a way that is feasible for the chronically ill, and because of this, many do not receive the correct treatment. As an effect, many will suffer more than they already do.

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## **Chapter I:**

### **A Personal Narrative of Illness**

Every day after returning home from school, my job was to feed the chickens, dogs, ducks, cats, and whatever other farm animals we had at the time. After gathering the eggs, washing them, and tucking them away in the refrigerator, I could do my homework. Once that was complete, I could finally go play. This day must have been a Friday, since my dad was home from work to spend time with me. Of course, being the little adventurer I was, I wanted to use the ladder to reach the top of the shed, where we could then climb onto the barn. After spending time gazing at the clouds and catching up, we made our way back down the ladder. In this moment, just a few steps away from the ladder was the spot where my life changed forever. Suddenly, I felt my ability to hear escape my left ear, while a horribly obnoxious ringing took its place, and the world around me began to spin.

After a sleepless night of extreme distress, fear, and endless prayers for the return of my lost sense, an appointment was scheduled with an otolaryngologist, who diagnosed my condition as Meniere's disease, which is a “disorder of the inner ear that can lead to dizzy spells (vertigo) and hearing loss” (“Meniere's Disease - Symptoms And Causes”). I can remember the physician asking me to roll onto my left side in order to show my mom that my pupils were actually spinning as a physical indication of the vertigo I was experiencing. For the treatment, he actually recommended that I simply sleep on my right side in order to achieve equilibrium from what he believed was a calcium imbalance. In time, I came to understand how the imbalance came to be. The tiny calcium stones or crystals, per se, reside within the inner ear canals in order to aid in balance. Typically, when you move about, “such as when you stand up or turn your head,” these

stones move as well (“Benign Paroxysmal Positional Vertigo (BPPV)”). Sometimes they move into an area of the inner ear known as the semicircular canal. Once in the semicircular canal, sensors in this structure are “triggered by the stones, which causes a feeling of dizziness” (“Benign Paroxysmal Positional Vertigo (BPPV)”). After a few months of sleeping on my good ear, the vertigo eventually ceased as the crystals regained their equilibrium. However, I was still referred to a hearing specialist at Vanderbilt hospital to uncover the hearing loss mystery.

Unfortunately, at Vanderbilt, I was diagnosed with Sudden Sensorineural Hearing Loss (SSHL), commonly known as sudden deafness. It is an unexplained, rapid loss of hearing either all at once or over a few days. SSHL happens because there is something wrong with the sensory organs of the inner ear. Sudden deafness frequently affects only one ear, and can be caused by a number of factors, such as Meningitis, Multiple Sclerosis, infections, vascular disorders, head trauma, post-ear surgery, ototoxic drugs, exposure to loud noise, virus or disease, autoimmune inner ear disease, heredity, aging, malformation of the inner ear, Meniere’s Disease, or Otosclerosis (a hereditary disorder in which a bony growth forms around a small bone in the middle ear, preventing it from vibrating when stimulated by sound, tumors, and other unknown causes) (Sataloff, 123). Since there was no physical damage within my ear and no indications of the cause, we were left with no true answers, and a final diagnosis of Idiopathic SSHL. I remember how surprised my physician was to see this chronic disorder occur in a 9-year-old girl rather than in a 70-year-old woman. I remember him telling me that I would likely never regain my ability to hear, but explained that due to the loss in the left ear, my right ear was overcompensating and now encompasses “over perfect, super hearing.”

Despite the gesture to highlight the bright side of the situation, the specialist failed to console me as I realized I would be living with this condition for the rest of my life. There was

no one to assist me along the path of adjustment and adaptation; I figured it out on my own. Today, I find myself switching sides in a group or in the movie theater so that no one is on my left side. At 9-years-old, I learned that people become quite angry quite quickly when they believe that someone is ignoring them. I cannot locate sounds from any particular direction, and I have constant tinnitus that is heightened in moments of stress. One might be surprised to find how much more difficult testing becomes when your anxiety causes a higher frequency pitch in your ear that you are unable to hear yourself think over. In the end, the most difficult obstacle to work through is the fear that I will become completely deaf one day. In fact, I actually had an experience this summer that led me to my knees praying that I would not lose what hearing I have left as well as to learning sign language in case my prayers went unanswered.

While I have met with medical professionals that since have mentioned how well I have adjusted, not one offered assistance, encouragement, or signs of empathy. Unfortunately, humanity maintains a peculiar relationship with the unknown. Physicians prefer to achieve a full understanding of illness, and when an issue such as Idiopathic Hearing Loss arises, the majority tends to shy from the topic because the title itself - idiopathic - offers no hope. In the world of hearing loss, a cause is needed in order to determine how the affected area should be cared for, and without a cause, there is no promising treatment plan. Due to the ambiguity revolving around the subject, many physicians neglect the patient (me) by not drawing up a plan, failing to follow up, or even by giving up at the beginning of the race. Despite living in a world with an ever-advancing medical field, there still remain so many unknowns regarding chronic illness. How is that acceptable? If one in three people suffer from chronic illness across the globe, why do healthcare professionals fail every day to care for the burdened 2.53 billion people worldwide (Hajat and Stein)? How can physicians and other healthcare providers develop a new approach to

the treatment of chronic illness that will allow them to properly care for patients, whose illnesses cannot be cured? This thesis will show that while there is a dire need to meet the needs of chronically ill patients, medicine across the globe still fails to do so. This is due to the numerous factors prohibiting progress, and because of this, there are research studies underway examining the possible ways to overcome the setbacks that continue to hinder progress in this area of medicine. Like many issues today, there is no single solution, but there is a multitude of possible answers that could help in solving the problem at hand. These ideas will be explored in further depth within this work.

## **Chapter II:**

### **A Day in the Life of the Chronically Ill**

According to the Centers for Disease Control and Prevention, “Chronic diseases are defined broadly as conditions that last 1 year or more and require ongoing medical attention or limit activities of daily living or both.” According to longitudinal research, cardiovascular disease, cancer, arthritis and diabetes, are among the most prevalent and costly of all chronic diseases globally” (Dixon and Whittemore, 2). Just in the United States, chronic illnesses are the leading cause of death and disability, accounting for seven of every ten deaths (Dixon and Whittemore, 2). More specifically, heart disease, cancer, and diabetes are the most common forms of chronic diseases that contribute to a large portion of deaths across the nation (“About Chronic Diseases”). In fact, there are over 90 million Americans experiencing pain, suffering, and lessened quality of life resulting from these various chronic illnesses and disabilities (Dixon and Whittemore, 2).

There is no doubt that chronic illness is disruptive. As individuals discover their inability to perform previously taken-for granted ways of life, resulting symptoms can lead to a lack of bodily control and limited activities, which causes the person to question their own normalcy. Research reveals how these people with different chronic illnesses share concerns about their functional abilities and maintaining normal lives. Of the chronically ill, the majority will experience at least one if not more of the following effects: limited activities of daily living, impaired functioning, loss of independence, changes in identity, emotional turmoil, and of course, pain. When individuals can no longer perform customary tasks, fulfill their roles, and live

‘normal’ lives, self concept is challenged, and a coherent sense of self can be lost (Townsend, Wyke and Hunt, 186).

In order to live with a chronic condition, one must learn to adapt to the ailment by adjusting lifestyle strategies, practicing self-management, and by taking prescribed medication. Self-management, in particular, is a “dynamic active process of learning, practicing and exploring the skills necessary to create a healthy and emotionally satisfying life” (“Chronic illness: the process of integration,” 2). Interventions designed for assisting individuals with a chronic illness have demonstrated reduced pain and healthcare visits as well as improved decision-making and quality of life (Dixon and Whittemore, 2). This highlights the importance of incorporating new health-conscious behaviors into the patients’ daily routines by indicating that constant adjustments must be made as unexpected changes come to pass in the individuals’ lives.

For further context, Arthur Kleinman, an internationally-recognized anthropologist and physician, is known for his work with chronically ill patients, especially after caring for his late wife for ten consecutive years after she had been diagnosed with early onset Alzheimer’s Disease. Kleinman is an expert in this area and clarifies the distinction between chronic disease and chronic illness.

Now, it is important to note that disease is the “science of what makes us sick,” which is what essentially leads to illness (Kleinman, “Treating”). While the *diseases* are recognized and deemed to be unfortunate circumstances, it seems as if little effort is invested into the evolving understanding of what it means to be the person suffering from the resulting *illness*. As a

distinction, “*Disease demands treatment, while illness calls out for care*” (Kleinman, “Treating”).

Given that chronic illness, “the human experience of being sick” long-term, is directly due to the biological changes in the body that are essentially permanent, chronic illness, or any illness in general, alters people’s normal way of life (Kleinman, “Treating”). In the long run, actively putting forth the effort to combat the challenging symptoms of chronic illness takes a physical and psychological toll on the human body. While symptoms of the H1N1 virus may last only 3 days to a week, arthritis on the other hand, is just as (if not more) physically debilitating and will last a lifetime. Similar to those suffering from chronic diseases such as arthritis, type 2 diabetics report stress, anxiety, frustration and difficulty coping with the demands of daily self-management (Polonsky, et al.). These chronic diseases stray from their role as a disease in order to possess the individual in more ways than one.

The impact overwhelms all aspects of life, including an individual’s vocational, physical, psychological, and social endeavors. To learn how to cope with these almost parasitic diseases is a treacherous task for even the strongest of people, and because of this, it is critical in this area of healthcare to have clinicians that go above and beyond to provide quality care to patients, who truly need a different kind of care, in the examination room and beyond. The goal should be to learn how to *care for the illness* rather than simply *treating the disease*.

## **Chronic Illness is a Challenge for the World of Medicine**

Despite all modern-day advancements in the medical field, much more is claimed than what is actually known. With this in mind, one can then see why chronic disorders are still so widely misunderstood. As a matter of fact, “most chronic diseases can only be managed, not cured, and their sequelae in long-term, disabling consequences such as blindness, amputation, and kidney failure in diabetes cannot be controlled either” (Kleinman, “Caregiving,” 100). An underlying issue here is that the “physician’s role became ‘curer of disease’ rather than ‘healer of the sick’” (Egnew). Healing in a holistic sense has faded from medical attention and is rarely discussed in the medical literature, yet it is a vital piece in care practices for the chronically ill. Healing is an intensely personal and subjective experience “involving a reconciliation of the meaning an individual ascribes to distressing events with his or her perception of wholeness as a person” (Egnew). Healing is defined as the personal experience of the “transcendence of suffering” (Egnew). In order to enhance their abilities as healers, physicians can begin by “recognizing, diagnosing, minimizing, and relieving suffering, as well as helping patients transcend suffering” (Egnew).

When caring for the chronically ill and walking them through their healing journey, it is generally impossible to cure the disease. Despite this, medical professionals sometimes promote false hope - not out of malice, but out of their own hopes to cure patients, rather than focus on their healing process. Let us consider schizophrenia and depressive or anxiety disorders for example. Our world has yet to create a single biological test for routine clinical use in diagnosis of these conditions. Instead they are treated with drugs in which 35% of patients are treatment resistant, while in most clinical trials, the placebo effect accounts for a 45% improvement (Kleinman, “Caregiving,” 100). Knowing this, one can conclude that the

pharmaceutical companies release percentage claims that fail to accurately depict the true impact of their drugs. Yet, consumers are easily persuaded by these pharmaceutical advertisements and continue to utilize drugs that they have been told will offer a tangible ‘quick fix’.

Overall, prognosis not only for mental health conditions, but for most chronic disorders remains difficult and uncertain. There is a rather large gap between “moral reality that encourages exaggeration of knowledge and treatment and the genuine reality of our existential condition” (Kleinman, “Caregiving,” 101). Clinicians want to be the superheroes that can fix all of your problems, while pharmaceutical companies want to be the ones that offer the quick fix in exchange for a quick dollar. Patients are misled by the media’s fake news that distorts the true ability of medication, while medical professionals are fooled by “routine hyping in the medical literature” (Kleinman, “Caregiving,” 101).

Globally, highly educated scientists, researchers, and clinicians are participating in this false understanding of medicine, which is leading to a global interest being distorted for social, cultural, and economic reasons. This makes sense as to why there is a widespread suspicion that health professionals are more interested in their own financial condition than in the patient’s condition, so one can understand why distrust of physicians has skyrocketed across the globe while the status and prestige of the profession has fallen (Kleinman, “Caregiving,” 101). A physician’s commitment to patients with the most serious chronic medical conditions is a great task that many physicians choose not to challenge.

Generally, physicians seem to forget that the patient’s illness, the experience of suffering, is not just a personal one, as it is also strongly influenced by cultural and historical changes in the illness meanings, socialization, and self-processes that contribute to moral life

being distinctively different throughout the numerous eras and societies (Kleinman, “Caregiving,” 103). Faced with the threat that chronic illness poses, many reframe the moral experience of suffering by designing new meanings, emotions and values through ethical, religious and aesthetic activities (Kleinman, “Caregiving,” 103).

Humanity seems to have this innate desire for all things to carry meaning, even the suffering from diseases and disabilities. The same remains true for physicians. After all, they are a part of humanity as well. When faced with their patient’s suffering or even their own, physicians also rework meanings, emotions and values in both their professional and personal lives. Those previously mentioned ethical, religious and aesthetic practices can contribute to professional caregiving by transforming the experience of the caregiver (Kleinman, “Caregiving,” 103).

Even physicians with the best intentions struggle to decipher what is best for the patient. This confusion is a result of the evolution of medicine, the unknowns of medicine, personal beliefs and feelings, diversity in patient populations, and economic means of support. As Western medicine continues in its advancement, it becomes more evident that these “bureaucratic structures and financial constraints of care undermine the art of medicine and interfere with the ancient task of caregiving” (Kleinman, “Caregiving,” 103).

When Kate Lorig, researcher and professor at Stanford University was asked “Could the health care system do a better job addressing chronic disease?” she replied with, “The system would probably need to be totally reorganized if it was really going to do that” (“Chronic Disease Expert”). For the physician, it all boils down to finding the true meaning of caring and making the effort to carry it out. According to the basis of most medical care studies, caregiving begins with an ethical act of acknowledging the situation of the sufferer, affirming

their efforts and efforts of loved ones to respond to pain and impairment, and demonstrating both moral and emotional solidarity with those efforts (Kleinman, “Caregiving,” 103). Once this first step is achieved, the patient must be present in pain management, symptom relief, treatment, and sagacious management of necessary technology. Patients should also become aware and gain the ability to control unnecessary or futile interventions (Kleinman, “Caregiving,” 104).

This is more than a one-person job, which means a network of co-health professionals, advisors, and family members is a major piece of the puzzle. Unfortunately, the medical system addresses diseases or parts of diseases, but fails to address the whole, complex person with multiple chronic diseases. So those suffering from chronic illness must see a primary physician in order to manage the day-to-day things as well as multiple specialists for the more specialized problems, which are then never shared across the board of the patient’s many physicians (“Chronic Disease Expert”).

All in all, to achieve this high-level of quality care, the physicians must allot some undivided time to their patients, take the time to listen to the individual stories and needs, implementing a plan that is broken down for the patient, as well as promoting the process of psychosocial, “describing the intersection and interaction of social, cultural, and environmental influences on the mind and behavior,” coping following the acceptance of chronic illnesses (*American Psychological Association*). From here, it is important to consider the complexity of the person’s illness and initiate collaboration with the other medical professionals that are a part of this process as well. Patients, such as a close friend of mine, struggle with their chronic illnesses, such as diabetes. In fact, many will admit that even when the illness becomes overwhelming, a supportive healthcare team can pick you up when you are down. However, if

the professionals fail to do their part correctly, the patient will undoubtedly suffer.

### **Diagnosis of Diabetes and the Lonely Path to Self-Management**

A friend of mine was diagnosed with type 1 diabetes at the age of 19. He had checked himself into a nearby walk-in clinic for what he believed was a urinary tract infection, but when the urine test came back with high levels of glucose, the nurse practitioner on duty was concerned for his health and had him rushed to the emergency room, where he was informed of the diagnosis. For years prior to knowing the truth, my friend had experienced possible indicators of diabetes, such as increased thirst, more frequent urination, migraines, fatigue, extreme loss of weight, yet not one health professional looked further into the symptoms. Now, his life consists of multiple daily injections of fast-acting and slow-acting insulin, glucose monitoring, carb counting, anxiety, and stress.

While reflecting on the weekend after diagnosis, my friend remembers being very nervous after just discovering his health was compromised and would be forever. He felt as if he was just thrown into it without proper training before leaving the hospital. Attending physicians did not provide him with a care plan that explained how to self-inject the insulin, how often, or how much.

My friend was not told how different foods, different daily activities, or even different common illnesses could affect blood sugar. It was quite stressful when he had to try and figure these things out on my own, especially when these experiences could have been a matter of life or death. The attending physician heavily relied on the fact that my friend would receive

an effective treatment plan once he went home several weeks later for break. To the scared young man in the emergency room, it seemed as if the physician was simply pushing the problems on to another doctor. Thankfully, once my friend returned home, he received a higher quality medical team that truly cared about him. It was relieving to meet with the endocrinologist, who asked questions regarding how my friend wanted to approach insulin portions that would best fit his lifestyle. For the first time since diagnosis, he was finally being heard and was not being judged for having this disease that he did not choose to have.

When specialists consider treatment for this disease, many fail to consider mental health as an area that needs attention. My friend expresses that he is now always exhausted from hauling around the anxiety that stems from the pressure of essentially keeping himself alive. In fact, he knows many diabetics that experience burnout, which is something he tries to avoid. However, that effort becomes a burden when physicians expect their patients to follow a very strict regimen that has much room for user error. After all, if the physician does not actually have diabetes herself, it is understandable for even the expert on the disease to not truly understand its ins and outs.

In summation, my friend believes the key to having type 1 diabetes is to find a balance between caring for oneself, ensuring personal health, and not allowing the disease to consume oneself. Even though he suffers from much anxiety and fears how this chronic condition will affect his future, he intentionally clings to the thoughts and actions that keep his mind and body at peace, such as the T1D community with members that share the same struggles and can relate to him when he feels no one else understands.

With this in consideration, a durable self-management regimen to keep him in good physical health, while also keeping disruptions at a minimum is an ideal treatment plan. This

is where integration, defined as “a human–environment interaction whereby new life experiences (i.e. illness) are reconciled with past and present identities and roles,” becomes necessary in healthcare (Dixon and Whittemore, 2). Unfortunately, this is a developing concept that many physicians have yet to comprehend, let alone practice. Chronic illness is infinite, and those stricken by misfortune deserve healthcare providers that treat not just their disease-induced ailments but also the resulting illness that consumes the human’s existence.

### **Everyday Interferences**

As far as the chronically-ill patient such as my diabetic friend is concerned there is an everyday battle between balancing the demands of the illness and the demands of everyday life. Each day, he is responsible for completing class assignments, handling the stress that comes with being a pre-physical therapy student at a four-year university, meeting a certain activity goal, eating the right foods to manage her blood glucose levels, and any additional curveballs that accompany the illness as well as everyday life.

In hindsight, little research has been conducted on how average daily situations interfere with self-management of the illness. Self-management is contingent upon the ability of patients to monitor their health status, take prescribed medication, interact with healthcare providers and manage the impact of the illness on physical, psychological and social functioning (van Houtum L., et al., 1). While this may seem like a concise regimen, the chronically ill possess “low rates of medication adherence, poor levels of disease control, and the modest positive effects of self-management interventions” (Van Houtum L., et al., 1). Ideally, if negative environmental influences of everyday life could be minimized, an immense burden could be lifted from the chronically ill community.

Realistically, the average human deals with the stress that stems from familial and marital relationships, financial lows, and employment and housing status every day. To separate these issues from the chronic illness is simply not plausible, considering the effect that these everyday stressors have on both mental and physical well-being. Based on the Social Production Function theory of Lindenberg and colleagues, people with chronic illness must prioritize their goals and decide where their resources such as time, energy, money and social support will go. Facing financial, marital or housing problems, people may prioritize coping with these problems as more important than managing their chronic illness (Van Houtum, et al., 2). In order to solve these problems, people require resources that must be prioritized and allocated accordingly, which is a pivotal step in self-care for the chronically ill.

### **Chapter III: Treatment and Care**

#### **Treatment Burden**

The treatment of chronic illness comes in many forms including surgery, physical therapy, psychological therapy and radiotherapy. However, one of the most common treatment forms is the use of medication (Sav, et al.). While treatment through these means may be

beneficial, little attention is paid to the burden or detrimental effects of a particular treatment plan. Treatment burden can be defined as “treatment work, delegated by health care systems to patients and its impact on their functioning and well-being” (Alsadah, et al.). Today, there are ever-growing demands on patients to “organize their own care and self-manage to comply with complex regimens” (Alsadah, et al.).

In one particular study on this topic, researchers use Rodgers' method of concept analysis, which is a review describing the ways in which treatment burden has been “conceptualized to define the concept and to develop a framework for understanding its attributes, antecedents and consequences” (Sav, et al.). These researchers have noted that although the burden resulting from chronic illness, recognized as disease burden or symptom burden, is well documented in medical literature, the burden associated with the treatment and management of chronic illness has not been well defined (Sav, et al.). Treatment burden on the other hand is shifty and almost puzzling. The majority of the definitions from other studies consist of “workloads/tasks and their impact on the patients' well-being” (Alsadah, et al.). However, none of these definitions include patients' opinions regarding treatment burden (Alsadah, et al.). While there is not necessarily a concrete universal definition, treatment burden cannot necessarily be separated from disease or symptom burden, and it should be identified in its distinct nature.

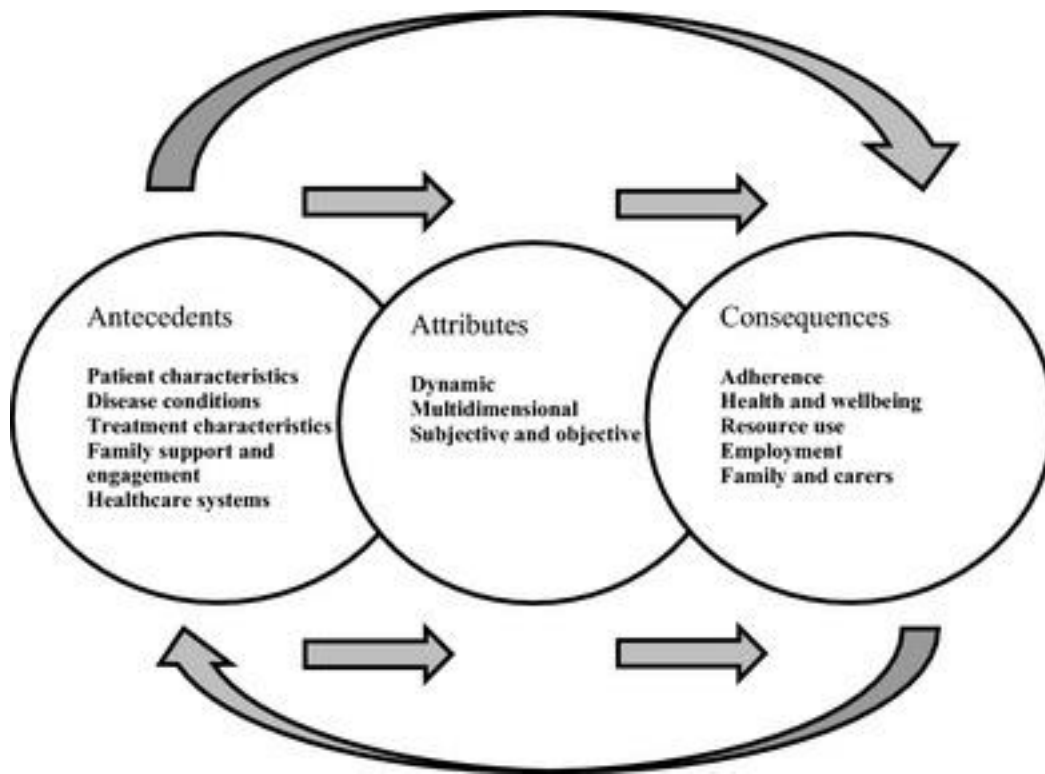
For example, the expenditures for medications are rather costly worldwide, and are creating financial treatment burdens for patients who require continual refills of Lisinopril to lower their high blood pressure or even multiple sessions of chemotherapy and radiation to *hopefully* shrink or kill the cancer invading their bodies. Given that many chronically ill patients must treat multiple chronic illnesses, the cost of treatment can become overwhelming even if some of the cost is covered by insurance.

In this study, the researchers identify four main tasks that contributed to the sense of burden, “namely learning about treatments and their consequences, engaging with others and mobilizing support, adhering to treatment and lifestyle changes, and monitoring treatments” (Sav, et al.). Unfortunately, there is a lack of a clear conceptual model of treatment burden, which has contributed to the “inability to measure its impact or identify people most at risk, thereby obscuring the health professional's role in assisting people to alleviate this burden” (Sav, et al.). It has given rise to misinterpretation that minimizes proper and timely management or prevention. To define the concept itself and then develop a framework for understanding its occurrence and impact is a vital first step in assessing treatment burden and articulating the role of health professionals (Sav, et al.).

After thorough research, it was found that treatment burden evolves over time, is more prominent in women, can lead to worsening health or possibly death, lessens in the midst of a reliable support system, heightens when healthcare practitioners fail to provide adequate information regarding treatment, and arises as a multidimensional concept, including physical, financial, temporal, and psychosocial time demands (Sav, et al.).

In a majority of cases, treatment burden results in patients’ non-adherence to a treatment plan designed to maintain or better their health status. The harsh truth of the matter is that without compliance, patients can fall in a downward spiral, especially if the prescribed medication is the only thing guaranteeing life. Because this (treatment burden and its negative outcomes) seems to be a common theme, researchers developed this chart to visually represent the multifaceted nature of treatment burden in a simplified manner.

Figure 2: Attributes, antecedents and consequences of treatment burden (Sav, et al.).



Living with treatment burden, and just living with chronic illness for that matter, is a difficult task for any person. This has been established. However, little thought has been invested in treatment plans that will focus on treating the person as a whole in a direct and functional fashion that will be feasible for the patient. A treatment plan such as this could help patients avoid treatment burden altogether, while also lessening disease and symptom burdens. Fortunately, some time has been allotted to methods, such as integration and practice facilitation, which have been proven to be effective for chronically ill patients. Approaches such as these two are ideal in lessened, if not diminishing, multiple forms of burdens that result from long-term illness.

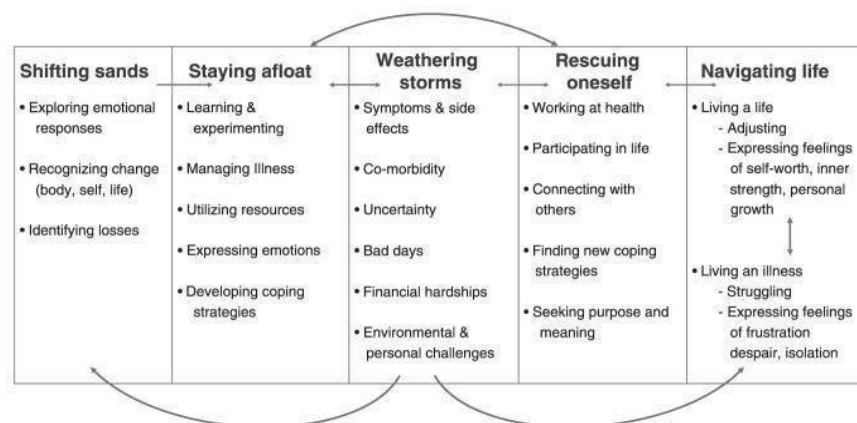
### **Methods of Caring for Chronic Illness Patients: 1. Integration**

To design a study revolving around the development of integration in healthcare is perplexing to even the best of researchers and practitioners. To weave together a plan that incorporates meeting the needs of the chronically ill is seemingly impossible considering that in American alone 133 million people (40% of the total population) suffer from chronic illnesses and 81 million of that subset bear the burden of more than one health condition (National Health Council). Despite all challenges, there are some devoting their studies to tending to this worldwide healthcare issue. In the study performed by Dixon and Whittemore, they created a system in which they studied the process of integration by 5 variables: shifting sands, staying afloat, weathering storms, rescuing oneself, and navigating life. “Shifting sands” tells the story about the diagnosis of their chronic illness(es), the emotional responses, and the initial experience of facing a changed life and many personal losses (Dixon and Whittemore, 5). In the “staying afloat” phase, subjects explained the work that was required on the road to meeting self-management needs, while coming to terms with what it means to live with a chronic illness.

At this time, participants described daily learning and experimentation, illness management, utilization of resources, expression of emotions and development of coping strategies (Dixon and Whittemore, 6). While the phrase “weathering the storms” says it all, participants had much to express regarding their endless hardships: treatment side effects, an uncertain illness trajectory, co-morbidity, financial hardships, and interpersonal and environmental challenges (Dixon and Whittemore, 8). In order to “rescue themselves,” conscious effort was put forth to weather the storms and to re-create a meaningful life, which

required hard work, connecting with others, developing new coping strategies and finding purpose or meaning in their new way of life (Dixon and Whittemore, 8). Even as they “navigated” through life, “participants fluctuated between ‘living a life’ and ‘living an illness’ as a result of a changing and unpredictable illness experience” (Dixon and Whittemore, 9). Days of adjusting, inner peace and positive self-worth were intermixed with days of struggle, frustration and even isolation (Dixon and Whittemore, 9).

Figure 1. Process of integration (Dixon and Whittemore, 14).



The World Health Organization recognizes the need for this integrative process as they predict that by 2020, chronic disease contribution is expected to rise to 73% of all deaths and 60% of the global burden of disease (“Integrated”). An integrated approach responds to the need of “intervention on major common risk factors with the aim of reducing premature mortality and morbidity of chronic noncommunicable diseases,” as well as the need to “integrate primary, secondary and tertiary prevention, health promotion, and related programs across sectors and different disciplines” (“Integrated”). By strengthening prevention practices that have been shown to improve the patient’s quality of life, the integrative process has the potential to become a dominant approach to caring for the

chronically ill. In order to move forward with the plan, it is pivotal that the healthcare system raise awareness for chronic noncommunicable diseases and ensure that prevention is “included in and placed on top of the agenda of health care policies” (“Integrated”).

All in all, it is important to note that anything worthwhile is never “easy.” Simply living life becomes a seemingly insurmountable challenge for the chronically ill, and many struggle to find their way back to a functional norm. The path to adjusting to chronic illness is far from linear and will require a multi-disciplinary approach, such as integration, that provides assistance with respect to the integration process that encompasses the existential, physical, emotional, social, and vocational work of chronic illness adjustment.

### **Methods for Caring for Chronic Illness Patients: 2. Practice Facilitation**

There is a dire need for proper care in the growing burden of chronic illness on global health, yet the chronic illness care system has remained broken and inconsistent in quality. The need for advancement is evident, given that in America, 86% of health care expenditures were attributable to chronic conditions in 2010 (Wang, et al.). As time progresses and the population continues to grow, more and more people are suffering from chronic medical issues. Because of this, the search for an efficient method of care is underway, and while there are many methods to consider, such as integration, many medical professionals prefer to study the effects of practice facilitation, as some believe this is the most promising technique.

Practice facilitation, sometimes referred to as quality improvement coaching, is an approach to supporting improvement in primary care practices that focus on paving the way for continuous improvement. It is a well-known supportive service provided by a trained individual or team of individuals (“Practice Facilitation | PCMH Resource Center”). The

MacColl Center for Health Care innovation claims that this practice helps to make meaningful changes designed to improve patients' outcomes. The trained team will help physicians and develop necessary skills to apply their clinical knowledge to the specific circumstance of their practice environment ("Practice Facilitation"). Individuals utilizing this method implement a variety of organizational development, project management, quality improvement, and practice improvement approaches and methods in order to build the core of this practice, which will in turn engage in longitudinal improvement both in-person and virtually (Wang, et al.). Alas, there has been a limited number of studies performed on the topic.

However, these few studies prove that when clinicians utilize practice facilitation to adapt their chronic disease management approach accordingly, the approach results in desirable outcomes. In this particular study, the effects of the technique on improvement of asthma, cancer, cardiovascular disease, diabetes, as well as breast, colorectal, and cervical cancer were studied, and key findings revealed beneficial effects for the diseases. The experimenters dive even further to discover that the "Asthma outcomes improved in several measures while cardiovascular disease outcomes for cerebrovascular disease, coronary artery disease, dyslipidemia, hypertension, myocardial infarction, and peripheral vascular disease improved in areas such as blood pressure control, cholesterol, and adherence to prescription medications and diabetes measures improved in diabetes screening and control of HbA1c" (Wang, et al.).

By utilizing these particular variables to measure the effect of disease on the human body, they were able to target these measurements in a way that allowed them to see progress on both a micro and macro level in personal health. Examining the effects of practice facilitation in the future could be enhanced by patient-specific outcomes along with their

individual electronic health records integrated across care sites to better portray a complete understanding of the patient as a whole (Wang, et al.). Since studies on this topic are relatively new, there are several kinks in the study, such as interventional self-awareness, variability in the quality and methodology of the studies, and reporting of studies with disease-specific quantitative processes and outcomes (Wang, et al.). Experimenters in this field hope to see more longitudinal data of numerous chronic illnesses in a variety of settings.

### **Continued Research**

Thankfully, there are scientists working to understand the concept of both practice facilitation and integration. In fact, J. Fleury (1991), in a study of adults participating in a cardiac rehabilitation program, reported that integrating change was a key aspect to the development of new and positive health patterns that promoted health (Dixon and Whittemore, 3). Just a few years later, researcher C. Hernandez developed an instrument to measure integration specific to diabetes, in which integration was defined as the ongoing process where the two selves (the diabetic and the personal) more fully merge to create an individual who is healthy, mentally and physically (Dixon and Whittemore, 3). In a succeeding 1996 study, Hernandez identified integration as the “central component to living successfully with diabetes” (Dixon and Whittemore, 3).

In a separate study conducted by the National Demonstration Project (NDP), experimenters compared two implementation approaches: facilitated and self-directed. The practices were randomly assigned to self-directed, which “establishing a pattern for health early in life and providing strategies for mitigating illness and managing it in later life,” or facilitated

change conditions (Grady and Gough). In the end, the research team found that facilitation increased the practices' capability to create a sustainable change that increased the patients adaptability ("Module 1. Practice Facilitation as a Resource for Practice Improvement").

Researchers are onto something with these very specialized studies. Hopefully, with enough positive outcomes supported by the research evidence, these care plans will be applied to chronic illnesses beyond just diabetes and heart disease. With increased proven success and greater support and promotion, these practices could potentially become the general treatment plan for chronic illness across the globe.

### **Applying Integration to Diabetics in Lower Socioeconomic Levels in Rural Mississippi**

The process of integration, as the understanding of the conglomeration of both past and current circumstances, permits the chronically ill to come to understand how to efficiently manage their new way of life in a manner that becomes normal. It is critical for physicians to take the necessary steps to explain integration to their patients and devise an integrative plan that will blend with their individual lifestyles. The key is to remember that each patient suffers differently and lives in different circumstances, which is the premise of being ill. The overall experience of illness varies drastically across the population.

For instance, a wound specialist may have several diabetic patients. One of those patients happens to be a college graduate, living comfortably as a member of the upper-middle class. He can afford one of the top healthcare insurance plans, has a very supportive family to

lean on, and is able to take time off of work, since he is ensured paid ‘sick’ days. While shadowing Dr. Hamilton at Baptist Memorial Hospital for my Medical Humanities class, the other type of patient is actually the more common one to come in contact with at Baptist Memorial Hospital (Oxford, MS).

This patient is the one who never graduated from high school and worked for minimum wage for the majority of his life. This patient lives in a mobile home, where he is unable to afford the price that must be paid to run air conditioning. Because of this, he sleeps on the living room floor next to the heater to keep warm in the winters. This man, who has always lived in poverty, was never able to afford healthy food options, and this essentially led to his diagnosis of diabetes. With limited means, this particular patient never learned to and never could afford the medical means to properly care for and maintain his diabetes. In this particular visit, Dr. Hamilton takes note that the man has had his right foot amputated and suffers from a third-degree burn on his left leg from lying next to the heater all night long and being unable to feel his lower extremities as they rub against the hot surface that inevitably burns the skin, which is now another area that requires medical attention given that infection has begun to spread.

For Dr. Hamilton, and other physicians who find themselves in similar circumstances, caring for this patient will require a different approach that includes more empathy, time, and compassion than the approach for the patient of a higher socioeconomic status and greater support system. For those with chronic illness living in less fortunate circumstances, the integration approach will take into consideration these additional everyday stressors, such as lack of financials, education, and overall access to necessary means of treatment. Consider that while the physician does not hold the power to turn on his patients’ air conditioning unit, he does have the power to provide extra ointment to treat possible future burns and more

medication in one prescription pick-up so that the patient need not worry about finding transportation for regular doctor's visits and prescription pick-ups. However, the physician must also be attentive to details that may indicate a possible drug abuse problem. If that were to be a factor in the equation, the physician would then turn to alternative approaches that would not necessarily include medication. Here, it is easy to determine the difficulty that comes with being both the chronically ill patient and the attending physician.

Patient cases such as these that require special considerations are quite common in Mississippi, especially in the more rural regions of the state. In 2016, "Mississippi ranked first in the nation for overall diabetes prevalence, with an estimated 308,295 adult Mississippians living with diabetes (over 13.6% of the adult population)" ("Diabetes Prevention and Control"). Following this, the prevalence of diabetes is also shown to increase with increasing levels of poverty ("Report on the Burden of Chronic Diseases in Mississippi, 2014"). Mississippians, such as the patient mentioned in the shadowing experience live with the complications of type 2 diabetes, such as loss of protective sensation, which is what leads to lower extremity burns as an ill, impoverished man lies too close to his heater at night just to keep warm. This is the painfully disheartening fact of the matter that does not even include the other side effects, such as "lower extremity amputations, end stage renal disease, blindness, heart disease and premature death" ("Diabetes Prevention and Control").

While large corporate institutions, such as the National Institute of Diabetes and Digestive and Kidney Diseases and the CDC's Division of Diabetes Translation, recognize the diabetes epidemic in Mississippi, they simply throw millions of dollars into research and education ("The Burden of Diabetes in Mississippi"). While this is helpful for the future of diabetes, this helps very little with those who are already suffering from the chronic illness.

Implementing a care plan, on the ground, for the 308, 295 chronically ill diabetics would be an effective approach to caring for these people.

## **Chapter IV: Roles of Chronic Illness Patients and their Healthcare Team**

### **The Difficulty with Determining How to Care for the Chronically Ill**

To consider the effects of preventative, as well as maintenance, interventions aligning with self-care in the integration process is pertinent for those with chronic illness as they learn to navigate this new way of life. Under these circumstances, the consultation between patient and clinician regarding the promotion of self-care takes on a growing importance. In order for

this to be possible, patient autonomy, which refers to a “person’ capacity for self-rule,” must first be established, and the physician must listen to the patient (Pierce and Randels, 31).

While this seems like a simple concept, problems arise due to patients’ blind faith in and dependence on the traditional authoritarian role of healthcare professionals, especially physicians. This is possibly the reason behind patients being more likely to contact a nurse (than a doctor) regarding their care. Nurses are seemingly more approachable. However, it is not the nurse who diagnoses chronic illnesses, nor should it be their duty, alone, to ensure that a projected healthcare plan is followed by the patient. Needless to say, nurses are a critical component in medical support, and while this is an undeniable truth, there is a dire need for planning and follow-ups by the attending physician. Studies have shown that “comprehensive, well-paced, user-friendly information is effective in supporting and promoting self-care management in a variety of ways. It informs and reassures patients and their families” (Rees and Williams).

Additionally, it is important that information is provided at diagnosis, and from then forward, so that the implications of positive self-care management and its relationship with long-term health goals and outcomes can be implemented and eventually achieved (Rees and Williams). Without a clear understanding of the diagnosis, patients will be left with blanks in their stories that could potentially harm them in the future. Because of this, it is critical that physicians are upfront regarding the diagnosis and provide a functional plan for the patient to abide by as they carry it outside of the exam room. At the bare minimum, these plans should include time, resources, consultations, easily accessible appointments and scheduling, a consistent doctor, and the opportunity for referral to other professionals and groups if necessary (Rees and Williams).

The overall general issue being faced with consultations is that self-care for patients with chronic illness tends to be medically-focused in the eyes of the physician. Because of this, it is easy for the physician to fail to open the discussion to the patient's feedback in regards to personal views of the routines and self-care practices that potentially benefit or hinder their individualized illness experience. If physicians truly want to make a difference in the patient's livelihood, they must assist with skills and competencies needed for self-care practices, share current knowledge and information, and encourage the patient to listen to his or her own body. Then, the physician must trust the patient's interpretations of their physiological function in order to revise professional advice and treatment plans that are in accordance with the patient's actual needs rather than the physician's speculations (Rees and Williams).

Nevertheless, it is simple to step back and make these statements as a third-party, but unfortunately, it is possibly even more difficult when actually participating in the equation - as either the patient or the healthcare professional. Step into the patient's shoes. As someone diagnosed with a chronic illness that will come to consume life as it once was, one will more than likely experience an assortment of emotions: sorrow, devastation, confusion, guilt, and fear. In positions such as this, "patient vulnerability was shown to be the antecedent of patient autonomy and arises due to an impairment of a person's physical and/or mental state" (Lindberg, et al.). If found in this place of uncertainty and weakness, patient autonomy is a gradual process of reconstructing confidence and trusting oneself to determine personal health status and what the future goals are under these circumstances. After all, an autonomous person "freely acts in accordance with a self-chosen plan," which requires liberty,

independence, and agency (Pierce and Randels, 31-32). Because of its critical role, autonomy has become a guiding principle in medical ethics.

### **Implications for Healthcare Professionals**

A person's profession is their public claim to use the highly specialized knowledge and skills they have acquired for the good of others. Regardless of the profession, the others being referenced are vulnerable in some capacity, which means they must be able to trust that the professional carries the best intentions (Pierce and Randels, 29). In fact, in a recent "research project on how women with breast cancer want their doctors to communicate with them, researchers found that women with breast cancer did not think about their doctors according to whether they 'communicated well', but rather, they were concerned with whether or not they could trust their doctors" (Meyer and Ward, 5).

All in all, the physician must pass a strenuous training in order to commit to memory an insane amount of knowledge that will assist in caring for patients, who rely solely on that care when in this role. Because of this, the physician is bound to a vow to abide by certain ethical principles – the well-known Hippocratic Oath. While this may be comforting for some, as time passes, bioethicists grow concerned that medicine's long-standing values are potentially losing value among physicians today. As medicine becomes increasingly commercialized, "clinics and hospitals are increasingly run like businesses" rather than havens for healing (Pierce and Randels, 30). In other words, rather than physicians asking questions such as "how can a practitioner develop interpersonal trust with a patient?" they are instead becoming increasingly concerned about the economics of the job (Meyer and Ward, 6).

Today, two views of the physician have surfaced. One has been developed through a business lens that features the doctor as a “technician” and the patient as the “consumer” (Pierce and Randels, 31). What relevant information is provided to the patient regarding treatment can then be utilized however the patient sees fit. In a different light, the physician is “omniscient and omnipotent,” which means only the physician alone can understand medicine and provide proper care (Pierce and Randels, 31). In the first view, there is strong autonomy by the patient, but in the second, one can see the strong paternalism radiating from the physician. While autonomy empowers the patient, paternalism has the ability to overshadow that power by “interfering with or ignoring patient autonomy” (Pierce and Randels, 32).

Thankfully another view of the patient-physician relationship is alive and well. Through this lens, the physician is much more than a technician and less than an omniscient presence. Here, the physician’s responsibility is beyond that of presenting information and includes “helping patients to understand their own values, cope with their fears, and learn to live with pain and suffering” (Pierce and Randels, 32). It is in this manner that chronic illness patients deserve to be cared for, especially since there will be moments when impairment of autonomous choice takes place. For instance, if the patient is heavily sedated, experiencing delusions, or in severe pain, the physician must be able to rationally work through the situation, properly care, and keep the patient out of harm’s way by considering the patient’s best interest. When diagnosed with a chronic illness, the patient may struggle to understand the depth of the diagnosis and as a result, there may be difficulty with coping and learning to maintain the illness.

In these cases, it is particularly important that the physician act in accordance with this third perspective by offering kindness, understanding, and the appropriate words and actions to assist the patient on this illness journey. This is a special loyalty to the patient, where the

physician commits to patient care in the beginning and remains “true to their promises” throughout the process (Pierce and Randels, 35). In return, the vulnerable patient must “trust that their doctor acts for their benefit, is competent, and will maintain confidentiality” (Pierce and Randels, 35). The concept of this stems to other healthcare professionals as well, given that loyalty from nurses and other healthcare workers and attaining patient trust are equally important components in caring for the chronically ill. Overall, one may argue that an “individual’s decision to accept and adhere to a healthcare professional’s diagnosis and treatment plan is dependent on their trust in the professional, which is a reflection of their trust in the healthcare system and all other systems that it interacts with/is influenced by (for instance, the economic system, the political system)” (Meyer and Ward, 6).

### **The Necessary Tasks of a Patient**

Likewise, patient honesty is a critical contribution to the relationship that must not be overlooked. In fact, the American Medical Association’s (AMA) first listed duty of the patient is to be “truthful and forthcoming with their physicians and strive to express their concerns clearly” (“Patient Responsibilities”). The AMA also states other patient responsibilities such as cooperating with consensual treatment plans, accepting care from medical students, residents, and other trainees under appropriate supervision, meeting their financial responsibilities with regard to medical care or discuss financial hardships with their physicians, recognizing that a healthy lifestyle can often prevent or mitigate illness and take responsibility to follow preventive measures and adopt health-enhancing behaviors, being aware of and refraining from behavior that unreasonably places the health of others at risk, refraining from being disruptive in the clinical setting, not knowingly initiating or participating in medical fraud, and reporting illegal or

unethical behavior by physicians or other health care professionals to the appropriate medical societies, licensing boards, or law enforcement authorities (“Patient Responsibilities”).

The notion of patients' duties has recently received occasional scholarly attention but “remains overwhelmed by attention to the duties of healthcare professionals” (Evans). While society tends to look to the physician with high moral expectations, the duties of the patient tend to be cast aside. This leads us to wonder what precisely is the point in seeing a physician, who takes the time and effort to establish a care plan, if the patient fails to offer information that will potentially enhance the plan? What is the purpose in seeking professional medical expertise if there is to be no follow-through on the patient’s end?

The process cannot fall entirely onto the physician’s shoulders, and because of this, there is a need for compliance, which pertains to the patient “communicating openly with their physician and abiding by recommended treatment plans” (Pierce and Randels, 37). Dangerous or harmful treatment is “almost never what the doctor intends,” and this factor provides us with a “reason to make compliance more sophisticated and sensitive, frequently involving additional responsibilities on the part of the articulate patient to maintain accurate self-monitoring and clear communication with clinical staff” (Evans). In other words, there is a need to unveil some sort of middle ground - a form of mutualism. With the progression of moral ambiguity, there is a rising need to remain attentive to ethical values and their evolution in the doctor-patient relationship.

This is yet another example as to why integration is an ideal approach when caring for the chronically ill. In order to live with a chronic condition, the patient must make adjustments in their daily routines. In order to understand the sorts of management skills they need to focus on, it is critical that the patient consult with the attending physician, who will develop a plan and walk the patient through every step of the way. Together, the physician and patient have the

ability to incorporate new behaviors into the patients' daily routines by determining which conscious adjustments must be made as unexpected changes take place in the individuals' lives.

## **Chapter V: Solution**

### **Steps Towards Bettering the System of Care:**

One overriding issue for those with chronic illness is the inability to be understood by outsiders. After all, one cannot truly understand the suffering of another without having endured the same circumstances, which for many healthcare providers is relatively impossible, given the vast diversity of their patient population. Because of this, the education should begin

in medical school, and the first objective must be to prepare students how to cognitively, effectively and morally undertake the tasks necessary for caring for the chronically ill. While these students thrived in their undergraduate science courses and on the admissions test, some have little knowledge or experience truly caring for the ill, especially those who will never overcome their illness. “This means teaching students how to listen to, be with, emotionally respond to, and communicate with patients and their networks” is a fundamental step in teaching future physicians proper care techniques (Kleinman, “Caregiving,” 104). In this process, students will learn to “interpret patient and family stories, better explain and interpret treatment and prognosis, and use their personalities, emotions, cognitions and values therapeutically” (Kleinman, “Caregiving,” 104). Then, when they go to take their Step 1 and 2 exams as well as their boards, they should also be evaluated in their competencies in the actual act of caregiving (not curing), since this, after all, *should be* the premise of modern medicine.

Without this understanding of how to care for other human beings, one may discredit another’s experience, resulting in a form of dehumanization. In fact, empathy and compassion are vital components of health care quality; however, “physicians frequently miss opportunities for empathy and compassion in patient care” (Patel, et al.). And unsurprisingly, most patients find being treated like objects or nonhuman animals to be aversive, and physicians should devote more time addressing how to treat patients more humanely (Haque, et al.). Additionally, while still in medical school, it is equally as important for students to learn critical self-reflection as it is for them to master their academics. This can be achieved through opening an experimental space for reflection and criticism, and the first step is incorporation of this practice into the medical school curriculum in a way that will ensure that the students will resonate with the concept and carry it into future practice. Despite evidence that empathy, compassion, and

self-reflective training can be effective, “the specific behaviors that should be taught remain unclear” unfortunately (Patel, et al.).

Fortunately, there are existing medical institutions promoting this image of a kind and caring physician and implementing courses that are designed to sculpt the student into this kind of future-physician. One such program, such as VitalTalk, aims to promote empathy in doctors and is a required course in clinical empathy for oncology fellows at Duke University (Litman). In this program, “seemingly simple advice is offered, such as maintaining eye contact or making sure that appointments where bad news will be delivered are scheduled at the end of the day” (Litman). To all intents and purposes, Stanford University “takes it one step further by having paid actors, called “standardized patients,” interact with medical students in a simulated clinical environment” (Litman). Stanford’s program is designed to assess students’ communication skills, diagnosis accuracy, general awareness, and overall level of compassion (Litman).

Notably, the Narrative Medicine program at Columbia University, and this course is designed to “emphasize the importance of patients’ personal stories when it comes to delivering comprehensive care” to teach physicians how to “recognize, interpret, and incorporate the patients’ various plights and circumstances when it comes to designing a unique care plan” (Litman). This sort of teaching is the idyllic foundation required for developing an individualized care plan for chronically ill patients. Most studies (75%) on programs such as these found that the “tested curricula improved physician empathy and/or compassion on at least one outcome measure,” which is a step in the direction of proper care (Patel, et al.).

While these programs are putting forth the effort to reverse the errors of the medical school system, there may be some factors hindering the training of physicians that they are not considering. During a lecture by guest speaker Arthur Kleinman on April 15, 2021, some of

these problems were brought to light by the wise physician. In this talk, Kleinman focused on the core tasks of caregiving and the challenges that follow. While discussing medical education, he shared a statistic regarding medical school students. According to several studies, it has been found that the majority of first-year students are drastically more empathetic and express a greater eagerness to care. On the other hand, fourth-year students seem to have lost this love for caring for others. Interestingly, Kleinman believes this is due to the final year of medical school being primarily under the direction of residents, who he says are the “unhappiest people on the planet” (Kleinman, “Soul”). Residents, in their late 20s and early 30s, are working 80-100 hours each week within the hospital walls (Kleinman, “Soul”). They are just in early stages of their careers, beginning to pay off their loans, wishing they were anywhere else, overworked, unhappy as ever, and also participating in the end of medical students’ training process. Kleinman stated that if there was one thing he could change about the medical school curriculum across the United States, it would be “keeping residents as far as they could possibly get from fourth-year medical students” (Kleinman, “Soul”).

Unfortunately, medical programs cannot possibly identify and avoid every drawback of the training experience. In reality, there is never enough time in the day, and this makes certain parts of education process quite difficult, such as preparing physicians for the ability to predict and manage time-awareness skills. One of the most notable flaws in the physician’s care routine is their seemingly little devotion to possibly their most valuable resource of care - time. Yet as both a “contribution to health care costs and as a key element in patient-doctor relationships, there is reason to believe that it deserves more attention” (Dugdale, et al. S34). In this time, physicians can develop relationships with their patients, gain knowledge, provide comfort, and derive ideas for their medical plan. Unfortunately, time is of the essence, and

there are only 24 hours in a day. In the 1995 Commonwealth Fund survey, it was found that 41% of physicians noticed a decline in the amount of time spent with patients and 43% noted a decline in the amount of time spent with colleagues (Dugdale, et al. S34). In more recent research from 2007, it was found that a median of only 5 minutes was spent on even the major topic in a visit and that visit length was insensitive to the contents of a visit (Tai-Seale, et al.). Furthermore, the median time for primary care visits was found to be even shorter - 2 minutes (Tai-Seale, et al.). With the social change occurring world-wide, both the job and livelihood of the physician has drastically changed in the last several decades. Now more than ever, many physicians have family responsibilities as well as lack of financial reimbursement from the Medicare program that reduce their available time for work.

As the problem continues to arise, critics have come to focus on what is the typical physician's conflict of interest that can lead to patient/family distrust, which in many cases, includes ethnic and class issues that lead to health disparities (Kleinman, "Caregiving," 105). With the focus being on social and economic disparities, some fail to realize the substantial impact that loads of excessive paperwork and the routinization also have on the physician's time management. The primary focus when in the clinic should remain on the patient, since patients tend to want to spend more time with their doctor - time to explain things and have things explained to them. Despite the mounds of paperwork that follows, if a patient had one wish, it would be for more time with their doctor (Stone).

Thankfully, panels such as the Institute of Medicine have found that due to lack of adequate time being spent on end-of-life care, physicians are able to receive a reimbursement for the additional time spent with patients approaching death. They are now able to bill Medicare "\$86 for an office-based, end-of-life counseling session with a patient for as long as

30 minutes” with no regulations on how they physician should approach the subject (Galewitz). This provides the patient with the appropriate counseling to prepare for what is in store, while also providing the physician’s office with rightly-deserved financial compensation.

Time is just one of the numerous reasons why physicians must critically examine themselves, which will in turn “empower practitioners not just to identify the problems but to attempt to resist and correct them” (Kleinman, “Caregiving,” 105). This is a clinical responsibility that does occur by second nature, but must begin with overcoming the shortcomings of the medical education system as they are detrimental to the quality of physicians being produced. Society may have already reached a point where the need for reform of the medical system is the only solution, and those with chronic illness, receiving low-grade healthcare, are sitting on the edge of their seats just waiting for change.

## **Conclusion**

Chronic disease is invading millions of people across the world by infecting and overtaking their bodies. For healthcare professionals, it is a daunting task to care for the distinctive illness that follows. While it is common to cure an ailment or disease, this is not a possible approach for chronic illness. In actuality, chronic illness renders a need for a specialized treatment approach - one that will help in the healing process for not only the patient’s physical malady, but also for the patient’s mental health and ability to perpetuate a proper care approach

for the rest of his or her life. Unfortunately, while there are some recommended approaches to caring for chronic illness patients, these have neither been actively promoted nor employed as a common tactic in medical facilities. The failure to generate and provide a general care plan for chronic illness that can be tweaked for the patient's special needs is a negligent oversight of the current healthcare system worldwide.

However, a solution is in the works for the millions of people suffering from one, and likely multiple, chronic illnesses. Their suffering is unique and includes not only battling the disease, but also facing financial, psychosocial, and other problems that follow the disease. Their illness experience deserves to be treated with empathy by a professional, specifically a physician, who cares enough to design the best plan possible for that patient.

There are studies and programs in place today that are working towards bettering this area of healthcare by testing different approaches for care plans as well as by instilling in physicians a desire and ability to be thoughtful, empathetic, attentive and devoted to proper care. Chronic illness is an area that will require much more time and effort to become more fit, and it is important to draw attention to this need as it has been overlooked for too long.

This thesis has shown that there is an awareness of the lack of understanding of chronic illness, which is inevitably leading to minimal investment in chronically ill patients. Ironically, because of the unknowns and unfortunate side effects of these long-term illnesses, these patients need even *more* time and energy invested in their well-being. The truth of the matter is that the world of medicine today prefers to aid in quick recoveries and to treat curable ailments. It has not been molded to meet the needs of the chronically ill's healing process. Chronic illness demands patience, empathy, acceptance of the unknowns, and caring medical professionals. In this work, there is evidence of hope for the future of chronic illness in medicine through the rising

awareness of the problem that needs our attention, evolving practice studies and methods, and open-minded medical professionals willing to implement new ideas.

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