Exploring the Illness Narratives of Women Diagnosed with Autoimmune Disease

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Formal Declaration

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Final Approval of Thesis

This is to certify that we have read the thesis submitted by Ms.Ammarah. It is our judgment that this thesis is of sufficient standard to warrant its acceptance by the Quaid-i-Azam University, Islamabad for the award of the Degree of M.Phil in Anthropology.

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DEDICATION

This thesis is dedicated to my parents who stood by me through thick and thin.

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ABSTRACT

Autoimmunity is a medical disorder where the immune system targets itself, causing harm to various organs. Women are more susceptible due to their double X-chromosome genes, making them more susceptible to autoimmunity. The immune system may target specific organs, such as skin, bones, kidneys, thyroid, connective tissue, or joint tissues. Autoimmune patients often feel alone, with feelings of rejection, isolation, and loneliness worsening. They may also experience depression, exhaustion, and poor health-related quality of life. The research was carried out in the city of Karachi. The research methodology used in this study was the Narrative method, which included an interview guide as the primary data-gathering approach. The researcher used purposive sampling to capture and record several autoimmune conditions seen among individuals residing in Karachi. The researcher used qualitative research tools for data collection, including interview notes, audio recordings, and transcriptions. Additionally, case studies of the respondents were employed to facilitate effective data collecting and analysis. The researchers used purposive selection to choose a sample of seven respondents who had different autoimmune disorders. This specific sampling method was chosen to facilitate serial interviews, allowing for in-depth data collecting that could be utilized to convey illness narratives. The study reveals uneven healthcare access due to insufficient knowledge, infrastructure differences, and autoimmune diseases prevalence. The internet facilitates health information access and promotes healthier lifestyles among young people. Autoimmune illnesses, require ongoing medical care and can impact fertility and reproductive health. The CSM framework focuses on open discourse, active listening, and collaborative efforts, focusing on women affected by autoimmune illnesses. Religion plays a significant role in providing strength, meaning, community, belonging, and hope for women struggling with autoimmune disorders.

Keywords: *Autoimmune disorders. CSM- Sensemaking. Research, Susceptible, Autoimmunity*

LIST OF ACRONYMS

MRI	Magnetic Resonance Imaging
CT Scan	Computed Tomography Scan
AIDS	Acquired Immunodeficiency Syndrome
HCP	Healthcare Personnel
CSM	Communicated Sense Making
MBA	Master of Business Administration
CCP	Cyclic Citrullinated Peptide
RA	Rheumatoid Arthritis
RF	Rheumatoid Factor
ESR	Erythrocyte Sedimentation Rate
HCQ	Hydroxychloroquine
PRP	Platelet-rich plasma
NCA	National College of Arts
IBS	Irritable bowel syndrome
AMH	Anti-Müllerian Hormone
FSH	Follicle-stimulating hormone
PCOS	Polycystic Ovary Syndrome
TSH	Thyroid-stimulating hormone
BMI	Body mass index
COVID	Corona Virus Disease
IVF	In vitro fertilization
SLE	Systemic Lupus Erythematosus

IT	Information Technology
ENT	An ear, nose, and throat doctor
DNA	Deoxyribonucleic acid
PEMA	Pakistan Emergency Medicine Association
IBD	Inflammatory Bowel Disease

CHAPTER 1

1. INTRODUCTION

Autoimmunity is a combination of two words, ‘auto’ and ‘immunity’ reflecting the nature of the medical condition where a person’s immune system attempts to build immunity against itself and as a result harms the person (Orbai, 2022). Autoimmune disorders are characterized as a condition in which the host's immune system mistakenly attacks itself. These disorders cause the immune system to cause a systemic reaction by attacking multiple organs or may be localized to attacking one specific organ. The larger number of genes originating from the X chromosome creates a far greater possibility of a larger number of mutations occurring. This puts women at a greater risk for the development of autoimmune diseases solely due to women having two X chromosomes, whereas men possess only one. The presence of two X chromosomes essentially creates a 'double dose' of genes present on the X chromosome and because of this, predisposes the female to autoimmunity (Angum, Khan, Kaler, Siddiqui, & Hussain, 2020).

Autoimmune conditions are far and wide and can have many different forms where the immune system might attack specific organs like the skin, bones, kidneys, thyroid, or tissues like the connective tissue or joint tissues. It is a chronic and sometimes debilitating condition which has no cure as of yet in medical science (Varma, 2023). A common theme that emerges among people living with an autoimmune disease is the feeling of being alone with their illness. Many find that family and friends are available and supportive initially or when there is a crisis such as hospitalization, but that support fades over the long run. Many people with chronic autoimmune disease feel that there is a lack of understanding among those closest to them about their experiences and an unwillingness to learn more about their illness. This can create feelings of rejection, which can lead to increased feelings of isolation and loneliness. Feelings of low self-esteem, sadness, and even depression are commonly experienced by people living with autoimmune diseases (Pryce & Fontana, Depression in Autoimmune Diseases, 2017). Up to 50% of patients with autoimmune diseases show an impairment of health-related quality of life and exhibit depression-like symptoms. The immune system not only leads to inflammation in affected organs, but also mediates behavior abnormalities including fatigue and depression-like symptoms (Pryce & Fontana, Depression in Autoimmune Diseases, 2017).

The current study attempts to look into the lived experiences of women living with chronic or mild autoimmune disorders with the perspective of illness narratives. The Illness Narrative is a theoretical and methodological approach which emphasizes on the patient experience in terms of their chronic illness (Burchardt, 2019) (Kleinman, The Illness Narratives: Suffering, Healing and the Human Condition, 1988). Illness narratives have been covered in literature in terms of doctor-patient relationship and the role of communicated narratives by the patient for better understanding between the doctors and their patients by (Charon, 2001). It has been also covered in terms of using illness narratives to help patients understand their own conditions and interactions with healthcare providers by (Frank, 2006) and in chronic conditions such as HIV/AIDS (Stutterheim, 2011), pediatric palliative care (Mcdonald, 2012), cancer (Jordens, Little, Paul, & Sayers, 2001), and heart conditions (Biglino, et al., 2019). However, illness narratives have not been covered in terms of female experience of autoimmune conditions, especially in Pakistan. With the help of theoretical frameworks like Communicated Sense Making (Kellas & Horstman, 2015) and Memorable Messages (Cooke-Jackson & Rubinksy, 2022) the experiential reality of women with autoimmune diseases was scientifically understood. With Narrative Analysis techniques the in-depth data gathered is presented in the form of narratives of various case studies that were significant in the research process and understanding. In the course of this study, it is essential to note that case studies cannot be conducted in isolation. Therefore, the researcher meticulously examined the case studies of various respondents as part of the analysis process. The case studies are inherently integrated into the study. The researcher's comprehension of the research was derived through the analysis of case studies.

1.1 Statement of the Problem

In terms of narrative studies and illness narratives in particular, the research is generally focused on specific chronic conditions or on special groups such as children (Mcdonald, 2012) and the elderly (Borkan, Quirk, & Sullivan, 1991). The research is also concentrated outside of Pakistan where the medical and social experience is much different and culturally unique. It becomes especially different when seen in terms of the female experience, something not exhaustively studied in Pakistan. The studies on autoimmune conditions in Pakistan focus on the medical and scientific part of the disease (Uddin, et al., 2021) (Aslam, Jalil, John, Fan, & Bhatti, 2018) than the social aspect (Shafiq, Rafiq, & Mahmood, 2019). Which why a study focusing on the social aspects of autoimmune conditions as experienced by its major victim: the female, is necessary for better understanding and treatment of patient with such conditions.

1.2 Research Objectives

The objectives of this research study are:

1. To relate the experiences of women in the diagnostic period of their autoimmune diseases.

2. To report narrations of respondents regarding the life altering experience of autoimmune diagnosis.

3. To understand the gendered nature of autoimmune diseases and resulting gendered experiences of these chronic illnesses.

The study was conducted in the city of Karachi, Pakistan using the qualitative research method focusing on the Narrative Research methods. The target population were women of any age diagnosed with any autoimmune condition residing in Karachi. The time spent in the field was almost eight months.

1.3 Research Question

What are the experiences of women suffering from autoimmune diseases pre and post diagnosis?

1.4 Definition of Key Terms

1.4.1 Conceptualization

1.4.1.1 Illness Narrative

Illness narratives are a genre wherein an illness and its effect on the patient's life are told as an autobiographical or biographical account. As Kleinman (Kleinman, The Illness Narratives: Suffering, Healing and the Human Condition, 1988) has argued, illness narratives are forms of meaning making. They provide insight into how patients and clinicians understand the why and how of illness causation and treatment, including how illness processes are linked to the broader social and structural contexts of patients, their communities, and their clinicians. As a form of meaning making, illness narratives can be created in a clinical encounter, wherein physicians and patients co-construct a therapeutic agenda that weaves together what the patient and the clinician know about the illness and its context (Le, Miller, & McMullin, 2017).

1.4.1.2 Autoimmune Disease

Autoimmune disease happens when the body's natural defence system can't tell the difference between your own cells and foreign cells, causing the body to mistakenly attack normal cells. There are more than 80 types of autoimmune diseases that affect a wide range of body parts (Orbai, 2022).

1.5. Operationalization

1.5.1. 1Illness Narrative

Methodologically, the term illness narrative captures a variety of qualitative data as well as forms of data collection. On the one hand, illness narratives are found in all sorts of reports patients produce for themselves, in other words: without the intervention of social scientists, such as diaries, letters, or novels. While in these cases researchers are presented with finished written accounts, there are other instances in which patients engage in oral productions of illness narratives, for instance, through testimonies in support groups, health movement rallies, conferences of international organizations, or in the mass media. On the other hand, social scientists elicit and record illness narratives through qualitative, open-ended interviews of different kinds or ethnographic conversations with patients. In such interviews, patients are asked to report and freely talk about their own experiences of suffering, diagnosis, illness, and recovery, and in doing so people typically place them in the context of broader life experiences. People may engage in the production of illness narratives in a singular event (e.g., a single narrative interview), but such narrative production may also unfold over time such that the illness narrative develops across several conversations between researchers and interviewees spanning different moments in interviewees' illness trajectories (Burchardt, 2019).

1.5.2 Autoimmune Disease

Common autoimmune diseases in women include:

- Rheumatoid arthritis, a form of arthritis that attacks the joints.
- Psoriasis, a condition marked by thick, scaly patches of skin.
- Psoriatic arthritis, a type of arthritis affecting some people with psoriasis.
- Lupus, a disease that damages areas of the body that include joints, skin, and organs.
- Thyroid diseases, including Graves' disease, where the body makes too much thyroid hormone (hyperthyroidism), and Hashimoto's thyroiditis, where it doesn't make enough (hypothyroidism) of the thyroid hormone.
- Celiac disease is a gluten sensitivity response which affects the small intestines resulting in the flattening of the villi and elongation of the crypts of the intestine.
- Vitiligo is a skin condition which leaves milky white spots on the skin due to the destruction of the melanocytes or the melanin producing cells in the skin.
- Type 1 diabetes, a condition in which the immune system damages the insulin-producing cells in the pancreas.

Symptoms of autoimmune disease may be severe in some people and mild in others. "There are different degrees of autoimmune disease," says (Orbai, 2022). "The symptoms a person gets likely relate to multiple factors that include genetics, environment and personal health."

1.6. Significance of the Study

The study on autoimmune conditions especially with context to the female experience is significant in producing data regarding the social aspect of chronic conditions. There is a clear gender bias to this type of disease/s and yet awareness or education regarding it remains little. Even patients themselves are left confused as to what is actually wrong with their bodies. It is imperative that we look into this topic and attempt to understand the relation of delayed diagnostics of autoimmune diseases and culture and/or lack of medical attention. A study of such a scope as attempted in this current study can help patients understand their bodies, communicate their emotions, and help health care professionals in assisting them in a positive way.

Such a research endeavor brings back the humanness of the people involved in the experience, the patients, their loved ones, and the doctors. Medical literature often dehumanizes the human experience of a certain disease and illness and breaks it down to the cellular and molecular level. This mystifies and sometimes erases the basic human feelings of going through trauma, such as fear, confusion, anger etc. (Haque & Waytz, 2012). The research will help de-mystifying such experiences and bring the relatability of suffering through chronic conditions on the table.

1.7. Outline of Thesis

The first chapter provides an overview of the research's topic. The problem statement, the aims of the study, and the critical terms utilized throughout the thesis and research are all covered in this chapter. It also serves to highlight the significance of the research.

The second part of this study provides a comprehensive review of the relevant literature about the problem at hand. It references prior research efforts, such as studies on autoimmunity and autoimmune illnesses. This chapter lays the groundwork for the pace and direction of the overall research effort.

The third chapter is divided into two discrete portions. The first part of the study is dedicated to the dissemination of information pertaining to the research environment or geographical area. On the other hand, the next section explores the process of choosing and using different research approaches and sample processes in order to get data that is both useful and relevant.

CHAPTER 2

2. LITERATURE REVIEW

Autoimmune diseases are chronic health conditions that cause the immune system to produce antibodies that attack and destroy healthy, normal body tissues, detecting these parts or processes of the body as disease (Gunning J., 2021). There are over eighty autoimmune diseases, many with similar symptoms, which makes diagnosing autoimmune disease especially difficult. Common symptoms include fatigue, joint pain, fever, dizziness, and cyclical flares of increased disease activity, caused by environmental-based sources like exposure to sunlight, stress, or hormonal changes (OWH, 2020). The onset of autoimmune disease brings with it adverse physical and emotional repercussions, identity, and relational disturbances, as well as a forced re-evaluation of individual priorities, values, and belief systems (Wilson & Stock, 2019) (Walker & Price, 2014).

The journey to autoimmune disease diagnosis is tumultuous, shaded with dismissal, invalidation, and misdiagnosis. On average, it takes an autoimmune patient seeing four doctors over the course of four years to be diagnosed and treated for an autoimmune condition (Gunning J., 2021). Over this four-year journey, the majority of autoimmune patients are misdiagnosed and told that symptoms are "in their heads," with 45% of these patients labelled as chronic complainers (Gunning J., 2021). This makes an already challenging diagnostic journey that much more difficult, for repeated ambiguous, indecisive, or dismissive experiences and messages by medical providers teach individuals not to trust their diagnoses, their lived experiences, or their bodies, thrusting them into "diagnostic vertigo" (Crimlisk & Ron, 2010); (Walker & Price, 2014)

Women have an added layer of difficulty, uncertainty, and illness identity ambiguity to bear, as these individuals are more likely to be assigned a psychogenic diagnosis, have prior diagnoses dismissed, and have their medication under-prescribed or withheld entirely by healthcare providers (Crimlisk & Ron, 2010). This is rooted in a sordid history of the presumed "hysterical" female patient, a diagnosis that can be traced to the Middle Ages (Dusenbury, 2018)

Persons living with chronic diseases are often designated as vulnerable. Vulnerability is an invariable premise of life. When chronic illness strikes us, we are reminded of our mortality. We are also more dependent on others, including professional helpers, and hence more vulnerable. Vulnerability often has a somewhat negative sense. This may put us in danger of overlooking the fact that living with illness may also contribute to personal growth and development. (Sellman, 2005) makes a distinction between objective and subjective vulnerability in relation to illness. She claims that there is no necessary relation between having a chronic illness and feelings of subjective vulnerability, even though the subject may objectively be more vulnerable. Research on the phenomenon of vulnerability in healthcare points to several dimensions: Vulnerability is an existential phenomenon that belongs to the basic conditions of life, and it is a contextual phenomenon, which varies depending on the situation and the cultural context. It is also referred to in the research as a relational phenomenon; the relationship with others may increase and/or decrease the feeling of being vulnerable (Burchardt, 2019).

2.1. Depression and Autoimmune Diseases

Depression is a common co-occurring condition among individuals with autoimmune diseases. Autoimmune diseases are conditions in which the immune system mistakenly attacks healthy cells in the body, and depression is a mood disorder characterized by persistent feelings of sadness, hopelessness, and loss of interest in activities. Studies have found that individuals with autoimmune diseases have a higher risk of developing depression compared to the general population (Pryce & Fontana, Depression in Autoimmune Diseases, 2017).

There are several potential explanations for this relationship. One theory is that the chronic inflammation and pain associated with autoimmune diseases can lead to feelings of hopelessness and helplessness, which can contribute to the development of depression. Additionally, the physical limitations and social isolation that often accompany autoimmune diseases may also contribute to the development of depression (Euesden, Danese, Lewis, & Maughan, 2017).

Autoimmune diseases can also cause changes in brain chemistry which can lead to depression. Additionally, the stress and emotional burden of dealing with a chronic illness may also contribute to depression. It is important for individuals with autoimmune diseases to be evaluated for depression and to receive appropriate treatment if needed (Morris, Berk, & Walder, 2015). It is important to note that depression can also worsen the symptoms of autoimmune disease and make it harder for people to cope with their illness. It's crucial for individuals with autoimmune diseases to have a comprehensive treatment plan that addresses both the physical and emotional aspects of the illness (Pryce & Fontana, Depression in Autoimmune Diseases, 2017).

2.2 Issues in Diagnoses

There are a number of issues that can arise before, during, and after the diagnosis of an autoimmune disease in the medical setting. Some of these issues include:

2.2.1 Before diagnosis

- Difficulty in obtaining a timely diagnosis due to the lack of clear diagnostic criteria for many autoimmune diseases, as well as the fact that many autoimmune diseases have symptoms that are similar to other conditions (Chauhan, Raina, & Nandi, 2019).

- Difficulty in obtaining a correct diagnosis due to a lack of understanding of autoimmune diseases among healthcare providers, leading to misdiagnosis and mistreatment (Chauhan, Raina, & Nandi, 2019).

- Difficulty in obtaining a correct diagnosis due to the fact that autoimmune diseases are more common in women, and that women's symptoms are often dismissed or not taken seriously by healthcare providers (Crimlisk & Ron, 2010).

2.2.2 During diagnosis

- Difficulty in obtaining a correct diagnosis due to a lack of access to diagnostic tests, such as autoimmune disease-specific blood tests, in certain areas (VincenzoLenti, Rossi, Melazzini, Gastaldi, & Bugatti, 2022).

- Difficulty in obtaining a correct diagnosis due to a lack of access to specialists, such as rheumatologists or immunologists, who are trained to diagnose autoimmune diseases (Chauhan, Raina & Nandi, 2019).

- Difficulty in obtaining a correct diagnosis due to a lack of access to appropriate imaging tests, such as MRI or CT scans, to help diagnose autoimmune diseases that affect internal organs (VincenzoLenti, Rossi, Melazzini, Gastaldi, & Bugatti, 2022).

2.2.3 After diagnosis

- Difficulty in obtaining appropriate treatment due to a lack of understanding of autoimmune diseases among healthcare providers, leading to treatments that are not effective or that cause side effects (Fugger, Jensen, & Rossjohn, 2020).

- Difficulty in obtaining appropriate treatment due to a lack of access to specialists, such as rheumatologists or immunologists, who are trained to treat autoimmune diseases (Chauhan, Raina, & Nandi, 2019).

- Difficulty in obtaining appropriate treatment due to a lack of access to newer or specialized treatments, such as biologics or stem cell therapies, which can be effective for certain autoimmune diseases (Fugger, Jensen, & Rossjohn, 2020).

- Difficulty in obtaining appropriate treatment due to high cost of treatments, leading to many people not being able to afford them (Walker & Price, 2014).

2.3 Illness Narrative: Theory and Methodology

In his book "Illness Narratives," Arthur Kleinman argues that the way in which an individual tells the story of their illness can have a significant impact on their healing process. He emphasizes the importance of understanding the cultural and personal meanings of an illness, and how these meanings can shape an individual's experience of the illness and their response to treatment. He also stresses the importance of listening to and valuing the patient's perspective, rather than only focusing on the biomedical aspects of the illness. He suggests that the way an illness narrative is written should be inclusive of the patient's voice and should take into account the social and cultural context in which the illness occurs (Kleinman, Illness Narratives: Suffering, Healing and the Human Condition, 1988) (Carlin, 1990).

In "Illness Narratives," Arthur Kleinman identifies several major components of an illness narrative:

1. The onset of symptoms: This includes the patient's initial experience of the illness, including when and how the symptoms first appeared and the patient's initial reactions to them.

2. The diagnostic process: This includes the patient's experiences with the healthcare system, including any tests and procedures they underwent, as well as the patient's emotions and thoughts during this process.

3. The lived experience of the illness: This includes the patient's daily experiences with the illness, including the impact on their physical, emotional, and social well-being, as well as the patient's coping strategies (Kirmayer, 1989).

4. The meanings of the illness: This includes the patient's beliefs, values, and cultural context that shape the way they understand and make sense of their illness.

5. The patient's goals and expectations: This includes the patient's hopes and fears for the future, as well as their expectations for treatment and recovery.

6. The impact of the illness on the patient's life: This includes how the illness has affected the patient's relationships, work, and overall quality of life.

7. The patient's experience with treatment: This includes the patient's experiences with different treatments and healthcare providers, as well as the patient's thoughts and emotions related to the treatment process.

8. The patient's sense of self and identity: This includes how the patient's illness has affected their sense of self, including how they view themselves and their place in the world (Carlin, 1990).

Marian Burchardt, a German sociologist, has proposed a framework for analysing illness narratives that consists of three key elements (Burchardt, 2019):

1. Illness story: This refers to the individual's personal account of their illness experience, including the onset of symptoms, the diagnostic process, and the impact of the illness on their life. The illness story is shaped by the individual's personal beliefs, values, and experiences, as well as by the social and cultural context in which it is told.

2. Illness identity: This refers to the ways in which individuals understand and define themselves in relation to their illness. This includes the meanings they attach to their illness, the roles and responsibilities they assume as a result of their illness, and the social and cultural identities that are associated with their illness.

3. Illness biography: This refers to the ways in which individuals integrate their illness experience into their overall life story. This includes the ways in which they make sense of the illness in relation to other events and experiences in their life, and the ways in which the illness shapes their sense of self and their future.

According to Burchardt, these three elements of illness narratives are interrelated and cannot be understood in isolation from one another. The illness story, illness identity, and illness biography are mutually constitutive and mutually dependent on each other. By analysing these three elements, researchers can gain a deeper understanding of how individuals make sense of their illness and how it shapes their lives (Burchardt, 2019).

2.4. Existentialism and Illness Narratives

Existentialism is a philosophy that emphasizes the individual's freedom, choice, and responsibility for their own existence and the meaning of their life. It can play a part in the study of illness narratives by highlighting the ways in which an individual's illness can affect their sense of self and their understanding of their place in the world (Aho, 2018).

In the context of illness narratives, existentialism can help to understand how the experience of illness can shape an individual's sense of identity and their understanding of the meaning of their life. For example, individuals with chronic illnesses may struggle with feelings of isolation and a loss of control over their lives, which can affect their sense of self and their understanding of the meaning of their existence. Existentialism can help to understand how these feelings may be related to their illness and how they may shape the way they make sense of their illness (Piette, 2014).

Existentialism can also help to understand how the experience of illness can shape an individual's understanding of the world around them. For example, it can help to understand how individuals with chronic illnesses may view the world in a different way than those without chronic illnesses, and how this may shape the way they make sense of their illness. In addition, existentialism can help to understand how the experience of illness can shape the way an individual relates to others and how it affects the relationships in their life. For example, it can help to understand how individuals with chronic illnesses may struggle to maintain relationships with others and how this may shape their sense of self and the meaning of their existence (Daniele, 2021).

Albert Piette is a French Anthropologist, known for his work on the intersection of anthropology and existentialism. He has written extensively on the subject of existential anthropology and his interpretation of Heidegger's writings on existentialism. Piette argues that existential anthropology is a way of understanding human experience that emphasizes the individual's subjective experience of the world. He believes that Heidegger's concept of "Dasein," which refers to the unique way in which an individual exists in the world, can be used as a lens through which to understand the human experience of illness. He argues that by understanding the unique way in which an individual experiences illness, we can better understand the meaning of the illness for that individual and the impact it has on their life.

Piette also emphasizes that in Heidegger's existentialism, individuals have an active role in shaping their own existence, and this is reflected in the way they make sense of their illness. He argues that individuals create meaning through their engagement with the world, including through their illness, and that this meaning is not something that is given but something that is created. This means that individuals have an active role in shaping their illness narratives.

Piette also argues that Heidegger's concept of "being-in-the-world" is particularly relevant to the study of illness, as it emphasizes the way in which individuals are situated in a social and cultural context and how this shape their experience of illness. He believes that by understanding the social and cultural context of illness, we can better understand the meaning of the illness for the individual and the impact it has on their life. Albert Piette argues that existential anthropology can provide a valuable perspective for understanding the human experience of illness, by emphasizing the individual's subjective experience and the unique way in which they exist in the world. He believes that Heidegger's concept of Dasein, being-in-the-world, and the active role of individuals in creating meaning can provide a framework to understand the emotional and psychological aspects of illness, which can be valuable in the study of illness narratives (Piette, 2014).

2.5. Sick Role Theory and Illness Narratives

The sick role theory is a sociological model developed by Talcott Parsons in 1951. It explains how individuals who are ill are expected to behave within a society and how society expects them to interact with the healthcare system. According to Parsons, the sick role has several key characteristics:

1. The individual must be considered truly ill by themselves and by society.

2. The illness must be considered a "legitimate" illness by society.

3. The individual is temporarily excused from their normal roles and responsibilities.

4. The individual is expected to seek medical help and follow the advice of healthcare professionals.

5. The individual is not held responsible for their illness, but they are expected to work towards recovery (Varul, 2010).

The sick role theory has been widely studied and applied in the field of medical sociology, and several authors have developed and expanded upon Parsons' original concept. Some notable authors who have worked on the sick role theory include, Peter Conrad, author of "The Medicalization of Society: On the Transformation of Human Conditions into Treatable Disorders" (Conrad, 2007), Irving Zola, author of "Illness as an Alienation" and Arthur Kleinman, author of "The Illness Narratives: Suffering, Healing, and the Human Condition (Kleinman, Illness Narratives: Suffering, Healing and the Human Condition, 1988)."

The sick role theory has been criticized for its assumptions about illness and its lack of attention to the social and cultural factors that shape illness experiences. However, it remains an important framework for understanding how society expects individuals to behave when they are ill and how they interact with the healthcare system (Varul, 2010).

2.6. Medicalization of Society

In his book "The Medicalization of Society: On the Transformation of Human Conditions into Treatable Disorders," Peter Conrad explores the concept of medicalization, which is the process by which non-medical issues come to be defined and treated as medical problems (Conrad, 2007). He argues that medicalization is a phenomenon that has become increasingly prevalent in modern society, and that it has led to a significant expansion of the medical sphere of influence (Bury, 2009).

Conrad argues that medicalization can have both positive and negative effects. On one hand, medicalization can lead to the development of new treatments and therapies that can improve people's health and well-being. On the other hand, he argues that medicalization can also lead to the overdiagnosis and overtreatment of conditions that are not truly medical in nature, and that it can also lead to the pathologizing of normal human experiences and behaviours (Bury, 2009).

He also talks about the impact of medicalization on society, he suggests that medicalization can have a significant impact on the ways in which people understand and experience health and illness, and that it can also have an impact on healthcare systems and the ways in which healthcare is delivered. Conrad's book highlights the importance of understanding and critically examining the process of medicalization, and the implications it has on individuals and society (Bury, 2009).

2.7. Illness as an Alienation

Irving Zola was a medical sociologist who wrote about illness as alienation. In his work, Zola argued that illness creates a sense of estrangement or alienation from oneself, others, and society. He believed that the experience of being sick can disrupt one's social relationships and leave the individual feeling isolated and disconnected from others. Zola saw illness as a form of social oppression, as those who are sick are often marginalized, stigmatized, and treated as outcasts. He argued that the medical system also contributes to this alienation by viewing patients as passive objects of care rather than active participants in their own treatment (Williams, 1996).

Irving Zola's work on illness as an alienation, as expressed in his book "Illness as a Metaphor", addresses the cultural and social meanings surrounding illnesses, including autoimmune diseases. He argues that diseases such as tuberculosis, cancer, and others are often used as metaphors for social and psychological issues and are therefore subject to cultural and political meanings that can have a profound impact on the experience of illness for patients.

In the case of autoimmune diseases, Zola argues that these conditions are often seen as mysterious and difficult to understand and are therefore stigmatized. This stigma can lead to feelings of alienation and a sense of being different from others, which can further exacerbate the physical and emotional symptoms of the illness. Zola also discusses the ways in which medical and scientific understanding of autoimmune diseases can be influenced by cultural and political factors and argues that a more nuanced and culturally sensitive approach to understanding these conditions is needed.

Irving Zola gave several examples of how diseases have been used as metaphors for various social, political, and psychological issues. Here are a few examples:

1. Tuberculosis was seen as a metaphor for moral decay, reflecting the Victorian era's preoccupation with sexual morality and hygiene.

2. Cancer was seen as a symbol of environmental pollution, reflecting the anxiety about industrialization and its effects on public health.

3. Mental illness was seen as a metaphor for social and political dissent, reflecting the way that dissent was perceived as a threat to the established order.

4. AIDS was seen as a metaphor for the perceived moral decay of homosexuality and drug use, reflecting societal attitudes towards these marginalized groups.

Zola's analysis showed how these metaphors served to reinforce negative stereotypes and justify social exclusion, thereby perpetuating the marginalization of people with these diseases.

2.8. Memorable Messages

The messages women receive about their health influence their perceptions of body and self, identity development, and perceived agency in medical settings and practitioner interactions. Memorable messages are short, highly impactful verbal messages that individuals can recall over a long period of time and shape identity, values, beliefs, and behaviours (Cooke-Jackson & Rubinksy, 2022). These messages effect the way individuals manage their health, impact selective disclosure and concealment, as well as shape their belief and value systems and how they view their bodies and roles in society (Gunning, Cooke-Jackson, & Rubinsky, 2019). Stemming from a variety of interpersonal sources including family, friends, and socializing others, these messages can be positively or negatively valanced and impact how individuals make sense of their lived experiences. In recent years, health communication scholars have used a memorable messages framework to study communication about stigmatized health topics and illness experiences, thus offering a fitting theoretical framework to explore the impact that messages received by emerging adults on their autoimmune disease diagnostic journey have on identity formation, sense-making, and disease management behaviours (Gunning J.   , 2021). (Cooke-Jackson & Rubinksy, 2022) theory of memorable messages (ToMM) posits that messages received during important events, situations, or episodes influence identity which in turn impacts individuals' self-concept, behaviours and actions, and subsequent formation and delivery of new messages to others. These messages can be both verbal and nonverbal and received from a variety of interpersonal and media-based sources.

Prior research on memorable messages in the context of long-term difficulty and illness offers a guide for the role memorable messages play in cultivating and enacting resilience, re-framing hardship, social support and compassionate care, and health behaviour adherence. Most memorable message research on navigating long-term health conditions has been studied in the context of breast cancer prevention and detection behaviours. (LaPlante, Smith, Kotowski, & Nazione, 2012) explored the use of framing in self-reported breast cancer memorable messages, finding that gain-framed messages, as opposed to loss framed messages, were found among participants, suspecting that gain-framed or positively valanced messages may be more easily remembered than negative or loss framed messages in the context of chronic illness.

In addition to families and peers, health care providers (HCPs) are a likely source of memorable messages. Despite this, limited research has used a memorable messages framework as it relates to HCP communication. In one of the few studies, it was found that memorable messages from health care providers are the least likely to be recalled by patients and have a larger impact on health behaviour change or adherence as opposed to identity formation. However, it is important for health professionals to know the topics and sources of memorable messages as they relate to long-term illness prevention and detection outreach (Gunning J., 2021)

2.9 Communicated Sense Making

Communicated sense-making (CSM) is a theoretical model introduced by (Kellas & Horstman, 2015) that offers a guiding framework for how individuals process and make sense of difficulty, identity, and relationships through communication. Under this framework, six devices for communicated sense-making are offered, including accounts, attributions, communicated narrative sense-making, metaphors, memorable messages, and communicated perspective-taking. Each device offers a unique approach to understanding the role of communication in sense-making “surrounding difficult, confusing, or complex situations and experiences, such as mental health and illness” (Koenig Kellas & Kranstuber Horstman, 2015, p. 32). Thus, CSM offers a fitting framework for analysing the illness narratives and memorable messages of emerging adult females navigating the disruption of autoimmune disease onset.

(Joyce & Jeske, 2020) identified the use of war metaphors, with patients employing attack language to describe their disease activity (i.e., attack, battle, fight, killing), resulting in their invisible illness becoming more understandable and recognizable to relational others. Utilizing devices of communicated sense-making offers a path for relational connection, understanding, and subsequent effective support in the face of disruptive health experiences, both for the patient and their loved ones (Gunning J., 2021).

CHAPTER 3

3. RESEARCH SETTING AND METHODOLOGY

3.1. Locale of the Study

Karachi

Karachi is the largest city in Pakistan, with an estimated population of over 14 million people. It is the economic hub of the country and home to a diverse population, including people from various ethnic and religious backgrounds. Karachi's medical infrastructure is considered to be the most advanced in Pakistan, with both public and private hospitals and clinics (Nawab, et al., 2014).

As Figure 1 shows the distribution of healthcare facilities and ambulance accessibility in the city of Karachi, indicating the spread of advanced emergency services and other services (Alhasan Systems, 2015).

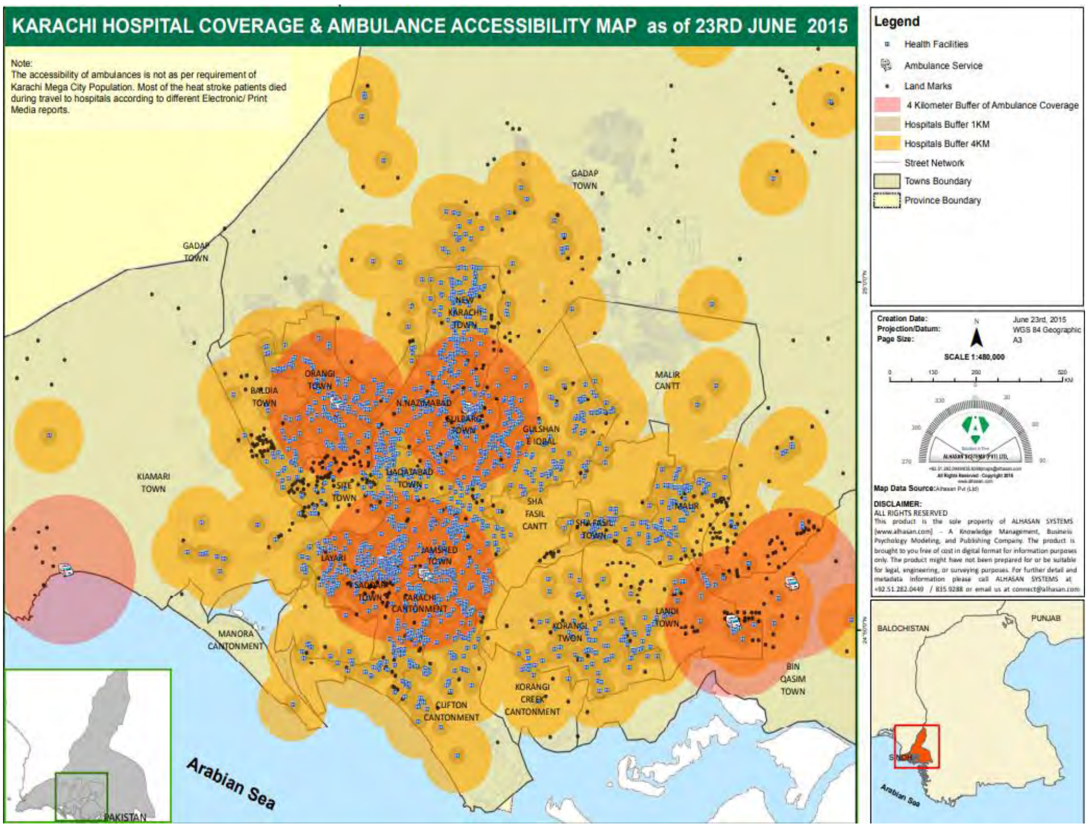

Figure 1: Karachi Hospital and Ambulance Accessibility Map (2015)

Source: Reliefweb.int

Autoimmune diseases, a group of illnesses in which the body's immune system attacks its own healthy tissues, are becoming increasingly common in Pakistan. These illnesses can have a significant impact on a patient's life, with symptoms ranging from mild to severe. Studies have shown that the experiences of individuals living with autoimmune diseases can be shaped by cultural factors such as gender and socio-economic status (Charon, 2001). Therefore, Karachi will serve as a valuable research locale to explore the illness narratives of women diagnosed with autoimmune diseases.

Autoimmune diseases, including rheumatoid arthritis, systemic lupus erythematosus, and multiple sclerosis, are becoming more prevalent worldwide. According to the World Health Organization, autoimmune diseases affect approximately 5% of the population globally, with women being more susceptible to developing these illnesses than men. In Pakistan, the incidence of autoimmune diseases is also rising, with rheumatoid arthritis and systemic lupus erythematosus being among the most common (Jawad, et al., 2021).

Research has shown that cultural factors, including gender and socio-economic status, can have an impact on the experiences of individuals living with autoimmune diseases. For example, women may face greater challenges in accessing healthcare and receiving appropriate treatment due to cultural norms that prioritize men's health over women's health. In addition, individuals from lower socio-economic backgrounds may face barriers in accessing healthcare due to financial constraints (Kurji, Premani, & Mithani, 2016). Therefore, exploring the illness narratives of women diagnosed with autoimmune diseases in Karachi can provide valuable insights into the impact of cultural factors on the experiences of these patients.

As Figure 2 shows the depiction of scores across Pakistan in relation to health-related factors. The particular maps show the score across Pakistan in terms of Community Health Index, which measures the health of a community from 0-1000, the greater the score, the healthier the community (Khan & Hussein, 2020).

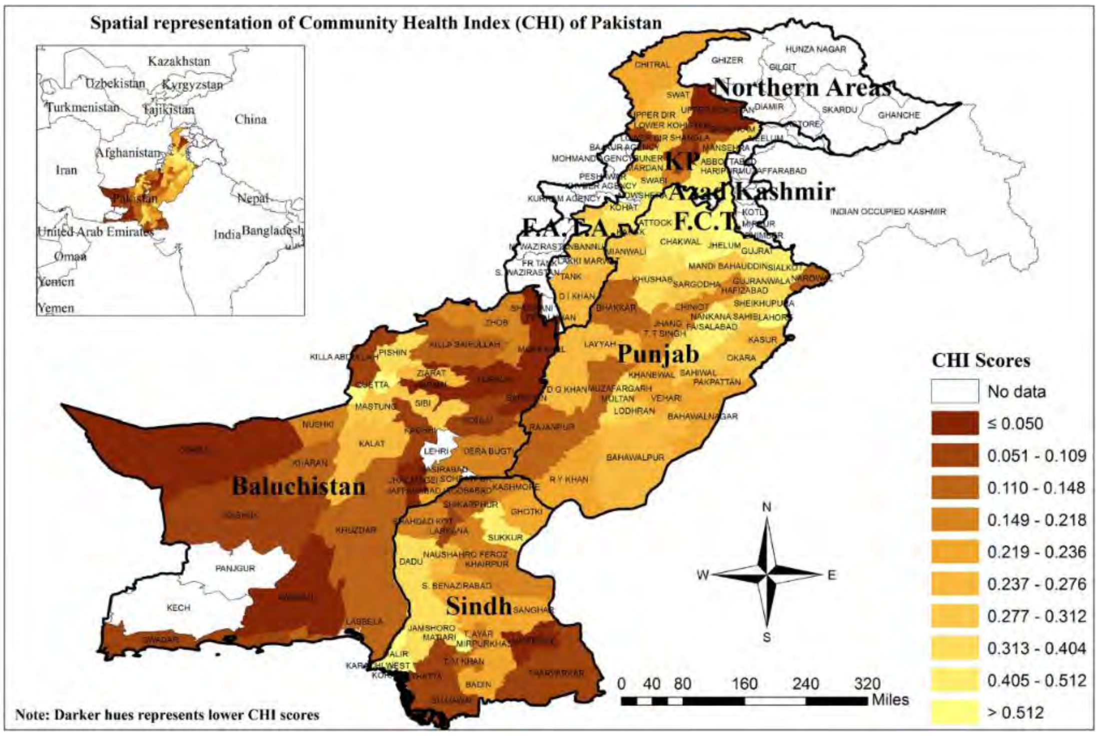

Figure 2: Spatial Representation of Community Health Index (CHI) of Pakistan (2020)

Source: Google Maps

3.2. Research Methodology

In line with the Interpretivist Paradigm which has the central endeavor of understanding the subjective world of the human experience and views reality to be socially constructed the Narrative Inquiry methodology is best suited in this type of research (Pervin & Mokhtar, 2022). In interpretivist research, the focus is on understanding and interpreting the subjective meanings that people give to their experiences, rather than trying to explain or predict human behavior through the use of objective measures or quantitative data. This approach emphasizes the importance of context, and the ways in which social, cultural, and historical factors shape the meanings that individuals ascribe to their experiences (Pervin & Mokhtar, 2022). The Narrative Research Method focuses on data gathered through a select number of respondents via interviews and documents etc. over a period of time and is used when exploring historical experiences, identity, and oral history (Ntinda, 2019).

Narrative research aims to explore and conceptualize human experience as it is represented in textual form. Aiming for an in-depth exploration of the meanings people assign to their experiences, narrative researchers work with small samples of participants to obtain rich and free-ranging discourse. The emphasis is on storied experience. Generally, this takes the form of interviewing people around the topic of interest, but it might also involve the analysis of written documents (Salkind, 2010).

Narrative research is an approach to qualitative research that seeks to understand and interpret the stories that individuals talk about their experiences. It is rooted in the interpretivist paradigm and emphasizes the importance of understanding how individuals construct their own narratives about their experiences, identities, and relationships (Pervin & Mokhtar, 2022). Narrative research recognizes that individuals make sense of their experiences through storytelling, and that the stories they tell are shaped by a range of social and cultural factors. These stories are not seen as objective descriptions of events, but rather subjective interpretations that reflect the individual's perspective and understanding of the world around them (Ntinda, 2019).

3.2.1. Sampling

The sampling technique that best suits this study is purposive sampling technique. Purposive sampling, also known as judgmental, selective, or subjective sampling, is a form of non-probability sampling in which a researcher relies on their own judgment when choosing members of the population to participate in their study (Newman, 2014). This sampling technique was used because it was crucial to study the population which was representative of the literature being discussed.

The researcher interviewed 20 respondents out of which 7 were selected purposefully to be presented as case studies in the research. These selected participants were chosen on the basis of unique stories, experiences, and illnesses.

3.2.2. Sample Size

The researcher selected a sample of 7 respondents with varying autoimmune illnesses from the total number of 20 respondents to assist in serial interviewing for in-depth data collection that could be presented as illness narratives.

3.3. Research Design

The research design follows the steps of qualitative research while focusing on the narrative aspect of the research methodology. The primary data was collected sequentially over the course of a few months using interview notes, audio recordings and interview transcriptions. The secondary was collected simultaneously and was used to verify or support data coming from the primary sources. It was then analyzed using the Narrative Analysis focusing on events, verbatims, and timelines. The analysis is presented in a chronological manner and was shared with the respective respondent for corrections and/or additions to avoid any mistakes. The focus was on the overall experience of respondents both personally and socially in the face of their chronic illness.

Respondents were found using Facebook groups related to autoimmune diseases, google survey forms that were shared via WhatsApp and Facebook, asking friends and family and by clinic visitations. The researcher spent weeks at the Liaqat National Hospital Services Center in Nazimabad to talk to Dr. Syed Mehfooz Alam's patients. Dr. Syed Mehfooz Alam is a practicing Rheumatologist with 22 years of experience who allowed the researcher to collect data from his patients and read their histories, with consent.

3.4. Data Collection

The data was collected using various tools and techniques in Anthropology focusing on in-depth interviewing, rapport building with respondents, participant observation and use of field notes.

3.4.1 Tools of Data Collection

The researcher made use of the following tools of data collection such as field notes, audio recordings, transcriptions, secondary data, WhatsApp and Facebook groups, and google forms.

3.4.2 Techniques of Data Collection

3.4.2.1 In-Depth Interviews

The researcher used in-depth interviews as a data collection technique and has access to a list of basic questions a researcher must ask when conducting and illness narrative study. Narrative studies refer to research approaches that focus on analyzing and comprehending personal narratives to get insights into individuals' experiences, perspectives, and interpretations. Oral history refers to the process of gathering and preserving historical knowledge by means of direct testimonies, tales, and personal encounters communicated vocally. It encompasses the process of documenting and transcribing people's recollections, contemplations, and narratives, offering a distinctive viewpoint on events, civilizations, and society. These questions were proposed by Kleinman in his famous book, The Illness Narratives. They are as follows:

1. What do you call the problem?

2. What do you think has caused the problem?

3. Why do you think it started when it did?

4. What do you think the sickness does? How does it work?

5. How severe is the sickness? Will it have a short or long course?

6. What kind of treatment do you think you should receive? What are the most important results you hope to receive from this treatment?

7. What are the chief problems the sickness has caused?

8. What do you fear most about the illness? (Kleinman, The Illness Narratives: Suffering, Healing and the Human Condition, 1988)

Researcher also used an interview guide developed by McGill (Groleau, Young, & Kirmayer, 2006) as reference to ask relevant questions but used the flow of the conversation to guide the interview rather than strictly following the guide at hand.

3.4.2.2 Rapport Building

It is the creation of a friendly relationship with respondents so as to become a part of their community to gather insider data from the respondents.

3.4.2.3 Participant Observation

It is the most frequently used tool of observation to not only systematically watch and record behavior of the respondents but to also participate in the activities that they engage in. In the context of this study the researcher intends on participating in the activities the respondents will have that are directly or indirectly related to their illnesses such as therapy, clinic visits, meal prep or others.

3.5 Data Analysis

The data was analyzed using the Narrative Analysis. Narrative analysis in the human sciences refers to a family of approaches to diverse kinds of texts, which have in common a storied form. Researchers use narrative analysis to understand how research participants construct story and narrative from their own personal experience. That means there is a dual layer of interpretation in narrative analysis. First the research participants interpret their own lives through narrative. Then the researcher interprets the construction of that narrative (Riessman, 2005).

3.6 Ethical Considerations

Axiology or the ethical issues that need to be considered when planning a research proposal. It involves defining, evaluating, and understanding the concepts of right and wrong during research. There are four criteria that will be accounted for in this research:

1. **Teleology:** Moral theory that doing what is intrinsically good is a moral obligation.
2. **Deontology:** That every action taken during the research is intended to benefit people.
3. **Morality:** That the intrinsic moral values will be upheld during research.
4. **Fairness:** That the need for fairness and due rights will be given to all respondents.

The principles of ethical considerations which are, privacy, accuracy, property and accessibility (PAPA) were upheld throughout the course of the research (Kijunva & Kuyini, 2017).

3.7. Challenges in Research

The current research came with its own unique challenges not just in my personal life but also in terms of finding case studies strong enough to represent the life histories of female autoimmune patients. Since case studies require serial interviews over the course of several weeks, it was difficult to find respondents willing to give so much of their time and energy.

CHAPTER 4

4. ILLNESS NARRATIVES OF FEMALE AUTO-IMMUNE PATIENTS

4.1 Sumaira

Sumaira is 30 years old, and was officially diagnosed with Rheumatoid arthritis at 27, she had been experiencing some symptoms for 7-8 years and 3 years of extreme symptoms before her official diagnosis. She has a degree in Applied Chemistry and is currently doing an MBA from Karachi University. She has 3 sisters and her parents in the family and there is a medical history of autoimmunity and Rheumatoid Arthritis. Sumaira is a vibrant individual and is passionate about the cure of autoimmunity through holistic measures. She herself went through a holistic journey after an extremely disappointing experience with the western medical system. She claims herself to be free from active autoimmunity and is living a medicine free life for almost 2 years.

Rheumatoid arthritis is characterized by painful, swollen, stiff joints, often accompanied by fever, fatigue, and weightlessness. It causes chronic inflammation of various joints due to the synovium of the joints being compromised. Typically, the synovium, which is soft tissue lining the joints and tendons, aids with movement, flexibility, and weight impact. Those affected by rheumatoid arthritis experience thickening of the synovium due to the inflammation, causing deterioration of cartilage and bone of the affected joint. (Angum, Khan, Kaler, Siddiqui, & Hussain, 2020)

Sumaira begins her story by explaining the different types of rheumatoid arthritis. She explains that there are two types, seropositive and seronegative. The seropositive type shows up on our blood reports, but the other does not. From the literature it states that Seropositive RA refers to the presence of RF and/or anti-CCP antibodies in a person diagnosed with RA. Seronegative RA refers to the situation where both antibodies are not elevated (Lim, 2018). Which means that in some cases an individual might have Rheumatoid Arthritis but when tested for RA factor, their antibodies would be normal and it would ‘appear’ that they do not have Rheumatoid

Arthritis when in fact, they do. This was the case for Sumaira as well, whenever her RA factor was tested, it would appear normal, and it was initially dismissed that she might have RA. Sumaira's degree in Applied Chemistry actually helped her understand her medical journey much quickly than a layman. Throughout her discussions, she would explain each and every test she got and what it was for. She identified initially that since her ESR would always come raised above normal levels, it must mean that she had inflammation in her body. She also explained that she herself got tested for albumin (protein) because protein negatively impacts autoimmune patients and causes inflammation. *"This is not something that doctors tell us, but it is what I learned from my courses in MS Chemistry."*

Sumaira begins her story from an accident which happened in 2017. She narrates her story as follows:

> *"I was walking down the road and a bike crashed into me. I was hit on my left leg. I had tire marks all over my thigh and I was severely bruised. I fainted on impact but as soon as I regained consciousness, I went to Agha Khan Hospital. In the emergency room they took my physical examination and said that there is nothing for major concern and I should just take these painkillers for relief. This was very painful for me to hear; I had visible tire marks on my body, and they were saying that there was nothing wrong. They even tested me for Lupus then, I don't know why, but they never considered to care about it. They just gave me a bunch of painkillers and antibiotics and sent me on my way. I was a teenager then and I used to go to college on crutches. I had to use those crutches for months, but according to them there was nothing wrong."*

Sumaira also claims fault in her naivete as a young teenager. She explains that as a young individual she did not care much for her health. She had an unhealthy lifestyle or what she calls the "burger life" as she was a zinger lover. She says that she did not eat healthily and that vegetables were her enemy. She almost always ordered food and drank soda on the regular. Sumaira says that her lifestyle was also a contributing factor in the rise of her illness and that she cannot just put the blame on others. She was also tested for Vitamin D at the time of the accident which came out extremely low at around 9.5ng/mL and the normal range is around 30-50ng/mL (Mount Sinai, 2022). Yet, she did not take her supplements which she again attributes to her naivete. She says, "When you are young you feel like you are invincible, and you do not think health is something you need to take seriously. Despite having that accident and being vitamin D deficient I did not pause to consider my health. I understand that now that I was harming my body and filling it up with toxins, but I did not know any better. I was too young, and my body was coping however it could. I just did not know I was about to experience the worst pain of my life."

Some years passed and after graduating with a degree in Applied Chemistry, Sumaira started looking for jobs in her field but was left disappointed. Despite Chemistry being her second choice when she could not get into medical school, she was faced by rejection a second time. She would give interviews upon interviews but never heard back from anyone. She did not have the experience to compete in the field yet, so she reluctantly took up teaching jobs in two schools. She explained her schedule as follows:

> *"My first shift was from 10 am to 12 pm and the second shift was from 12:30 pm to 2 pm. After that I would go straight to the gym. I was overweight then and a little conscious about it too, so I joined the gym. I wanted to work on myself and do better, I did not know I was putting my body through copious amount of stress. On top of that, I was in a pretty bad mental condition. I was sad and depressed that I was not getting any call backs from pharmaceutical companies. I was disheartened for the second time in my life. This led me into a spiral of mental stress, and I was deeply depressed."*

The most fascinating thing about Sumaira's story is the miniscule yet catalyzing incident, a bead. A simple bead in her *qameez* (long shirt worn most commonly) brought her immobility for 8 months. She narrates the incident as follows:

> *"I remember that day vividly. I had come back from my last shift teaching at the school. My qameez had beads on the border. When I put my knee on my bed the bead got pressed between the bed and my knee and hurt me quite badly. Generally, when something that small hits you like that, you feel pain and a jolt but after that you will be fine, but I was not fine. The bead had hit me in my left knee the same knee from the accident. My knee slowly started to swell where it had been hit by the bead. I did not understand what was happening, but I did not think much of it."*

Sumaira shares that she believes she needed rest at that time but could not do so due to her commitments with the school. The students were about to appear in board examinations and the school needed her to teach. They even arranged for her classes to be held on the ground floor but what she needed was a break from her exhausting routine. Sumaira slowly started to see her right knee swell up as well when nothing had hit that leg. She also started to see small blisters appear on her fingers, hand, forehead, and the sides of her back. These were tiny blisters that were itchy but would not leave a mark when they went away. Sumaira went to many places for the treatment of those blisters. She went to National Hospital and the doctor told her that these blisters were not contagious but she should take these antibiotics to get rid of them. She says that they were third generation antibiotics of high dosage which she took for 21 days. Although the medications reduced the appearance of the blisters, she also lost most of her hair as a side effect. Which is a common but short-term side effect of most antibiotics (Gotter, 2018).

Sumaira taps into her holistic health perspective and shares that she now knows that these blisters were actually a sign from her liver that there is something wrong with her blood. That her liver needs detoxification, a word she would use often during conversation. She said that despite this being a very clear indication of toxicity in her blood, her blood work would always come out normal. She also said, "I did not realize at that time that these were *anti-biotics* meaning medicines that work against your life. I did not know that I should not have taken them for such a long period of time. I lost so much hair that you could not even see them."

During this time, she was still in pain and her knees were still inflamed. She went t to many doctors and many hospitals for a diagnosis, but she was unsuccessful. She went to Agha Khan Hospital, Ziauddin Hospital, Liaqat Hospital, Iman Clinic among others. She shared many stories of her experience with the various health care providers that she encountered in her illness journey. Her primary health care provider who treated her for 6 months was from Ziauddin Hospital; a senior orthopedic whose name she refused to disclose. She narrates her story as follows:

> *"He was a very senior doctor at the hospital. He asked my age; my father told him I was 28 years old. My father said to him, 'doctor, she is going to be married soon, please tell us what is going on,' so that the doctor would take my issue seriously. He would never tell us what was wrong. He first gave me a medicine by the name Danzen for the inflammation and some painkillers, but we saw no change. At that time, I was in the worst condition of my life. For eight months I was lying still on my bed. I couldn't even toss right or left, going to the bathroom was agonizing for me. My knees were swollen like balloons and looked red; I could*

> *not even bend my legs. Whenever I would ask my physician what was wrong with me, he would scold me and say, "You have poor diet." I was afraid of him, and he would never directly tell me what the issue was. I was under this doctor's care for around six months and for half that time he gave me steroids. I took his medications for 6 months not even knowing what I was being treated for. He always got my ESR tested and every time it would come abnormally high. He knew that I had rheumatoid arthritis because now I understand what the blood works were for, but he never shared that with me, which was unfair."*

Sumaira then gave a moving statement, she said, "Bad diagnosis is better than no diagnosis." She shared her disappointment at being left in the dark the whole time of her treatment. The doctor would check her legs, see if the knees were bending, see if her joints were changing shape but refused to tell her what was wrong or what medicines she was taking. She felt betrayed by her doctors at not just the diagnostic level but also the treatment level. She says, "Patients deserve to know what is going on with them. I feel bad for people who are undereducated and trust their doctors blindly because they have no other option. If the doctor educates their patient about the issue, it can help them better understand their condition. *What am I supposed to do with 6 painkillers?*"

A strange event while in the care of this doctor was that he recommended her to tie dumbbells on her ankles and lift them up.

> "It's preposterous to ask someone with debilitating joint pain to lift weights on their inflamed joints. I got severe inflammation in my ankles thanks to him. *I don't know what prayer to give him*."

The doctor at Ziauddin gave her painkillers, DEMARD by the salt name of Sulfasalazine, HCQ, and Deltacortril which is a steroid. DEMARD's are Disease-modifying antirheumatic drugs which are commonly given to patients with Rheumatoid Arthritis and work to suppress the body's immune system also known as immunosuppressants (Cohen & Canella , 2022). Deltacortril belongs to a group of medications knows are corticosteroids which are used in the treatment of many autoimmune diseases and have been known to cause weight gain, behavioral changes, thinning of bones, ulcers and others if taken for a prolonged period of time, like over 2-3 months (Willacy & Tidy , 2021). Sumaira shared her sadness about being given these dangerous and high dose drugs without being given any explanation of what they were or why she was taking them. She only found out about what these drugs were after a doctor friend of hers looked at her reports and told her that in fact she had Rheumatoid Arthritis. She looked up on the internet what this disease was and looked into what medicines she was taking all by herself. Sumaira herself explained to me what her medicines were doing to her body, she said,

> *"These medications that I was taking caused me to have extreme constipation, I can't even explain the amount of pain I had when I went to the washroom. It felt like I was excreting rocks. I was taking DEMARDs, which are a group of medicines that stop your bones from twisting. I wish I could say this to my doctor but isn't it so unfair that a young girl was given these disease modifying drugs even though she is in the most initial stages of the illness. My bones were perfectly fine at the time and my little finger actually changed shape after I stopped taking them. When my body is still young and I have a better immune system then I would later in life, why was I given Sulfasalazine (DMARD)? I took 6 pills of Sulfasalazine daily; it was not necessary. The steroids kept my body falsely active, but it was not real, my body was being pushed to the limit by them. I'm not pointing fingers at the doctors, but they did not look into the root cause of my inflammation. I took HCQ which weakened my eyesight. My fingers were not bending, and considerably speaking, I was still in the early stages of arthritis. I took these high dose medications, and they affected my body terribly, my hormones were disturbed, my menstruation cycle was affected, I gained so much weight and all for what? 25 out of the 24 hours a day I would be sleeping because of these medicines."*

Sumaira also tried PRP therapy which stands for Platelet-rich plasma therapy. PRP is a product of one's blood which contains higher levels of platelets than normal. It is reintroduced into the body for the treatment of the synovial fluid in the joints, though it has been seen to be effective in osteoarthritis it is still in its experimental phase in patients with Rheumatoid Arthritis (Badshah, Harifi, & Murrell, 2020). Sumaira recalls that at that time she paid Rs.50,000 for each time she did the treatment. Her PRP therapist was trained in America and looked at her prescriptions from her previous doctor (from Ziauddin) and asked her to stop taking them all. Despite this being common knowledge, that steroids should not be stopped suddenly but should be gradually tapered off to avoid withdrawal which causes fatigue, joint pain, fever, weight loss and more (Berstein, 2022). This doctor instead prescribed her Lefora (salt name Leflunomide) which is also a DEMARD. While talking about this she said, "*do you know as long as Lefora is in your body, you cannot get pregnant? Did I not have the* *right to know that?"* Literature suggests that it can cause birth defects and a pregnancy should not be conceived until 'washing out' treatment has been done. Otherwise, it can stay in the patient's body for up to two years (UKTIS, 2022).

Sumaira was extremely disappointed by her condition and said that she kept thinking whether this was going to be her life; taking one pill after another to numb her pain. She started searching on the internet, "How to reverse autoimmune disease?" and there she found a video by Seema Rumashankar, her video was titled "How I cured my Rheumatoid Arthritis". Seema is a life coach and content creator who created a course of dietic practices that can heal a person from autoimmune illness. She runs a YouTube account by the name of Satvik Movement and a Facebook group by the name of Satvik Lifestyle. She herself was diagnosed with Rheumatoid Arthritis when she was 21 and lived with it for around a decade before she changed her diet and saw results (Umashanka, 2020). For someone like Sumaira to hear Seema say that Rheumatoid Arthritis is curable or that it is reversible or that you can be free from medicines was music to her ears. These words were more than what she could hope for. Sumaira took an initiative that day and said, *"I have spent 8 months in this unbearable pain, I cannot waste 8 more years of my life to this."* She purchased Seema's course for Rs.6000 which was of 30 days. It was divided into 4 weeks, and each had directions on what to do each week. She had given one very clear guideline that even if you start the course, you must not suddenly stop taking your medicines, especially the steroids. Unfortunately, Sumaira had flushed her medications down the toilet when her PRP therapist suggested her to stop taking all her previous medications and start taking Lefora. However, she did slowly taper off her steroids because she was aware of their withdrawal.

> *"I used to take 2 a day I came down to 1 and half then I came to 1 than half of that and then quarter of that and eventually stopped. If you are addicted to alcohol and your body is swinging in its pleasure, you cannot expect it to act fine if you make it quit cold turkey. Steroids were just like alcohol to my body, and I was surviving off of it. It is like there is a huge wall and its cracking and breaking and instead of fixing its foundations you bring a strong army to hold it in place. Autoimmune medicines work in the same way, they don't cure your illness, they just hold off the disease until you collapse. I, however stopped my DEMARDs except Lefora suddenly and it affected my body, some of my fingers changed shape a little but I cannot complain much about it."*

Sumaira shared the details of each week as follows: Starting from the first week the individual should start weening off sugar and by the second week they should completely stop taking any form of sugar except through dates or honey. The diet is very restrictive in its initial stages where one is not allowed to eat gluten, rice, dairy, vegetable oil, or meat. Sumaira recalls that it was very difficult for her to do initially because she loved all kinds of food and to leave out so many food groups altogether was difficult for her. She would drink raw spinach smoothie every day. The smoothie contained spinach, coriander, mint, and cumin. Initially that was the entire menu day and night. Sumaira said that her family would eat delicious foods in front of her and offer it to her, but she was resilient and refused each time. After two and a half weeks, she introduced papaya and coconut water into her diet.

I saw a significant reduction in the swelling of my knees, I would see the real color of my skin show up and it would give me so much hope. But eventually I got stuck, I talked to my friend from the same Facebook group-Satvik Lifestyle, and she said, "Even if we heal our bodies completely, do you really want to eat grass for the rest of your life?"

Sumaira's friend introduced her to another health mentor by the name of Ravinder Kaur who had followed Seemas' diet for a while, but she eventually had to get her hip joint replaced because she lost all joint fluid in her hip due to lack of fat in her diet. Ravinder suggested that Sumaira start taking Omega 3's. She did not drop her course, but she started taking Krill Oil supplements and gluten free flour.

"I would make roti with that flour and eat it, despite it being inedible. I would drink cucumber, carrot and beet root juice for breakfast, spinach smoothie for lunch and gluten free roti with some kind of boiled vegetable for dinner."

"On the 14th day of taking Krill Oil supplements, I drove my car for three minutes after months of being bedridden. I was able to push my knees enough to drive. It was exhilarating! I started cupping therapy on my own because in hadees it says that cupping has cure for 72 diseases. I don't know what those are, but I believe that I could also benefit from it somehow. The first time I got hijama I got three large cups on my knees because they were so big from the swelling and when the doctor placed cuts on my knees, I screamed at the top of my lungs due to the pain. The rest of the girls at the clinic got scared because of my screams. I used to get 17 cups at a time then, now I just do the sunnat points. I also did autoimmune points which are between the chest and on either side of the back."

Sumaira now lives a medicine free life after spending years in pain and months in bed wondering whether she would be able to walk or run. Sumaira shared that during her time at the peak of her illness she learned the very important lesson of who really cared about her. During the time when she was bedridden, hardly any of her friends came to check up on her or ask about her health. She felt the loneliness hit her then the most. However, her family stuck by her side.

> *"My father took me to whichever doctor I asked to go, gave money for whatever treatment I wanted to do. Not once did I feel dejected by my parents. My father would go every appointment with me and would be my pillar. My mother would wash my face and cry seeing me in pain, but my parents never lost hope that one day I would be all well and their prayers worked."*

Sumaira had to quit her job when she couldn't get out of bed due to her pain and illness. At that time, she felt like she was good for nothing and that she was a dependent who could not even perform basic tasks like walking or go to the washroom. Her cousin said a very powerful thing to her which helped her tremendously. He said, "If you can't move your legs, move your fingers and write."

> *"I became a content writer for the 8 months that I was in bed, and it gave me the feeling that I was doing something with my life like I had something to do. My medically numb mind found something that would keep it active. Now I am a digital marketer and an SEO Executive. I am doing MBA and arthritis is what brought me into this field."*

Sumaira is intuitively connected to her Rheumatoid Arthritis and can 'feel' her illness showing face. She said that even with a little stress she notices that her knees start to hurt. If she is happy and eating 'normal' food, she does not notice an effect on her body. She can feel it when dairy hurts her body or when toxins are accumulating in her body. She self-monitors her health by getting yearly X-Rays and ESR tests. Despite her tumultuous experience with Rheumatoid Arthritis, Sumaira sees her illness as a blessing in her life. It taught her the value of health, the value of family and the value of people who really mattered in her life. She refuses to blame her illness for anything because it was all a necessary experience in her life. She lived through it and she is positive she can live through many other such periods. She talks to her illness and says, "*Tum achi ho tum chali jao, aur tum chali jao gi"*. (You are nice, you should leave and you will leave.)

Analysis

Knowing

In addition to having a thorough cultural and medical understanding of her sickness, Sumaira also has a deep emotional understanding of her condition and its origins and manifestations. This is due to her extensive education in the field of chemistry. And when the doctor gives her medication, she knows exactly what it is for and how it will affect her body, thanks to her familiarity with the corresponding chemical formula. Then she discovered the medicines doctors had prescribed were doing little to alleviate her symptoms. They are only applying bandages to her wounds.

Diagnosing

Sumaira was diagnosed with rheumatoid arthritis when she was 27 years old. Her age at the time of diagnosis was not significant. She is well aware that she suffers from an illness. Her self-actualization and her awareness of sickness are both quite profound. Even if her trip through therapy is excessively drawn out and difficult, she makes extremely good use of the time she has, especially during the most chronic time period of her disease.

Curing

Sumaira took the choice to switch her treatment strategy from scientific medicine to ayurvedic medicine when she became aware of the limited effectiveness of scientific medicine. She was able to get information about the "Satvik Lifestyle" by following the direction of a powerful man who was originally from India. People who follow this specific way of living avoid ingesting any food products that are known to have components that might cause inflammation in the body. Sumaira's diet consisted only of unseasoned green vegetables for a considerable length of time. In addition, she was an active member of various Facebook groups, which is how she learned about the strenuous character of the previously described diet and how the absence of lipids in this diet plan has been connected to reduced lubrication within her skeletal system. She did this so that she could obtain information on the laborious nature of the diet. Her consumption of lipids starts to increase on a more gradual basis during the course of her diet. She is able to properly control her ailment without the assistance of pharmaceutical treatment thanks to the implementation of this food plan.

Coming to terms with the illness

During an eight-month period of complete bed rest, Sumaira's cousin made a remark that had a significant impact on her. Her cousin made a statement suggesting that her legs are unable of functioning, but her hands possess the ability to perform tasks, therefore advising her to engage in productive activities while taking a break. Upon receiving such remarks, she discovered a potential advantage within her disease. This message held significant resonance throughout her experience with illness, serving as a reminder to prevent the condition from overpowering one's skills.

4.2 Zunaira

Zunaira is a 25-year-old architect who was diagnosed with Lupus at the age of 18. She is also an artist and draws children's books as well as works in an architect firm. When she was 11 years old, she had terrible asthma, and she was given steroids to combat her illness. Zunaira believes that this is where illnesses began. She shares that as she was living in Multan when she was young and did not have access to better physicians or knowledge of what steroids were, she became susceptible to lowered immunity which rippled into her teenage diagnosis of Lupus. Zunaira narrates her story when she saw the first symptoms of Lupus in her life:

> *Two months after my 18th birthday I woke up and I was feeling so exhausted and tired this does not usually happen. I am very morning person, and I am usually very active the minute I wake up I am ready to do anything and go about my day. However, that day I could not even get up from bed, I got scared as it had never happened before. I tried to home my hair and I couldn't do it try to make a fist and I couldn't do it I didn't know that something was wrong with my body. I try to walk down the stairs but it's like I could not take to steps and I felt like gravity was pulling me harder. When I got downstairs, I tried to cut an apple, but I couldn't hold the knife. I was very scared but now I know that it was an arthritis attack that is why my joints were numb. From that day on my life changed completely. The night before, I had come back from my farewell party drenched in the rain for some reason I believe that the cold downpour became a catalyst and the cause of my arthritis attack.*

Later that day Zunaira was taken to a doctor, Dr. W, but he misdiagnosed her and gave her a vaccine which according to Zunaira she should not have been given[1]. She said that vaccine is dangerous if given two times a year. She was planning on taking an entry test at NUST university and was scared whether or not she would be able to go. After Dr. W she went to a rheumatologist who also misdiagnosed her. Zunaira had studied her reports and through the internet had figured out that she had Lupus, her doctor on the hand, did not agree with her. He said she had arthritis because he saw her arthritis attack as a clear indication of arthritis disease. The doctor gave her a steroid injection so that she could appear in her exam the next day. For a while after that Zunaira was on steroids and was misdiagnosed at the same time. She went to two or three doctors before she found her current physician.

> *I think due to lack of knowledge or awareness doctors tend to misdiagnose patients. I also think that since doctors in Pakistan are not professionals or specialists in lupus but do specialise in Rheumatoid arthritis, they tend to treat many conditions with the same formula as they would with RA. This might also be because they want to make money and they do not want to lose a customer. My reports said that I had Lupus, but no one wanted to give me that label because it was not lucrative.*

A year later Zunaira found her current doctor, Dr. B who had done research in the US about Lupus and worked in a foundation specifically for Lupus called Lupus America. This doctor diagnosed her with Lupus and has been treating her for the past 6-7 years. He told her that her condition was chronic and was not going away so she had to learn how to deal with it. Zunaira has been on steroids the entirety of the past 6 years. If she misses even a single dose her condition worsens and becomes very bad. When asked if her family had a history of autoimmunity, it turned out that her paternal aunt has rheumatoid arthritis, and her paternal grandmother has untreated thyroid issues. Her sister shared her feelings:

> *Whenever she gets an arthritis attack it's unbearable to hear her screaming in pain. My mother and I try to do everything we can to ease her pain, but it never seems enough. I think concerned from my little sister and I try to help her as much as I can, and I wish I could take away her pain but it's not something in my power. She is a resilient person and never complaints about her illness.*

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[1] The researcher did not cross verify this claim with the doctor mentioned."

Zunaira shared that she was lucky that she found her current doctor so soon and did not have to live with a misdiagnosis for a long time. She said that since her condition affects connective tissues the most which in turn affects major organs like her heart, her brain, and her kidneys it was best that she found a professional so soon. She shared horror stories of her friends who had experienced much worse treatment and she had. A friend of hers in Lahore had Lupus which was undiagnosed. She underwent large intestine, small Intestine and stomach operations with an active Lupus is while remaining undiagnosed. Zunaira on the other hand, feels thankful that she did not have to go through such drastic interventions and was diagnosed with the help of her internet savvy research skills and her doctor. She still not completely happy with her health care professionals and shared those experiences later on.

When asked to explain how she explains to others what lupus is, Zunaira shared her struggles of making people understand what her illness actually is. She finds it difficult to share the pain that she experiences is daily not only with strangers but also with family members. She said that Lupus is an unusual illness to have in our culture not many people know about it, and it is not their fault. People know about arthritis, but they do not know about lupus so when she tells people that she has joint pain and hair loss they assume that it is arthritis.

> *In my family I think my sister is the only one who genuinely understands my condition. My parents sympathize with me, and they try to help, but they do not have an understanding of my illness or the kind of treatment I deserve. If I tell people, I have an autoimmune disease they think is arthritis and then that is the stamp I get. Everyone judges according to their own knowledge.*

Zunaira is currently on corticosteroids called deltacortril by Pfizer. She takes 5 mg daily, six years ago she started with 10 mg and has been gradually weaning her body out of it. If she goes too fast her body is unable to recuperate and she has to go back and take more. She intense to eventually stop taking artificial steroids because she does not want her body to become addicted at such a young age and stop producing natural steroids. She wants her organs to do their job as affectively as a can without or with little external interventions. She also takes immunosuppressants in the form of hydrochloroquinine (HCQ) 200mg per day. Zunaira said that:

> *In chronic illnesses patients are given artificial steroids to boost their bodies and for us to not feel the pain that our body is going through. However, they cannot replace the natural thing and they come with side effects. It also signals our body to not to not produce natural steroids which can be harmful in the long run, but if we slowly and gradually reduce the number of artificial steroids that we take we can warm up our hormones and regulate our bodies to respond naturally to flareups. If one is lucky, they might eventually not have to take any steroids but only taking immunosuppressants which are a must and which we have to take our whole lives.*

Zunaira is an optimistic and cheerful person and does not allow negativity to consume her days. She tends to focus on the positive side of things and tries her best do not let her condition define who she is. However, she has had some painful experiences in her young life. She shared one story in particular:

> *I have not received any bad treatment from people around me but once I did get struck by the words of my teacher. In my entire degree at NCA I only took one leave of absence and that too was because I had a horrible flareup. I came the next day and asked my teacher if she would take my late assignment and consider it. I told her what my condition was and explained to her that it was due to this reason I was unable to come the day before and complete my assignment on time. She said if it is that horrible you should not have taken any stress. I was struck by her words and felt a wave of disappointment. She didn't know what I was going through, and she boiled it down to "stress". Even my educated colleagues do not understand when I share with them the reality is of my condition. My friends do not understand why I cannot come to every gathering or party or event and when they do not understand it, they tend to grow distant. They think I am making excuses because they cannot physically see what is going on inside my body. Like with cancer patients they grow bald because of chemo or when you break a leg you get a plaster, and everybody can see their pain but what I have is like an invisible handicap situation.*

Speaking of the medical healthcare system Zunaira shared her disappointments and said that it is uncommon to find a medical professional who is interested in the holistic aspect of treatment. She wanted help in not just medications but was looking for alternative practices such as diet and exercises. Her doctor, however, is not interested in things beyond her medications and her reports. Zunaira shared her opinion:

> *Doctors make sure that the patient keeps coming to them, so they intentionally keep you out of the loop sometimes. They want you to visit them every two months and they do not care what is happening to you to just want to give you medications and that's it. They are stone hearted people and in Pakistan it's much worse. They're not even interested in listening to you. I try to ask my doctor about the side effects of my medicines, how they are destroying me and how can I reduce the risk. What should I eat, what shouldn't I eat but he never listens. He thinks that I am overthinking it or that I have depression or anxiety. I want him to know that I want to take care of my body with natural ways as well. I follow a doctor on the internet who also has Lupus and has treated herself with natural methods. She gives awareness about exercises, healthy alternatives and herbal methods to heal our bodies; she is married and has two kids. I don't think I will ever be able to have kids, I don't know what my body has become on the inside and I have been taking steroids to the past six years.*

Zunaira has also experienced good doctors. She shared that she went to a neurologist once, Dr. M, who asked her to get physically active and start swimming. He also advised her to get enough protein in her diet like eating eggs.

> *He was a genuine doctor who did not want you to get on medications and would rather see you get better using nature. If you ask him, when should I come next? He would say, never. It's in the hands of the doctor to some degree whether or not a patient gets better I am thankful for Doctor Babar, but I have had to figure out a lot of things on my own. I have learnt how to self asses my condition and look for symptoms of inflammation by how my body reacts to certain foods.*

Zunaira used the internet to learn about autoimmune diseases and Lupus. She shared that it is difficult to get information regarding diet and lifestyle from her doctors. If they do give recommendations, it is usually abstract or incomplete.

> *Dr. B is a good doctor, and he did not misdiagnose me, however, beyond giving me a prescription he doesn't do much. I have learnt through the internet how to read my reports and learn what deficiencies I have. I have learned from observations the red meat does not suit me and causes inflammation. if I ever eat anything inflammatory like red meat, I get constipated and if this indigestion goes on for more than a day then I get flared up. My wrists swell and my hip joint completely chokes, and I become immobile.*

Zunaira also believes that she had a better experience with her diagnosis than most patients in Pakistan do. She feels grateful for family and sister for taking her symptoms seriously and getting her the help that she needed.

> *I am thankful for my family, especially my sister who figured out a lot of alternative methods and techniques that I could use to better my health. In terms of food, she introduced me to broccoli, sweet potatoes, and smoothies. She would literally steam broccoli and sweet potatoes and bring me them to eat. She changed our oil from seed oils to olive oil and coconut oil. She introduced me to papayas which help me immensely and detoxify my body.*

When talking about her life and its relationship with her illness Zunaira feels like she does not allow the negativity to impact how she lives and walks in the world. She does not let her illness to drive or dictate the limit to her ambitions and attributes most of it to her will power.

> *Lupus impacts everyone differently but it has been kind to me. My doctors find it strange that even though I have been taking steroids for the past 6 years I have not gained an unhealthy amount of weight which is quite common. I think it's because I don't take any stress or try to control my condition. I have pretty quickly understood that I have this illness and I do not let it impact my state of mind. What is, is; and I have left the rest to Allah.*

This does not mean that Zunaira does not take her illness seriously. She makes the best possible efforts to to remain on top of it and reduce her flare-ups.

> *I take my health seriously now. I am responsible for how I respond to my condition. I can be lazy and not took after my body and then complain of pain or I could look after my body and complain much less. Sometimes I do think if I will ever be able to live a normal life, but I think this thought motivates me rather than discourage me towards working on myself. I see the elder ladies in my family who do not take care of themselves. They wear heels even with arthritis and if you tell them that they should wear medicated shoes they say that they want to look tall. With conditions like ours it sometimes feel like our bodies are working against us, but some things are in our control like our lifestyle and diet. What we put inside our bodies also determines who is the enemy of whom.*

When asked what keeps her motivated throughout her illness and how she is able to lead a stress-free life, Zunaira shared that she has a lot to do which keeps her active and engaged with things other than her condition. Zunaira is content and okay with her life and says that she does not stress over things that are beyond her control like the fact that she has Lupus and no one else in her family does. She has a calm personality and thinks that everything comes from Allah. She does not believe that her illness is holding her back in her career. She even said that she thinks she performs much better than her colleagues at work and would laughingly say that it is probably because she takes steroids and has much more energy than the rest of the girls. She said that despite being new at it, she has the best performance at work.

I have not lived the life of a normal individual for many years. For most of my youthful years I have had lupus, it is what I know. I have a lot to do throughout my day and I am by nature a workaholic. Before lupus I used to work well hours a day just painting not eating anything until I was done. even now my routine is hectic for a Lupus patient. I wake up at 6, make my breakfast and lunch, travel one and a half hour into the city for work, come back at around 7:30, eat, work some more and then go to bed. Sometimes I overwork myself and then get sick which makes me bedridden for the next two or three days but after that I get myself back up and continue to work. I still have pain, but it has become a part of my routine now.

From our discussions it seemed like Zunaira has it all or that she has achieved everything she wanted to achieve despite her illness. But it is not all like it seems, Zunaira has hidden barriers and challenges which were revealed later on in our discussions.

I think I am quite content with my life; I can paint, I can make whatever I want to make. I have a gold medal; I have an amazing job. I am doing freelancing and I am making children's books. I think I have achieved everything I have wanted to achieve. I wish that I had an infinite amount of time to do everything that I want to do. I have found entertainment in my own company. I don't need to go out to eat, watch movies and listen to songs. I have understood that whatever Allah does is good for me. If He wants me to get better, I will get better, and if not, then it's okay because He is forgiving my sins. The only thing is that I cannot get married.

When probed further on the last statement, Zunaira revealed that:

I have decided for myself that I do not want to get married. At least at this point in time when I am in my 20's. I think I am enough for myself, I don't know what will happen later. I think it is a strange concept for a person with chronic illness to get married. I know many people who have and live good lives. I know myself and that I will be a great wife and a great mother. I know I can perform better than most girls, I am a hard worker and I know everything. I know I will not be a burden on anyone, and I don't let it become that way. But I also understand that I am saying this knowing my current condition. What if things get bad and I get sick or what if the medications I been taking for the past 6 or 7 years have made me infertile? I don't know the answers to these questions.

When asked her what her concerns regarding her illness and she were shared that she was concerned over getting married. She said that marriage can be tough for someone like her because it can be difficult to have children with her condition and that it is a degenerative disease. It is going to get worse over time. She believes that traditional marital relations rely heavily on performance and perfection of girls in all aspects like appearance, housework, childbearing, and financial outcomes. Although she knows that she would be a great wife and mother and has the capacity to meet all expectations, she fears that society would prefer “healthier” girls over her. She feels like in a marriage she should be appreciated for what she has to offer but it might turn out that her in-laws will treat her like they have given her a favour by choosing her for their son. The thought of being treated like a charity case in a relationship is repulsive to her and that is why she is not entirely sure if she wants to get married.

> *The toxic Rishta culture in Pakistan is also something I am wary of. Love marriages are different but an arrange marriage does not look at people with conditions like mine kindly. I know everything is in the hand of Allah even my own uncle; when he got married, his wife was diagnosed with the brain tumour the next day. Her family knew that she had brain tumour for years prior, but they did not tell anyone. They thought that their daughter would get married, and everything would be better. But not only did they use dishonesty, but they also remained unkind to their own daughter. She died a couple of months later. I have no intentions to lie about my illness, but I also know that after knowing what I have, most people would not be interested in marrying their sons to me.*

> *I do think it depends on the people, today most girls are not interested in housework, or taking care of children, or making dinner. When these girls get married, they are unable to manage the home, sometimes they get divorced, and people get annoyed at them. But if someone asked me about my illness, I would tell them everything and then it depends on them whether or not they want me. I think that Aunties would be more willing to marry their sons to those girls who don't do anything then to a ‘sick’ girl. I cannot prove my abilities in a couple of meetings that I can run a household and do a job because right now I am doing two jobs. I can clean myself, organise myself and do everything that I am expected to do but the point is, does it matter that I can do all these things if I also have a chronic illness? Most people would think that it will be an emotional and financial burden to take on a sick wife. Another fear I have is that I do not know if I would have fertility issues because of all the medications I have been taking I also don't know whether or not I will pass on this illness to my children. These things stop me from considering marriage as a future prospect in my life.*

Analysis

Knowing

When Zunaira was 18 years old, she was given a diagnosis of lupus. She is now 25 years old. And in comparison, to the majority of other patients, her interactions with her physicians have been really good. She learned of her sickness while coming through the rain to go back to her house after attending her farewell party. Due to the excessive pain she was experiencing in her joints the next morning after her fare-well party, she was unable to go down the stairs to have her breakfast. She had to stay in bed. She didn't waste any time and went straight to the rheumatologist, who quickly identified her condition.

Diagnosing

Even before the physicians could, Zunaira had a diagnosis for her sickness based on her reports and the symptoms she was experiencing. She discovered that she had lupus as a result of increasing her self-awareness and self-understanding.

Curing

She is continuing to take the medication prescribed for her condition, but in addition to that, she is also attempting to recover via dietary changes. She is treated with disease-modifying medications such as steroids, Demark, and others. She is quite knowledgeable about the side effects that these medications have on her body and she is prepared to deal with them. And as a result of the several medications she takes and the ailment she suffers from, she is quite concerned about her fertility. In addition, our research revealed that the literature suggests that women who are afflicted with chronic diseases may potentially have problems with their fertility. They are also hesitant to get married, despite the fact that they are aware that such women are capable of being both a good mother and a decent wife.

Coming to terms with the illness

She has a generally optimistic outlook on her disease, although she does have some gloomy concerns about her infertility and marital prospects. She feels helpless since her condition is standing in the way of her wedding day.

4.3 Nida

Nida, 25 years of age, is an Anthropology graduate and has been married for almost three years. She was diagnosed with Celiac at age 23. Celiac disease is an autoimmune disorder which is characterized by gluten sensitivity to the extent that even consuming a little gluten damages the villi of intestine (Celiac Disease, 2021). Cereals that contain gluten include rye, wheat, and barley (Ciao, et al., 2019). Before her diagnosis she also suffered from sciatica which is distinguished as a pain that originates from sciatica nerve in the spine and travels down to the legs. The pain can range from a dull ache at times to intense pain accompanied by numbness (Hochschuler, 2019).

She starts her story by telling about the sciatica pain that she suffered from at age 23 and how that started off the trajectory of a long and arduous journey of diagnosis of Celiac. She narrated that:

> *"About two years ago, I started having pain in my abdomen. Whenever I used to share this with my family, they insisted that it must be a side-effect of all the heavy medication I was taking for my sciatica pain, and because it was a sporadic thing happening on and off, I didn't consult any doctor. My stool wasn't normal either which concerned me, but I also relegated it as side-effect of the medicine. At that time, I also had to consult a dermatologist because of a severe breakout of acne. The dermatologist prescribed me antibiotics and I had to start that course. Obviously, my acne wasn't supposed to be treated by antibiotics and what happened was that my acne became more severe and so did the potency of my medicine. By then, my stomach pain was a constant thing."*

For her persistent pain in stomach, she had to consult a number of doctors including a homeopath which her mother recommended. The homeopathic medicine like the allopathic ones were only helpful for a temporary relief and her stool problem persisted. She describes that by then, she had lost faith in doctors.

> *"I stopped going to doctors and couldn't get myself to believe them anymore. All failed to diagnose me, some considered my symptoms as IBS, some outright just said that there is no pain to begin with. When any doctor diagnosed it as IBS, I had to take even more allopathic medicine which brought more pain, my condition all the time got more severe. I knew by then that I've had enough and only solution is to consult a specialist."*

She then consulted a gastroenterologist who specializes in treating disorders of digestive system (McCallum, 2022) and he diagnosed IBS. Irritable Bowel Syndrome (IBS) is a disease of digestive system in which patients feel a multitude of complications related to such bowel movements as constipation, diarrhea and pain in abdomen (Chang, 2022). Based on her medical knowledge from researching on internet she narrated:

> *"The gastro made out IBS to be a very normal condition only to be treated by medicine. He didn't give me any dietary restrictions and I knew that in IBS many foods are to be avoided. I just assumed that he must be right because my pain actually reduced. When I went to him for a follow up he again prescribed me heavy medicines to be had on empty stomach but they had a negative impact on me."*

Throughout the interview, Nida exhibited a good grip on doing research on her symptoms from the internet. She recounted that in the end it was not the doctor who diagnosed her but herself. She had already stopped eating *roti* (round flatbread common in South Asia) made from wheat and when she shared her fear with another gastroenterologist, the antibody test and endoscopy confirmed what she already suspected. Endoscopy showed the damage to her villi, and this is how she was diagnosed with Celiac disease along with hiatal hernia (another digestive tract condition).

Sharing her experiences of sciatica, she spoke about the harsh pain she had to suffer in her legs to the point that she couldn't even bend her legs. She believes that her autoimmune was actually what caused her bones to become weak, even before when she was eating wheat and especially now when she's stopped eating it because she's not getting all of the required nutrients. Malabsorption is in fact a complication of Celiac disease where damage to villi of intestine causes some nutrients to not get absorbed which leads to additional complications (Celiac Disease, 2021).

Nida concludes that she was left disappointed with doctors and her overall experience with them was very dire. One particular story she shared:

> *"I didn't exactly have good experience with my doctors but I found the second gastroenterologist as quite nice. Most doctors, when I tell them about Celiac immediately get wary that how I could have this disease at this age. They repeat the same process, ask me about my age, and deny that I could have Celiac. It's as if they don't even want to consider its*

possibility. But Dr. S was different. I found him well-read on new diseases. He listened to me, told me the precautionary measures I had to take, caution with utensils I had to make. He also prescribed me some syrups to be taken before meal to protect the walls of my villi.

Coming back from one of the visits to Doctor S, I forgot to take a prescription for a medical test. My husband told me to stay in the car while he went back alone for the prescription. What came as a shock to me was that behind my back, he told my husband that I don't have Celiac and that I take things to my head too much. I was astonished and furious. I had gone to him with the last of my hopes that maybe I don't have a chronic condition and that it'll go away with time, but he gave me my diagnosis. Now when I had made peace with my disease, had started adjusting by taking all the precautions necessary he was suddenly telling me that it's all stress, nothing more."

Nida continued that her husband then inquired the doctor about whether she can start eating wheat. He also mentioned about going to perform *Umra* soon. Hearing this, the doctor immediately became reluctant to the idea of eating wheat again. Nida stopped going to that doctor again.

She describes another experience with her gynecologist. After Nida had too low and too high results for AMH and FSH infertility tests respectively which signaled that her menopause was about to start she disclosed in an amazed tone: "My gynecologist told me that I've come to worry her. As my doctor, she was supposed to give me solace at this news but instead was acting as if she was supposed to have that consolation."

Nida shared that during all of her experience with the doctors and healthcare system, another thing which concerns her, are the doctors' and medical expenses. "Going to the doctors again and again knowing that an autoimmune disease can't be cured can make these expenses start feeling pointless."

Regarding expenses, based on her experience with dermatologist whose recommended face wash she believed actually worsened her condition and who kept on giving her antibiotics, Nida concluded that "doctors just want to make money off of patients. They have affiliation with pharmacies and only refer medicines of a specific pharmacy."

Because Celiac disease is genetically transmitted, Nida asked about family history of any auto-immune disease from her mother. Nobody had been diagnosed with autoimmune disease in her family, but her mother believes that her phupo (father's sister) used to complain about stomach pain due to which she couldn't even eat or drink. Eventually her liver deteriorated, and she died. Her mother surmised from Nida's condition that maybe she died of autoimmune because of lack of awareness in the past.

Nida believes stress to be the factor that triggered her Celiac. She shared that she was taking a lot of stress for not being able to conceive and remembers particularly one night when she was so stressed that she couldn't even sleep when her stomach pain got triggered. She expressed that her mind wasn't made up at the time of her marriage and believes herself to be stressed since then.

"I was taking a lot of stress after I got sciatica, but much was going on with my life that I couldn't help it. I was trying to conceive, my in-laws weren't letting me study ahead, so I had a lot on my mind those days. Celiac is also linked to stress so those days I experienced a lot of pain."

Nida mentioned the additional stress she started taking due to her self-research on her symptoms. She added:

"It's quite common that reading through symptoms on the internet makes you think that you check off on all of them. The same happened to me. I got a reality check from my dermatologist who told my husband to make me reduce my screen-time. So, I stopped researching about my disease for a while and that made me somewhat better. But the thing is that, only my own research has helped me in getting my diagnosis."

Living with sciatica was a tumultuous journey which impacted Nida emotionally. She paints a picture of that painful time:

"During my sciatica I lived at my parents' house for about three months, but I never felt burdened because parents never make you feel like that. When my condition improved, I came back to my home, but my sciatica relapsed because of picking up my nephew and I found myself again limited to my bed. That time was especially challenging for me. My in-laws were busy in their own lives, my husband had to work at the office the whole day. I knew my husband used to come back all tired, and then obviously husbands have needs. But almost every day I used to find myself annoyed at everything and everyone. I realize that my behavior got rude. But I was living with persistent pain, my mouth was blistered with all my meds, going to washroom was taxing. At my parents' house my sisters used to bathe me but at my house I had to do that by myself along with some of the chores that I could do from my bed. It

> *took me 6 months to fully recover from sciatica and now I do all of my work by myself because I don't want to be a burden on anyone.*
>
> *Now, even in my pain and Celiac and the fact that I get tired easily because of my disease I have to tend to others' needs. My husband wishes to go out with me on weekends and I do that for him. I can't show that I'm tired to my in-laws because I then sense a changed attitude from them as if I'm making excuses for not doing chores when I seem fine going out with my husband. But they can't seem to fathom the toll it takes on me to do that."*

Because of her gluten-sensitivity, Nida described the dietary modification that she had to make in her disease. She doesn't eat wheat *roti* central to Pakistani meals. Boiled rice has become her primary food because she finds the taste of other gluten-free things bland, making the taste of other things also weird.

Nida does not want sympathy from people specifically her family and in-laws but just wants them to understand and be cautious of her symptoms. Because gluten is harmful for celiac patients, even a grain of wheat is harmful for her. She shared that because of inconsiderate behavior of her family members like leaving culinary on the shelf on which roti is made, she has to be extra cautious. She has to wash her culinary and kitchen shelf multiple times, and also has to take extra care to wash her nails so as to remove all grains of wheat flour after making *roti* for her family.

> *"Frankly, I don't like their sympathy. They tell me* 'bichari kha nhi sakti' *(Poor girl, can't eat) but neither do I need their labels nor their sympathy. I can eat everything. There are many glutens free things. Until I had my diagnosis, whenever I used to tell people my problem, it seemed to me that no one could actually comprehend my situation, so I just stopped talking about it. People always had some piece of advice to give me which I just listened to all quietly. But those all were redundant phrases like 'You've got to eat or else it's going to get worse' or 'you don't stay happy' and things like this and these were all useless to me. Until I got my diagnosis, I just wanted people to understand me or just someone who could. I didn't want their sympathy. When I got my diagnosis, it was as if people suddenly understood the gravity. By then, I didn't want their understandings."*

Nida describes her husband as supportive throughout her health-related trials, helping her with dietary modification, buying her gluten free things, helping her switch to lactose free milk, accompanying her to the doctors. She said that she sometimes feels guilty that her husband has to accommodate from the home's expenses but she also recognizes this to be her husband's responsibility. However, she added that the support from her husband has developed, because initially it was tinged with an air of non-seriousness toward her condition. She added:

"I used to think that he doesn't take my pain seriously because when my tests used to come out normal, he would say that the pain's all because I don't try to remain happy as if my pain was in my voluntary control."

Nida talked in length about not being able to get pregnant. Watching social media influencers or cousins getting pregnant, Nida shared that she unconsciously finds herself complaining to Allah that if girls her age are able to do that, she should be also:

"In my mental distress I find myself complaining to Allah that if girls my age are able to have babies, my menopause should also start after 30, I pray to him to give me a child, I pray to him to make me normal like others. I also get brain fog now from this anguish. Words seem to slip out from my head, or I find it hard to bring them to my tongue."

In this turmoil, she finds strength in her husband. She narrated:

"He loves kids very much but when I asked him to take me to a gynecologist, he told me to leave the matter to Allah. He knows about all the medication that I had to take and knows how much I suffered through them and didn't want me to go through that again. Recently I went to the gynecologist and when she advised me that it'd better if I don't tell my husband about Celiac, I told her the same thing that my husband supports me. When my mother-in-law told me to start treatment my husband told me to strictly tell others that it is up to Allah. He tries to make me understand and console me and even say that it'd be okay if we don't have a baby, but I think that life would be very strange without a child. It's always instilled in the mind of a woman that primary role in life is to reproduce so what even is my purpose anymore. What's left of it? I didn't always use to think like this. I believed having a baby to be a huge responsibility, one I wasn't ready to have. At first my husband and I didn't start trying to have a baby but after almost a year my husband told me that we should try now. That made me feel a lot of emotions; I was scared, I was angry, I felt as if I was being forced but when I started having these issues my point of view changed."

Telling about the way Celiac changed the course of her life, she thinks she has to take extra caution which consequently makes her stressful sometimes. By way of example, she shared that she doesn't trust the food made by someone else and has completely stopped eating food not made at home.

> *"More than Celiac my concern is Hashimoto disease, which is an autoimmune disease of thyroid gland, because it's more dangerous but I try not to think about that all too much. I don't think I have been at peace in the last two years because it's like I have gotten one problem after another, and I am just tired of it. One thing that my autoimmune has changed is that I want to enjoy freely as much as possible but now my pain hinders me in doing so. I also now have to plan everything before going outside, have to fit in a proper rest time and also have to make up my mind. It's actually started to feel like some homework."*

Nida feels that at her age a person is supposed to be very active. She shared that she used to love going to amusement parks for rides. She adds, "I console myself by thinking if 2 minutes of happiness is really worth it." She tells about her routine that how she has to eat her breakfast, then has to do the dishes and clean the kitchen, prepare lunch and by noon when she comes back to her room to offer Namaz, she's too tired to even get up from bed. She thinks that a normal person can do all the things without getting so tired.

Nida shared about finding a WhatsApp group on Celiac where patients share their understandings of this disease and information about diet. She found the group only beneficial at first because she soon realized that inquiries about medication were not readily answered even if information related to diet was constantly shared. She once asked about using painkillers but got no reply.

In the two trying years of her difficult journey, she feels that she's got closer than ever to Allah both in her faith and her commitment to her religion as well as in her finding comfort against her disease. She concludes that her bond to Allah that grew out of her tribulations gives her peace and is the greatest support for her.

Analysis

Knowing

After her marriage she came to know about her illness that she has and her sufferings start after marriage. Due to her stress for marriage her symptom appears. She got married before all her sister's despite of not being an oldest child. All her symptoms appeared after her marriage. Her marriage was stressful for her but this factor cannot be pinpoint as the reason for her illness. Her symptoms start before two years of her diagnostics. She felt severe pain in her abdomen. Most of the time when she consults her condition with doctors, they end up saying that due to anxiety you felt pain in abdomen.

Diagnosing

Nida was diagnosed with Celiac. In Celiac, patient suffers from gluten allergy. Nida also has symptoms of hashimotos, but there is no diagnosis of it. She suffers due to her illness for a very long time. It takes two years to diagnose about her actual illness. And she diagnoses herself that she is suffering from celiac. She checked her reports and studied her condition on the internet. Her doctors didn't take her condition seriously.

Curing

She is not cured properly until now. And at this stage she has extreme fertility issues. And according to her doctor she has begun her menopause and she will have no children in the future or so. This is a very painful diagnosis but she is still trying to have children because she believes that without children life will tough. And this is something that is beyond her control. Despite of that, faith plays a very huge role in her life. Her relation with Allah Almighty goes stronger. Though she is suffering from a very painful disease but this illness brings her closer to Allah as well.

Coming to terms with the illness

In the case of Nida, one thing researcher finds out that her husband challenged her and ask her to take test if she is not satisfied with doctors. He also believed that Nida is exaggerating her condition and there is nothing much serious about her health. And in reports result it was mentioned that she is suffering from Celiac. One thing is very clear in our society that if medical reports mentioned some illness everyone agreed to that but if a person said that he/she is suffering from some kind of illness no one believes. During discussion one more thing researcher found out that during her illness she thought too much about her condition and if she had a normal headache, she searched that on internet too. So, after some time she managed herself to not use internet for every small issue. Along with all these issues regulating in her life she is not content with her life. She wants her life better and normal like other people. She is still in the phase of an excruciating pain.

4.4 Hania

Hania Masood Aweja, 33 years old, was diagnosed with hypothyroidism at age 23. She also suffers from PCOS, a condition of reproductive system since she reached puberty. She was brought up in Canada, and her family frequently shifted from Pakistan to Canada and back. She aspired to be a filmmaker but diverged to become a chef by education and profession, and was married in November 2019, before COVID-19 pandemic. Currently, she carries out freelance work in new recipe development and menu development projects. Adding to her culinary proficiency is a food blog and YouTube channel that she manages as a hobby.

Hypothyroidism is an autoimmune condition where thyroid gland produces thyroid hormone in such low amount that it remains unable to meet energy needed for normal functioning of body organs. For this reason, hypothyroidism is also known as underactive thyroid. Deficient energy results in fatigue, slow heart rate, joint and muscle pain. Other complications associated to hypothyroidism include weight gain, fertility problems and depression (Hoang & Burch, 2021). Polycystic ovary syndrome (PCOS) is a condition characterized by cysts formation in ovaries with abnormalities in hormones, producing such complications in body as irregular periods, weight gain and excess body hair (Polycystic Ovary Syndrome, n.d.).

At 11 years of age when she hit puberty, Hania started with heavy periods and painful cramps. She believes that around thirteen years of age she started having PCOS's symptoms which went undiagnosed till 2009. Narrating the story of her diagnosis of PCOS, she mentioned prolonged periods with heavy bleeding which led her to consult a doctor. When she got an ultrasound test, a cyst was found. Among other symptoms she only experienced weight gain but no unusual facial hair growth. She received a standard treatment of Glucophage, which is medicine primarily given to diabetic patients, and she believes it to be the real culprit in messing up and worsening her conditions. She especially condoned healthcare practitioners in failing to emphasize the significance of nurturing gut's health or importance of minerals and vitamins to normalize progesterone and estrogen levels and for getting normal periods instead of giving heavy medication.

Healthcare system in Canada requires every individual to register to a family doctor and to run yearly tests and regular check ups. In 2013, during one of these visits, when she went to consult about issues of drowsiness and low energy, which she thought signified anaemia, she got diagnosed with hypothyroidism. TSH (Thyroid-stimulating hormone) test which is a blood test for checking the level of thyroid (TSH test, 2022), confirmed it. She was prescribed Eltroxin supplement for hypothyroidism and Hania shared that her weak gut cannot handle any more medicine. She also takes IVs or iron drips to compensate for low levels of Vitamin D, B and iron. She shared that there are certain tell-tale signs that automatically signify low levels, for instance her eye starts twitching.

Hania believes that she predominantly acquired PCOS hereditarily because in her family three of her aunts as well as her sister have been diagnosed with PCOS and her cousin is diagnosed with endometriosis, another reproductive condition. As far as autoimmune is concerned, her *khala* (mother's sister) is diagnosed with hypothyroidism and another cousin with arthritis.

Furthermore, she also attributes a weakened gut as a contributing factor of hypothyroidism. She reflected upon a distressing incident of her life when only one and a half years of age she received 3rd degree burns from scorching water spilled on her. She believes that because of lot of medications which included steroids, her gut's health reduced. Also, at age 16 she suffered Bell's palsy for which again steroids were prescribed for 21 days. Bell's palsy is a neurological condition which causes paralysis of one side of the face (Eviston, Croxon, Kennedy, Hadlock, & Krishnan, 2015).

> *"A lot of steroids messed up my gut. From all the information that I've collected indicates that the gut has a lot to do with PCOS and hypothyroidism and you can manage these conditions if you're able to maintain a healthy gut. And I feel like that all medications which I had to take from my childhood, my gut became very weak. Now I also realize that my hands and feet used to get very hot that meant I had a lot of heat trapped in my gut."*

Hania shared that her autoimmune disease has a relation with PCOS. Her research showed that many people diagnosed with PCOS also have hypothyroidism. Furthermore, she attributed this to hormonal changes happening inside the body that start affecting thyroid hormone also. Additionally, she thinks that modern lifestyle is what gets you in trouble. Firstly, the sedentary lifestyle that prevents going out and taking up less Vitamin D affects thyroid gland. Secondly, *maida* or processed wheat and food made from it, including pizzas and burgers, cause inflammation. These two factors, she added, became the reason for her hypothyroidism. Additionally, she mentioned her love for Tabasco during a phase of her life where she didn't eat any meal without it, damaged her gut and caused chronic inflammation. With that phase ended she recounted a second phase where she started eating a lot because her food blogging required it.

She found considerable disparity in the diagnostic and treatment approach between Pakistan and Canada. She found Pakistan's diagnostic process characterized by rudeness and abruptness, with healthcare professionals primarily focusing on prescribing medications or advising weight loss without offering comprehensive guidance.

"Doctors in Pakistan are very quick to give medication. They prescribe antibiotics even for flu. In Canada instead of giving antibiotics, they recommend gurgling warm water and taking steam to build up your immune system. Here doctors prescribe Augmentin for sore throat which gives relief but totally disrupts the immunity."

In contrast, she found the healthcare system in Canada to be considerate and empathetic towards patients, taking proper time to listen to them. Medical professionals in Canada not only diagnose the condition but also take the time to educate patients about their condition and provide them with knowledge to navigate their daily lives. Patients are offered a holistic understanding of the challenges they may encounter and are provided with tailored solutions for their specific problems.

"With all the advancement in medical science, I still somehow find myself with doctors in Pakistan who tell me to lose weight for PCOS and hypothyroidism. They make it sound like there is no problem except my weight that hinders management of these diseases, but never explain how and why I should accomplish this. I obviously can get behind the why aspect of losing weight but not the how because my conditions are exactly what became hindrance to losing weight. They are actually the root of my increased weight. I am physically unable to have a normal BMI because hypothyroidism makes metabolism very slow. A lot of symptoms in hypothyroidism mimics pregnancy where I perpetually feel myself in a state of being pregnant. I have to cater to a state of constant nausea and hormonal changes. And then when I get my periods, I experience not cramps but full blown contractions where I feel the urge to push something out and you can only imagine the brutal pain that I experience."

However, the aspect in Pakistan's medical system that she praised was the doctors' ability to think out of the box. She shared that while for her Bell's palsy, Canadian doctors only prescribed steroids, doctors in Pakistan also recommended physiotherapy and electrotherapy, with chewing gum and balloon inflation exercises, which she found more helpful for strengthening her muscles. She mentioned that doctors in Canada have to go by the book because in any case of medical mishap, people can sue hospitals or doctors, and this can cost them their licenses.

Regarding her hypothyroidism, Hania stated that because autoimmune diseases have become prevalent in South Asia only in a decade or so, therefore, endocrinologists lack enough experience and only help in setting up a suitable dosage but are not able to treat the inherent cause. According to her, a good doctor must be able to listen attentively to the medical history and think out of the box to provide tailored treatment. She especially mentioned Dr. I in Pakistan who for some time practiced in Saudi Arabia and UK before coming back. She commended his practice of not giving medicine unnecessarily and refusing to take money when he was not able to give a definite diagnosis over a text message. She also appreciated Dr. S and Dr. S for taking proper time to listen to her inquiries.

Hania remembers herself before her autoimmune as a very ambitious and hyperactive person. The name Hania means happy, and she believes that her name has a projection on her personality, and it is this reason that she is intrinsically a very happy and positive person. However, Hania believes that after hypothyroidism her energy has been affected tremendously. With the diagnosis of hypothyroidism, Hania shared that the impact of this disease on her personality and emotions was the most unforeseen consequence that she had to deal with. She understood the hormonal challenges but a profound decrease in her energy and an unexplained fatigue was totally unanticipated. Furthermore, she found herself being anxious and overthinking which highly contrasted with her jubilant and carefree personality. She realized that the hormonal change in her body affects her mental health and that activities that she used to effortlessly engaged in, now require additional strain from her part.

"At my diagnosis of hypothyroidism, I really had no idea what I was going to go through, and then the symptoms hit me. Only diagnosed with PCOS I was doing a lot better. The kind of person I was didn't get easily bothered about much. I never recall sitting and stressing over

> *my disease. Subconsciously, in the back of my mind if I did feel stressed, I never let it overwhelm me. Pre-hypothyroidism Hania was a completely different person, who always donned a smile on her face. But after hypothyroidism I felt my energy lower down out of nowhere. The lightness that I felt in my bones was gone, replaced by a negativity I never knew I was capable of. I was never an anxious person. I never knew what anxiety or overthinking was supposed to feel like, but with hypothyroidism not only my thyroid hormones but even my vitamin D started getting low, and I felt it affecting me mentally. The chemical and hormonal changes happening in my body was bound to impact my mental health. I've come to realize I cannot do many things that I was able to do before without my body getting extremely burned out. The same goes for PCOS. It also disrupts my mental health which I didn't know before. Now you can find much information regarding PCOS but when I was diagnosed, knowledge was very inadequate. This depletion of energy came as a shock at first. The health-related jolts hit you very differently. These problems open up another world for you."*

Hania shared that she felt her stress level all time high after marriage. Her father-in-law got diagnosed with cancer. Moreover, just after two months of marriage COVID threw life in a lockdown which added to the stress. She especially felt difficulty to adjust her sleep cycle which was considerably different from before her marriage. She relates that where before she was sleeping and waking up early, here with her in-laws she had to stay awake for most of the night that "stressed out my body to no end." She added:

> *"At first two years of my marriage I used to fall sick every two weeks. I didn't understand before but now that I have researched, it was because my body was so stressed out that my thyroid gland just could not take it. It came to a point that my mind and my body started crashing."*

She shared that after her father-in-law's death when entire family was grieving, she took charge and efficiently handled all the tasks. Her mother informed that everyone was amazed and didn't expect her to take on such responsibilities, especially considering she had only been married for three months and this considerably motivated her.

> *"During that time, only I knew how exhausted I was. I was in constant pain, and my body would give up on me at night. Guests used to visit frequently, and my schedule used to be packed with chores, often leaving me awake until 3 or 4 am. But these words of appreciation served as motivation for me. They reminded me that even though I was dealing with illness, I could still accomplish things. I could still be myself."*

After marriage the major complication that resulted from her autoimmune was that her gall bladder got removed due to severe infection and stones. She experienced pain in front and back of right side of her stomach which used to leave her doubled over and sweating. However, doctors only used to dismiss her with a casual remark that its only stomach pain which must be due to her eating food from outside and just like that she suffered for almost three years. She narrated:

> *"Last year I experienced the worst possible attack of gall bladder stones in my life, not even knowing that it was my gall bladder having this pain. It was a burning sensation lasting 36 hours. I couldn't eat anything, only kept throwing up bile. I was prescribed two pain killers, Toradol and Tramadol through injection which lasted for 2 hours, and it started hurting again. Then we went to another doctor who prescribed me painkiller and also recommended an ultrasound. It was 10 o' clock at night and due to late hour, we thought to put it off till morning, but the intensity of pain reached the point that we immediately went to Agha Khan Hospital. The doctor there hinted stones in gallbladder and I got admitted in emergency. Ultrasound revealed 30 small stones in gallbladder and a risk of rupture led to immediate operation."*

She continued that laparoscopy was initially planned for the surgical removal of the gallbladder but due to the severity of condition, open surgery became necessary. The main reason of severe infection and complications of gall bladder was the delay in diagnosing for those two years.

Hania expressed the general perception of medical professionals and many people that removal of gall bladder does not impact a person's life. However, Hania holds a different opinion based on her experience. According to her, the absence of the gallbladder can lead to various issues, particularly when combined with hypothyroidism. A person suffering from hypothyroidism with gall bladder removed is more likely to face decreased metabolism which leads to slow body-functioning and slow digestion due to the leakage of bile. A person also cannot consume a lot of fatty foods and fried dishes as they can exacerbate indigestion. She added that with time your body does gets habituated to fatty or fried foods, but you still shouldn't eat them because the main enzyme producing digestive organ is removed. She told that after surgery, on her first Ramzan she didn't know this, so she faced extreme pain but even when she stopped eating fried food in Iftar it was still painful for her but to a very low degree.

She shared that people with hypothyroidism have a tendency of rheumatoid arthritis because bones start calcifying and bone density starts lowering. In winter season she notices that humidity hurts her joints, and she feels stiffness in them. She recounted from last winter that her pinky finger stayed bent for almost four weeks. She narrated the challenge of low energy during Ramzan:

"You would often hear healthy person complaining that after many hours of fasting, they feel their body crashing at iftaar. My hypothyroidism makes the crash doubled where I need proper 3 to 4 hours peace and rest to function properly again."

Hania navigated her disease with a complete positive outlook but marriage added some of the woes in her life:

"I have never taken a self pity route and don't think of my disease as a calamity but after marriage my condition got bad that I started thinking that why is it happening to me. I started feeling helpless and somewhat guilty that my husband probably thinks that he got married to some patient who is constantly ill."

Hania shared feelings of isolation while she was trying to make sense of her hypothyroidism. She found it increasingly difficult to get her physically and mentally prepared for the plans she made with her family and friends, and she found it much easier to cancel them altogether. Making people understand that she has no control on her body was difficult. This isolation led to depressive episodes. Although she finds her in-laws very accommodating and supportive through her autoimmune, she has her own guilt to account for. Hypothyroidism and PCOS impact hormonal balance and infertility and so Hania faces difficulty in conception. She narrated:

"My sister-in-law got married after me and she has a baby. I'm really happy for her and only have well-wishes in my heart. I also know that other people have all the good intentions, and they are not trying to make me feel bad but after hearing about the birth, people have often lamented that Allah will also grant me a baby. Or this one time, we went to see some relative who was going for umrah, and the Aunty told me that that she will pray for me there to bring happiness to my home. Remarks like these make me feel really bad and left out like I'm the reason we're not happy, although we are. These remarks also make me feel like I have a problem and that it's already too late to conceive."

She described her mother-in-law as supportive and found her motherly advice to consult a doctor as very kind. She shared that she consulted a concept clinic in

Clifton, Australian Concept Feryility Clinic, and explained that she isn't pursuing the IVF treatment because there are also other alternate options. Her main goal is to lose weight which she gained, almost seven kilograms of it, through hormonal pills for PCOS. Besides the clinic also didn't give any consultancy, so for now, she only seeks natural remedies e.g. seed cycling, natural herbs and trying to lose weight before she has to take medical route. Talking about her trying to conceive, she again tapped into her personality and how it changed over time. She shared that the change in her personality started impacting her relationships.

> *"Initially I didn't understand this. But now looking back I think my autoimmunity really did impact my relationships a lot because I got annoyed easily and was always nagging at people. I isolated myself and would try avoiding meeting people. I also used to be a touchy type of person. It was my habit, say for example, I would touch my mother's hand casually while talking, also with my husband but after my illness the need to build contact just vanished. Thankfully my husband was understanding. But I also felt an inexplicable anger towards him. I had never felt that kind of anger before. It was rage and I didn't know where it was coming from. I didn't lash out at him thankfully becauses if I did, it would've damaged our relationship. But a little annoyance on my part I think started affecting our relationship. I was not able to fathom what was happening to me and why. Recently, we had a talk and my husband said that he actually started getting scared of me. It was heartbreaking to hear because I never thought I would ever be a person who would give someone a reason to be scared of."*

She thinks that the crankiness owes to the quarantine and lockdown situation of COVID and her gall bladder operation but most importantly, the hormonal birth control that she was on the first year of her marriage. Her circadian rhythm was also messed up which brought out anxiety and negativity. To cope with this, she started conducting extensive research to understand her body. While delving into this research, she came to know about cortisol level and how it's important for managing stress. She also realized the importance of sunlight that improved her mood considerably. "If I don't see the sun, my entire day goes tired and lethargic and even two minutes of basking in sunlight I feel rejuvenated and in a good mood."

Hania shared a disappointing experience with a nutritionist who provided a plan that did not align with her specific health conditions, including hypothyroidism, PCOS and her goal of conceiving. The recommended breakfast lacked the necessary nutrients which could be considered as healthy meal as well as the grams that she should consume.

> *"The thing is that, every other woman is self-acclaimed dietitian, working from home. They only focus on reducing calories while instead they should be recommending nutrient dense meals because you cannot simply starve yourself to lose weight. I used to make my own diet plans. But after marriage and Covid, the planning stressed me out, so that was the first time I actually went to nutritionist. Unfortunately, I've not been able to find a holistical nutritionist."*

To a patient of autoimmune who might not want to get married because the infertility it causes, she added:

> *"Granting kids to humans is up to Allah and not in our control so a woman should focus on the things that she can control and leave other matters to Allah. Our conditions don't define us. We just have to manage our disease. We can't let ourselves go down the road of self pity."*

If, by stroke of luck, she got a chance to revert to a completely healthy person who did not suffer from hypothyroidism, Hania would take it because she thinks that then she would have been more active, would have excelled in her career, and wouldn't get lazy. She believes that she is able to do all the things that she loves but her career has taken a back seat. However, her autoimmunity has taught her to take better care for herself. She thinks that before her disease she was too careless and carefree person but her disease has made her put herself at a top priority. She now has a regular sleep cycle and overall a healthier lifestyle.

> *"My priorities have shifted as I've gotten older. Back when I was young, being careless was not an issue but as you get older, it impacts your quality of life and now I don't want to compromise on that. One of the challenges of hormonal weight gain is that it accumulates around your belly basically. Offering namaz gets difficult, prostration can't be done for a long time, and my muscles hurt. I am only 33 so I shouldn't have these kinds of problems. It's not that I have any self image issues or about how fat I'm looking. It's about not being able to do certain tasks and being sick constantly. It's about choosing a healthy lifestyle; it's about living life to the fullest."*

Hania shared that modifying her diet was made easy because her mother set a healthy standard to look up to where she successfully controlled her blood glucose level without medicine. She derived strength from her mother which prevented her from feeling sorry for herself.

> *"In my opinion, holistic treatment is actually a lifestyle and with diet and exercise you can heal yourself. What you put in yourself is what heals you. I have added holistic nutrition in my diet, which I learned from my mother. Because of her diabetes, we only used to eat whole wheat flour and not processed wheat. At my in-laws, instead of using sugar we eat gudd (cane sugar). I also only eat sour dough bread because it's fermented and helps me with my gut. These are some of the minute changes that I have incorporated in my diet. I used to eat a lot of food from outside but now I don't. If I do have to dine-out I only eat salad. I also have my dinner at max 8:30. I have also incorporated exercise and workout in my routine and especially take time to bask in the sun."*

Hania compares her research on hypothyroidism and PCOS from before and present time and shared that there is a lot of information which can be read and researched upon which wasn't available before. Moreover, she experienced a promising change in the recent years where women are becoming vocal about their conditions and openly discussing their issues. This has helped Hania in navigating her disease because she believes that the knowledge, she now possesses regarding PCOS from these women cannot compare to information gathered in a decade from health professionals. She concluded with this remark:

> *"I believe that my autoimmune has given a positive direction to my life. I was very careless about my health and myself but now that I know the negative implications regarding my physical and mental health, it has motivated me to be at optimal level of my health by taking an active approach to change my lifestyle. Now I take care of myself. I prioritize taking out time for myself. I give myself room to say no to whatever that becomes a hindrance to my wellbeing. I also have gotten more in-tune with myself that has brought me to a journey of self love."*

Analysis

Knowing

Due to imbalance hormonal issues she came to know about her PCOS condition. But her hypothyroidism also diagnosed very early. She lived in Canada and during her regular medical tests her family doctor came to know that Hania's PSH is very low. And she took her complete thyroid test and very quickly her illness diagnosed.

Diagnosing

Hania diagnosed with PCOS and hypothyroidism. She has diagnosed with PCOS when she was in her teens and she also diagnosed with hypothyroidism almost ten years ago and at time she was 25. Her experience with medical professionals is from two countries Pakistan and Canada because she has both country's nationality. Her diagnostic period is shorter as compared to other case studies we had and the main factor is that Hania is from upper class and also very well educated. And this helped her in diagnosing her illness earlier than other respondents.

Curing

After diagnosing her illness, she was put onto medication of thyroid stimulating hormones and tried to balance her hormones. She is now 33 and when she got married, she was 30 years old. And due to her PCOS and hypothyroidism she is also facing some fertility issues. Her metabolism is very slow and fluctuating hormones. The main thing is that her hypothyroidism is playing a very major role in her PCOS and her fertility concerns. Despite of trying for a child for two years she was unable to do so because she has no potential to lose weight to carry a child. She is also a chef and she tried to overcome her illness with diet. She does not take any medicine for PCOS and she tried to control her illness through her diet.

Coming to terms with the illness

Her knowledge towards her disease is that in her condition genetics and her very weak gut plays a very significant role. Because when she was young, she has given steroids for her burns. PCOS is in her family history and this is also a major cause for her having PCOS. Researcher also ask Hania about her experiencing of consulting doctors of both countries Canada as well as Pakistan. She replied that in Pakistan doctors immediately prescribed medicines and in Canada doctors tried to cure disease with other method before prescribing the medicines. Pakistani doctors choose practices which are out of the book to cure the disease but Canadian doctors could not do so as they are afraid of being sued by their patients. Internally she does not feel that her fertility issues impact her life but the outside world especially her parents and other females in her family make her feel that she is at loss. She has something missing in her life. And she should have tried even harder to have children. Her memorable message she never forgets during her illness journey is that one of the females in her family was going to Umrah and she said to her that I will pray for you specially that you will have a child soon. Instead of being happy after hearing her words she felt very bad about that as she thought she is being told that you are in capable of conceiving a child and you need prayers for that. She is at her terms with her illness in the sense that she doesn't feel like that her life is anything but good. She is grateful to God what she has in her life. Her illness helped her to adopt a healthy lifestyle. The only thing she feels during her illness period that her family doesn't understand her pain she is going through and they she is exaggerating her condition.

4.5 Shazia

Shazia is 43 years old and has been braving the challenges of Systemic Lupus Erythematosus (SLE) with Sjogren's syndrome since the age 36. After two years of struggles she was officially diagnosed at age 38. Her parents originally belonged to Kashmir but shifted to Lahore where Shazia and her siblings' upbringing took place. She was married at age nineteen just after she completed her FSc. The marriage was exogamous in a Punjabi family. She has been married for twenty-two years now and has five kids. After graduation, she discovered her passion for Computers, leading her to pursue skills in the field of information technology. Currently, she teaches Computers in Jamia tul Mosanat, Karachi. Shazia's journey with autoimmune disease started off before her last pregnancy, marking a significant turning point in her life and making her deal with the chronicity of her condition.

Systemic Lupus Erythematosus (SLE) is an autoimmune disease characterized commonly by joint pain and skin rashes and may cause organ damage as further complication. Inflammation or swelling also accompanies the skin rashes. Women are more commonly affected by SLE at child-bearing ages. Other symptoms of lupus, also reported by Shazia, include sensitivity to sunlight, hair loss, mouth sores, fatigue, chest pain, headache, and depression (Lupus, 2021). Sjögren's syndrome, also an autoimmune condition is common with people, mainly women suffering from Lupus or rheumatoid arthritis. As an autoimmune disease, it attacks the glands responsible for making moisture in the body including salivary glands. The consequence is that body experiences extreme dryness in mouth, eyes, or other areas (Sjögren's Syndrome, 2021).

Shazia's chronicle of her journey, like other women grappling with autoimmune diseases, begins with the daunting difficulties she faced after the onset of her symptoms, but even more so in making sense of them because she was not getting an accurate diagnosis. She starts her story from 2015 when she was pregnant with her youngest child. She recounts how tired she used to remain at that time and the mental health issues she tackled.

> *"Even before my very last pregnancy, I was consumed with lethargy which was absolutely new to me. I was a person who could proficiently multitask up to three chores at a time. But suddenly I found myself getting tired more often than not. My mental health was also disrupted. And when I got pregnant with my youngest daughter, my condition was such that I would put my four earlier pregnancies on one side and this particular one on the other; my condition this time around was incomparable to those I experienced before. I was in a lot of pain. I did some medical tests and the reports revealed that the baby isn't growing. This pregnancy also left me unable to do any work."*

Other problems she related from that time include depression and losing a lot of stamina with persistent back pain and headache. For this she had an MRI scan which showed that her muscles between the bones of vertebrae had been damaged. She recounts that even getting up became painful and she remained tethered to the bed most of the time. She thought keeping herself busy with IT would help but it proved to be of no avail. She also recoursed to alternative treatments including *Hijama* therapy, more commonly known as cupping. After the birth of her youngest daughter in 2016, she said that her older children helped raise the youngest.

After many treatments till 2019 and doctors still not being able to successfully pinpoint the underlying cause, Shazia was left in a state of uncertainty and distress. However, the more treacherous symptoms were yet to manifest. As the disease progressed, Shazia experienced debilitating mouth ulcers making it critically difficult for her to eat or speak.

> *"Initially, I suffered through a constant soreness in my throat which then developed into ulceration. For this, doctors usually prescribed me pain killers or antibiotics. But medicine never worked for me, and the ulcers got so bad that it extended from my throat to mouth. I couldn't eat or drink anything nor could speak properly. I had heard that ENT specialists can heal mouth ulcers so I got admitted to a hospital for 15 to 20 days but even they couldn't diagnose me. I endured this pain for 7 to 8 months. By that time the ulcers were oozing pus and eating was naturally out of the question. After that, an ENT doctor recommended me a mouthwash which was only available at Shukat Khanam Hospital. The treatment involved combining the content of a specific capsule and another tablet after*

grounding it into a powder which was then to be mixed with the mouthwash. This treatment used to leave a sort of cooling effect in my mouth and was helpful for numbing the pain for a short amount of time, but the ulcers persisted."

ENT was just the first of specialists and doctors Shazia had to consult who couldn't diagnose her which would have followed a proper treatment. When ulcers continued, ENT doctor suggested to her that it must be some kind of problem in the molars causing mouth ulcers, so he referred her to a dentist. However, the dentist, after analyzing the X-ray report also cleared her saying that there is no problem with the molars and then continued on to refer her to an oral health department of a medical college. She narrates that:

"I met with Dr. T in the medical college. After giving him a lengthy and extensive history, Dr. T deemed that my all problems must be linked to the stomach, so he referred me to a stomach doctor who again gave me antibiotics. I also consulted a doctor from M Hospital. He gave me some new medicine and also prescribed Folic Acid. That medicine instead of reducing my pain increased it."

From ENT doctor and dentist to other countless doctors, Shazia found herself frustrated to the point that she asked oral health doctor to just be straightforward with her about whether medical science has a cure for her or not, to which he had no reply but recommended a skin specialist. Consulting the skin specialist turned out to be helpful for Shazia because now she got clarity regarding two facts about her disease which had somehow been overlooked thus far.

"I learned two things from the skin specialist. He checked my reports which showed that ESR is 80, a high value, which not a single doctor had highlighted before. And the second thing that doctor pointed was that high ESR value indicates inflammation in my mouth. Based on these findings, he started my treatment and prescribed me anti-allergy as well as steroids. He had this proper planning where he started with low potency to high, but this method was too slow and I wasn't having any kind of reprieve from the pain. He then told me that it must be a kind of cancer and to go to Shaukat Khanam to get a biopsy."

Erythrocyte Sedimentation Rate (ESR) is a blood test, and its high values signify inflammation which can be caused by number of health issues including immune system or blood disorders and cancers (MedlinePlus, 2022). Being informed that she might have cancer she went to Shaukat Khanam Memorial Hospital, where they ironically refused to do tests on the ground that she should first confirm whether she had cancer or not. Disheartened when she went back to the skin specialist, he further identified a low hemoglobin count, for which he prescribed blood transfusion and iron injections to be had on a weekly basis.

However, at long last, through a referral from a friend, she got to meet Dr. A, who after examining her medical records, taking her history, crossed her previous file and ultimately concluded that the earlier treatments all had been inaccurate. Dr. A diagnosed Shazia with Systemic Lupus Erythematosus (SLE) and recommended a DNA test which confirmed it. He then referred her to Dr. S, a rheumatologist (specialists who treat rheumatoid arthritis) who diagnosed Sjogren's syndrome as well as SLE. Shazia described this condition as the inability of the body to produce moisture. She further explained that when saliva does not form, which is indispensable for mouth filtration and which consequently leads to mouth ulcers. Shazia continued that in addition to the challenging symptoms affecting her oral health, she also experienced other issues. Sores and wounds lined her nose and she experienced pain even in her nails. Continuing about her experience with S, she narrated:

> "*Dr. Sumaira made a whole treatment plan taking into account all the complications and made sure that I was well-informed about them as well as the treatments that I would be getting. She also emphasized that I should again seek out specialized treatment for all the complications but this time I should specifically tell the doctors about my diseases so that they would address those issues accordingly.*"

Dr. S recommended a treatment plan that involved a course of injections every six months. However, she found the cost of that treatment to be very expensive, so she didn't take it. Nonetheless, she was not to leave the hydroxychloroquine (HCQ) treatment which is used to treat arthritis. Regular follow-up check-ups were scheduled every three months by Dr. S to assess the impact of hydroxychloroquine (HCQ) on Shazia's eyesight. If no significant changes were observed, the dosage of HCQ was to be doubled. HCQ was prescribed to control her condition of Sjogren's syndrome, although it had some side effects. Shazia experienced full-body aches as a result of the treatment. At that time, she also got diagnosed with fibromyalgia (condition with high sensitivity to pain) and she had to get treatment for that too. During this period, Shazia received advice from a peer regarding a normal diet plan. The purpose of adopting this plan was not solely weight loss but rather to adopt a healthier lifestyle. Shazia shared that following this diet plan yielded miraculous results for her, as it significantly reduced her fatigue and her hair fall issue improved. This led her to discontinue the HCQ treatment as it did not prove effective in addressing her specific symptoms. Although she continues to experience joint pain, she endured it.

Owing to her autoimmune disease, Shazia still tackles many complications. With regard to skin conditions, she explained:

> *"My skin problems are especially challenging for me. My skin has become so sensitive that even a little sweat makes it irritated. Cleaning the sweat with a cloth also gets the skin scrapped. Wearing undergarments is uncomfortable. The skin issues stretch all over the body including arms and chest."*

Dr. Sy, skin specialist associated with PEMA provided Shazia with essential information regarding ointments, which resulted in significant relief. As time progressed, Shazia's condition improved, and now she finds winter season much more manageable. She shared that she has to be extra vigilant of clothing choices, as she can't wear wool or materials like Marena. Her other concern is sunlight sensitivity. Additionally, Shazia has trouble walking and she occasionally experiences pressure on the side of her head. Furthermore, when lying down, she encounters pressure on her heart, leading to an accelerated heartbeat.

Although now she has discontinued her medicines for about 4 to 5 months her symptoms are anything but gone. Shazia shares that her feet are a source of discomfort for her, and she experiences pain in her feet even while sitting. She cannot put them directly on the floor and has to use soft slippers. She also needs assistance while walking and has to drag her feet on the ground slowly until the stiffness and numbness diminishes. Shazia finds it difficult to start her day. Upon waking up in the morning, she feels the same stiffness in her hands and shoulders impeding her mobility. These physical limitations affect her ability to perform daily tasks, for example making *roti*, but even if she pushes through her limit, it results in headache for the rest of her day. Furthermore, she experiences insomnia. Medicines used to help her in getting her sleep but with discontinuation of her medication she now sleeps restlessly in the night. She describes that despite these challenges she is somehow managing. Shazia believes that her illness has made her reliant on others and she considers this as the worst aspect of the way autoimmunity has impacted her life. She also reports a ringing sensation in her ears as a symptom. “When I think of something with attention my ears blare with sirens. This makes me unable to concentrate on anything now”.

Shazia's personal experience with the healthcare system during her autoimmune disease journey made her come face to face with reality of medical sector in Pakistan. She expressed her surprise from her experience that auto-immune disease is not even taught properly in medical colleges. She told, “At my appointment with my dentist when I told him about Sjogren, he didn’t know what this disease was.” However, she also narrated a positive experience with an eye specialist who was knowledgeable about autoimmune conditions. Her morale increased due to the confidence he instilled with his encouraging words.

Regarding family history, Shazia shared that her mother had more or less the same symptoms and problems including pain in joints and nails but was never diagnosed formally with any disease. Psoriasis had been diagnosed, but that has shown improvement over the past two years. Moreover, she shared that her niece who is nine years younger than her, is diagnosed with rheumatoid arthritis. She has been married for three years and has no kids. Shazia disclosed that her niece faces more severe problems than her. For instance, her skin resembles that of old people although she’s only 33 or 34 years of age, and her skin has darkened while she was fair colored before her marriage and disease.

As to the cause which became the reason of Shazia’s autoimmune diseases, she believes that her reasoning does not matter because health and illness are part of a divine plan and what is destined to happen will eventually happen. She strongly holds the opinion that because Allah wanted her to experience the hardship of misdiagnosis, He did not put the thought in the doctors’ head that her symptoms can indicate an autoimmune condition. She added, “When I went back to my previous doctors and told them about my SLE and Sjorgen, I found them to be baffled at themselves wondering why they couldn’t get a proper diagnosis despite clear symptoms.” She also believes that when her diagnosis came, it also was predestined by Allah. He had chosen the time when doctors were to diagnose her correctly. She continued:

“At the time of diagnosis my family was going through financial crisis, and I was also sorting some issues with my in-laws. I was going through a lot of mental stress, crying almost all the

time. Perhaps, my habit of taking medicine without consulting the doctor first became the reason for my autoimmunity. One doctor which treated my daughter conjectured that it might be a side-effect of antibiotics. But almost all women face emotional issues, and we don't find every one of them suffering from autoimmunity. Therefore, to point out a specific reason that triggered my autoimmune would be hard."

Shazia reflected from her experience with autoimmune disease, that there is a serious scarcity of understanding and compassion from others around them. She feels that autoimmune patients are not perceived as "real" patients in the same way as those with more commonly recognized conditions such as diabetes, jaundice, or high blood pressure. For most of them, only these patients are deemed ill while autoimmune patients are considered as exaggerating their condition. She further explained:

"The torment that autoimmune patients go through is incomprehensible to people. If anyone were to come and meet me, they wouldn't be able to see the pain I'm going through because in their eyes they will see me as healthy as I can be. Donning on a little makeup will make me look all nice and freshened up with no problems whatsoever. Take my skin problem as an example. Rashes are at every part of my body, but clothes hide the worst of them. All those areas which are exposed to people including my hands and wrists do not have rashes. Feet and face are also secured. My covered area is much sensitive and abrasions happen there. Now I can't really show them to people, can I? One time, during extreme heat of summers, the principal of the school where I teach asked me to come to the school urgently. My skin problem was so bad that I had to wear a very thin lawn shirt. I often have to sit in a position and wear such fabric that maximum air reaches my body. In this condition my principal was forcing me to come to school at all costs. So, begrudgingly I had to send a picture of my wounds to tell her why I can't come. To how many people can I bare my scars like that?"

Shazia found support from her family members and relatives lacking. "I've heard this phrase a number of times from my relatives; '*iss ko bs adat hai haye haye krny ki* (She has made whining her habit'). She expressed her hurtfulness of the fact that people who are supposed to be closest to her also need evidence and constant reconfirmation of her suffering.

"What hurts the most is when you eventually realize that even your children have limits when it comes to your diseases. When I was very ill, in fear that their mother would die they took care of me and even raised my youngest. But when I started getting better, they now think that I am perfectly okay and have put my disease behind me. Even my siblings don't bother to ask

my reason of absence. They don't bother to check if I'm okay or not. They take everything related to my disease as normal. I'm not stating that my children don't care about me, but they have their own mood swings, their priorities and their schedules. How much time can they spend holding my knees and tending to my needs? Those people who are closest to you, who care about you the most, when you start seeing them getting tired of you that's when your vulnerability hits you. Only one thought crosses my mind then. For Allah to take me to Him with enough integrity so as to save me from the humiliation of being dependent on anyone."

Shazia strongly condemns the lack of awareness of autoimmune diseases among people. She also expressed her concern about people's lack of awareness regarding which doctor to seek for a specific problem. She shared that despite her informing her niece to consult a rheumatologist, she still opts for an orthopedic specialist. She narrated a tragic incident of her cousin whose lack of proper diagnosis resulted in kidney failure and the need for dialysis and eventually her death. Shazia's remarks about lack of awareness in people as well as the problem of not having enough psychological support sheds light on the significant challenges faced by individuals with autoimmune diseases.

"I believe that awareness of autoimmunity is very low, so it all comes down to patients themselves because what they need most is psychological support which is close to none. Everybody takes this disease as if it's something like flu where medicine or some totkay (home remedies) will do the trick. They don't comprehend the chronicity of this disease. So, to make people understand the struggles of autoimmune is very hard because they don't even know what this entails."

Shazia shared that her autoimmune conditions have impacted her personality. She feels that before her disease, even if she would have gotten the urge to sever ties with a person because of some dishonesty displayed by them she would've quelled that urge. But now she has become bad-tempered to the point that she disassociates from anyone displaying any immoral trait. She also does not feel much energy to have long conversations with others and finds it difficult to maintain ties. However, amidst all of her struggles she also recognizes the positive aspects of her disease. She shared that she is much more thankful to the blessings which she used to take for granted.

"Before a calamity befalls them, human beings are usually very unappreciative of their life and think of themselves as invincible. But when Allah reveals to them the depth of their misery and their dependence on others, only then do humans truly comprehend the magnitude of the

blessings they once had and what they now find taken away from them. One more thing that came out good in my illness is that I have forgone whatever problems were between me and my in-laws and have tried to mend all my ties. The uncertainty of my life made me scratch out all hurt from my heart and now I try to forgive and forget all."

As she draws back the drapes on her innermost feelings, some profound reflections hiding underneath her positivity surfaces.

"Overall, when I reflect upon myself, I find positive changes much more prominently in me but deep down in my heart I want the last five years of my life to disappear, as if they never happened. I want to remove them from my life."

Following this, she revealed that her depressive thoughts travelled one too many times on the road leading to suicide. If not for the unwavering support and assistance that she found in her close-knit community, her friends from Jamaat, she definitely would've found herself going down that road. Shazia shared that through her autoimmune disease her friends greatly supported her and used to cry and pray for her health. Shazia's mother, along with her paternal aunt and uncle, diligently fulfilled hospital duties while also tending to the needs of her children, but she wonders about the support from her colleagues from Jamaat who despite of having no blood relations supported her financially and mentally.

"They used to fill my house with food and fruits. If not for them, I would not have survived or simply would've killed myself. I was having numerous suicidal thoughts and once even tried killing myself with an electric switch. Hospital and medical expenses as well as responsibilities of the house had become very overwhelming. But one day, a woman of Jamaat came to my house with a home baked cake and told me to not get disappointed because Allah is very Raheem (the most merciful). Often people ask me to pray for mercy from Allah because my illness might've been a result of my sins. This statement would upset me deeply. But this woman encouraged me so beautifully that it left a mark upon my heart."

In her closing remarks, she advocates for the implementation of awareness programs to highlight the role of cousin marriages in increasing the risk of inherited conditions. She narrated:

"When I went to the funeral of my cousin in Kashmir, I saw that many people there had problem of joints and girls of very young age had skin problems. I discussed this with one of my relatives who is a doctor and he told me that this is an autoimmune disease which has

spread to our family because of cousin marriages. I tried very hard to convince some of the family members to curb cousin marriages, but no one considers this as problematic."

Shazia emphasizes the utmost need for individuals battling autoimmune diseases to have unwavering support from their family and friends, as this can keep them going through the toughest of times.

Analysis

Knowing

Shazia's sickness started subsequent to the delivery of her most recent child. The individual experienced the development of ulcers inside her oral cavity. During her most recent pregnancy, she saw the manifestation of her autoimmune problems. Due to her pregnancy, it was widely speculated that this occurrence was a direct result of her condition. Between the years 2015 and 2019, her medical issue remained undiagnosed. During that period, the individual had significant discomfort due to the presence of ulcers in her oral cavity, resulting in the discharge of fluid from these ulcers and rendering her unable to articulate verbally. She went to several physicians i.e. ENT specialist, research lab and many other specialists. However, all of them were unable to accurately identify her medical condition. A family acquaintance approached her and requested permission to share her case information with a physician whom she is acquainted with. Shazia consented and relinquished her file to a familial acquaintance. Upon reviewing the patient's medical records, the physician identified a diagnostic indication of lupus. Furthermore, she requested that the individual undergo a DNA test. Upon doing a DNA test, it was revealed that she had the genetic markers associated with the autoimmune disease known as lupus. She revisited her physician, who was unable to provide a diagnosis for her medical problem. The individual inquired if the doctor had conducted an erythrocyte sedimentation rate (ESR) test and whether any indications of autoimmunity were detected. The physician concurred that my comprehension of this condition as an autoimmune disorder was lacking. One of her physicians also informed her that the topic of autoimmunity was omitted from their medical curriculum throughout their course of study. Due of its limited prevalence in Pakistan. There seems to be a lack of interest among individuals in the pursuit of learning or instructing on the subject matter of auto-immunity. The information she disclosed is a matter of great concern to all parties involved. This is a prevalent medical condition characterized by persistent and severe symptoms, mostly affecting women, and currently without a known cure.

> Following her first diagnosis, she sought the expertise of a rheumatologist who subsequently prescribed hydroxychloroquine (HCQ) as part of her treatment regimen. The patient had a high level of satisfaction with her rheumatologist. Additionally, she conveyed that with the amelioration of her symptoms, her physician exhibited less interest in providing further treatment, which caused her considerable distress. In the case study of Shazia, it is evident that her experience of isolation was quite pronounced. The individual saw that both her physician and her family, including her children, were lacking in empathy towards her suffering and illness, ultimately becoming desensitized to her circumstances. This syndrome is often seen in individuals with autoimmune disorders.

Diagnosing

Shazia has been given a lupus diagnosis, but she has also been given a sjorgan's syndrome diagnosis. Shorgan Syndrome is characterized by the desiccation of bodily fluids, resulting in severe detrimental effects on several organs. The case study examines a persistent and debilitating discomfort that the individual experienced, characterized by a heightened sense of alienation and isolation throughout the course of their sickness. The individual's mental health has been significantly and detrimentally impacted. The case study clearly indicates that individuals with autoimmune conditions had a severe manifestation of psychological distress. The level of emotional distress experienced by Shazia is intolerable.

The case study includes an incident in which the subject attempted to insert her finger into the switch of a washing machine with the purpose of causing fatal harm to herself. She has had a really distressing encounter. The diagnosis of her condition required a duration of two years, despite the early manifestation of symptoms, which first eluded detection by medical professionals.

Curing

Shazia gradually discontinued her medicine prescription and adopted a dietary method to alleviate her sickness.

Coming to on terms with her illness:

As a community member (Jamat e Islami), Shazia's religion and relationship with God were vital. Her struggles were much-alleviated thanks to this community. She kept herself busy by volunteering in organizations important to her community and faith. This assisted her in combating her sickness.

4.6 Khawlah

"I do not remember a time when I was not in pain."

Khawlah, 55 years of age has been facing the challenges of rheumatoid arthritis since the age of 28. She currently lives in Lahore with her sons but moves back to her primary residence in Krachi in winter. Her life revolved around multiple places of residence primarily Karachi where she was born and married. She has four children, two of whom were born after her diagnosis. This chronic ailment has been a constant companion throughout her life which was supplemented by other conditions including skin condition and cervical problems in the spine. She is also suffering from ulcerative colitis, another autoimmune condition, which presented additional set of challenges.

Rheumatoid arthritis is autoimmune condition characterized by inflammation in joints which causes them to become swollen, deformed, or stiff. Initially rheumatoid arthritis starts from fingers and toes of hands and feet respectively and then spread to other joints including wrists, elbows, and shoulders. In severe cases of rheumatoid arthritis, the pain and swelling can grow into physical disabilities (Rheumatoid arthritis, 2023). Ulcerative Colitis is also an autoimmune disorder and is one of the two diseases of Inflammatory Bowel Syndrome (IBD). IBD is characterized by inflammation of gastrointestinal tract (Inflammatory bowel disease, 2022) and Ulcerative colitis specifically is characterized by ulcers in large intestine which causes a variety of symptoms including bloody diarrhoea with urgency, nausea, tiredness, joint pain and mouth sores. In some cases, arthritis is causal disease of Ulcerative colitis (Ulcerative Colitis, 2020).

Gathered from Kahwlah's interview was a strong belief on Islam as a guiding source which she drew strength and inspiration from to lead her life, and which provided with resilience to confront the obstacles in her autoimmune journey.

Moreover, her persistent determination to work and fulfil her responsibilities was the driving force that led her to adapt to the limitations that arthritis posed. Not in any circumstance she was ready to yield to her physical limitations including a constant stiffness and pain in the joints and continually did everything in her capacity to stay active and achieve the tasks required of her.

Khawlah was married in 1991 and it was in 1995 that her diagnostic period started. She narrated:

> *"It started in 1995 when I went to my village for one month. It was the first time I went outside from Karachi. During my stay, I experienced severe pain in my right hand without any apparent source like swelling or wound. The house was an old one and from the store we could hear snakes, so people suggested that snakebite might be causing the pain but there was no sign of a bite. Then in a span of one month, gradually the pain expanded to the wrist of right hand accompanied by swelling. Pain also increased. By the time I came back to Karachi, pain became unbearable. I went to haddi jor (chiropractor/physiotherapist) and local maalishi (masseuse/orthopaedic)) but the pain kept increasing. Then I went to Liaquat Memorial Hospital in Karachi where my hand was plastered but it didn't help my pain. After that Dr. Waqasi suggested to get my uric acid checked. So, then I guess I got to know that rheumatoid arthritis can happen even in young age. Dr. Waqasi was the one who diagnosed me and started my allopathic treatment which included a high dose of painkillers."*

Before her diagnosis she underwent operation for hand pain. For surgery, she had to stay in Liaquat Memorial Hospital for 24 hours. Before that her right hand got swelling and she was having much pain. With dealing with it, she shared that "I still did all my work thinking that Allah has blessed me with two hands and so I started doing all my work from left hand and used right hand as a support for it." Before her diagnosis she also tried alternative treatments for her hand. *Maalishi* and *haddi jor* can be considered as alternative to physiotherapist and orthopaedic doctors respectively, giving alternative treatments different from standard medical procedures. After her diagnosis of arthritis in 1996 following the birth of her second child, she also consulted Dr. Farzana, a homeopathic doctor. She also listed other doctors and hospitals which she consulted. She shared her experience of treatment from Shifa hospital and reported the doctors there to be very experienced both in dealing with her and in the medicines which they gave her. Khawlah showed the colours of two fingers of right hand which was darker than the rest of the hand. She said that it was because these two fingers had to be put in an instrument which helped with the pain.

Then in 1998 she started suffering from Ulcers and severe pain in stomach. At that time, her house was under-construction and her husband had been away from his family in Sheikhupura for one year due to employment there. Suffering from both of her auto immune conditions she narrated:

> *"We built the upper portion of our house in 1998. I got extremely ill, got Ulcer. A partition occurred in the house and there was no kitchen in my part. I was overworking myself; admitted my eldest son in kindergarten, managed the house, paid the bills, and rent; hence everything was my responsibility. Only Allah and Quran were my support at that time. Allah and Quran were in my life, only then it continued the way it did. Otherwise, I was as good as disabled. If I hadn't made living by the name of Allah and teachings of Islam, hadn't made it my aim, I couldn't have found the will to carry on. My duty to Allah gave me the strength to plan the day-to-day activities in a way that my work could be managed with the necessary rest that my body required. It helped me managing my diseases as well as pain. At that time in Karachi, the doctors had also advised me to refrain from conceiving because my weak bones would not be able to handle the pregnancy."*

When considerable time had passed with Khawlah managing her life and children with her disease without her husband, she shared that her eldest son started getting aggressive at school and getting in fights. They surmised that he must be missing his father. Her husband's colleagues were also getting settled there with their families, so Fouzia and her husband decided that it's as fitting a time as it ever could be to move to Sheikhupura. It was always decided that wherever they would live, her mother-in-law would also live there so, she also came with them after spending some time in the village.

> *"Our decision was based on our children. We saw that our children are suffering and needed their father. Other relatives and friends also advised this, and I also understood this to be the best course of action. My parents and siblings helped us move."*

She related the story of her migration to Sheikhupura on a hot summer day of July. By then she was blessed with three children. Her journey started from 6 a.m. when she had to leave with her three kids. Upon reaching the train station they were told that at 12 noon the train was supposed to leave so they spent their time in scorching heat.

She describes this as the most difficult travel of her life. When her husband started working there, it had been the first time she heard of Sheikhupura and had no idea what to expect from the city. Continuing narration of her life in a new place, she described that she was already suffering from extreme bowel conditions and then also suffered from right ovarian cysts during a new pregnancy. Then her youngest child was born after which she had another pregnancy which led to miscarriage. Before her eldest son was born, she already had two miscarriages, so this was the third one but after this experience, she got operated to block her reproductive system. Her youngest came to the world with operation in Sheikhupura. She was in Jamaat-e-Islami office when she was taken to a nearby hospital where the doctors and staff got alerted by her condition. From there she was transferred to Lahore's Fatima Memorial hospital. She narrated:

> *"There the doctor was senior and experienced by the grace of Allah. I got operated at night. She took care of me for three days and discharged me after removing my stitches. Still, last stitch got infected with pus. During my pregnancy and when feeding I didn't used to have the oral medicine, only injections. Otherwise, I used to tolerate without the medicine."*

Another of the condition she faced was the coagulation of blood in her left leg for which she had to go to Shalimar Hospital. Sharing her experience, she told:

> "*Clotting of blood in my left leg happened due to which it became cold and swelled from knees to feet and pain became beyond tolerating. My body was burning up with 103/105 degrees, but that leg was cold. For fever, a strip of cloth soaked with cold water was put on my forehead. Otherwise, they suspected that fever would travel to the brain. Doctors at the hospital were very good and treated me very nicely. Both doctors for blood and ulcer were nice. They directed me to keep my leg straight and warned me of the dangers of clotting that how clot could move towards any part of the body and can cause blockage there. I knew the danger that I was in, but I always had people with me who support me. My husband used to ask constantly from his office over the phone about my health. Women of Jama'at also used to ask after my health and provided me food whenever necessary."*

During the time, when she had blood clot problem, she also got skin allergy for which she wore only clothes made of cotton even in winters. Silk or wool was totally prohibited for her.

Her ulcer got aggravated to the extent that blood came out through urine. She consulted Hakeem Saeed and Hamdard, but nothing more than temporary relief came.

Her ulcerative colitis was officially diagnosed through endoscopy. She got treatment from Agha Khan Hospital in Karachi where three injections were given, and medicines were prescribed for several months which they used to buy in bulk for quite some time. She also consulted Dr. A from F Hospital, who prescribed another colonoscopy, but it posed serious hazard to her health, so she did not go through it. Moreover, a medicine provided to her by Dr. A caused swelling in her mouth and black spots on her skin. She shared that normal feel of the skin was altered somehow.

> *"I experienced this type of skin condition before once when for my severe fever doctors prescribed me Augmentin. The medicine reacted to my skin and an allergic reaction appeared on my body resembling scales of fishes. That was only cured with homeopathic medicine. The homeopath advised me to tell all doctors that I have penicillin allergy."*

For her chronic conditions, she had to take steroids which started from 1998 including HCQ. She remembers that she got injected with steroids to spend winters without pain. Upon asking whether she knew the side effects that steroids entail she answered in affirmative. "I knew about the side-effects. I knew what steroids will do to my heart, eyes, and other organs. My stomach was already affected by then, but I had no choice."

She also has experiences kidney problems. They moved back to Lahore in 2009 and she got treatment for kidneys there. Doctors recommended her not to drink water and she thought this to be quite interesting and unusual because usually people are told to increase water intake. Her kidney problem got treated swiftly.

Since her diagnosis, Fouzia remembers many injections and medicine which she took to manage her life and deal with the pain. She currently consults a doctor from R Hospital who conduct annual check-ups and Dr. H, rheumatologist from S Hospital for her arthritis.

> *"In these 25, 26 years I got to consult best doctors, every doctor better than the last but due to the incurability of the disease it has been difficult to manage. Then there is the matter of the side effects of medicines. There is no cure other than temporary relief. Then there are some conditions which don't even have a temporary reprieve and so you can do nothing other than endure them. Sometimes I get in this state where I think to myself that what it would be like to not feel pain, that how life would be like without this constant agony. The pain which is supposed to be abnormal has become very much normal, the standard state of my body. My*

> *body has grown accustomed to the pain as if it's a part of life. It stays with me all the time, never leaves me. However, I only have had one expectation from medical science and healthcare providers: to make me as productive as possible, even with a transient relief. I don't care if I do not get cured. I just want to live my life with minimal pain so as to keep on working and to not become dependent on anyone even for one moment."*

She described her condition from the initial years of her chronic diseases as:

> *"With the severity of my disease, my body naturally felt the impact but the psychological brunt was too much. I fell into yaaslik-pasandi, a lethargy cutting deep to the bone, a negativity in every facet of being, a tenacious hopelessness. I was the one who people depended upon; my mother-in-law relied upon me to be her aide not less than a right hand. To live up to that role I stomached high dose of pain killers, even doubled the medicine to conquer the pain and shoulder the responsibilities I was expected of. I made this no less the aim of my life. The painkillers that I took were double the dose a normal person would take because I gave myself no luxury of rest. It was also my need to prove myself that I am not ill and can do any work I set my mind to."*

Khawlah shared that she has never liked telling people about her ailments and conditions and never likes getting pity or sympathy from others. She only wants to uphold her responsibilities diligently, regardless of her health challenges. She expresses her concern that people tend to stigmatize health conditions and implicate individuals as responsible for their own afflictions, as if the illness and pain are result of people's own wrongdoings and flaws and there is no one but themselves to blame.

> *"I've never liked telling people about my ailments and condition. I do not want people to throw pity at me in anyway. Humans need love but not pity. And it's not as if they give discount to you due to your condition. People also get accustomed to your illness as well as to your being ill. They start to think that it's commonplace and that I've made habit of being ill as if humans have any control on this. At this stage of my life, I've come to realize the attitude of my close relatives. Nobody wants to spend time with me and is waiting for the last news. I believe this as the truth and try my best to recite as much as Quran for my salvation and forgiveness. I have also started being carefree and stopped caring what others think of me or if I've made other happy or not. I just try to fulfil my duties thoroughly so that nobody gets a chance to point a finger at me or the way I handle my obligations. Pleasing people has long stopped being the aim for me."*

Khawlah shared that she has also met people who like her have suffered from autoimmune conditions. While living in Sheikhupura, she got acquainted with a woman with very young kids whose fingers and toes were bended making her life difficult and walking a grim task. She also met mother of her husband's friend living in Multan having arthritis. Furthermore, when she was diagnosed, she came to know that her cousin also suffered from autoimmune disease which eventually became the cause of her death.

Regarding the aetiology of her diseases, she couldn't think of a particular cause that led her to this disease. She also couldn't remember something to fault from her time spent in village when her pain first originated in the hand. But continuing her narration of experience she said that she did take stress about whether she should marry among extended family or not.

> *"I had good expectations. I was young. Firstly, I found the lifestyle in the village and the environment there very weird. And then life in my initial years of marriage got to the point, you can blame the restrictions or pressure, that I even forgot for some time what my favourite colour is. I had to face restrictions in every matter of life, when to wake up, when to sleep that I thought that my husband has handed me over to my mother-in-law, just to make me do housework, and to mould my very being in her colours. The image that I had made of life that I took to my new home slowly and gradually started slipping away and ended nowhere to be found."*

She conjectured these factors that might have become the cause of her chronic conditions at such a young age. She shared that over the years she has learned to not idolize life and to stand her ground. Khawlah also shared that she reckons her body as an energy saver, into which she can store only limited amount of energy. She now has fully understood that she doesn't have the luxury of unlimited energy and so only engages in those activities which increases it and spend it efficiently.

Khawlah believes that if she didn't have chronic conditions, she would've been more pious, with more faith, and would've been able to cultivate a more devout household. She also believes that without her diseases she would've been more productive and efficient in worldly tasks and would've been active in welfare work for the people. However, reflecting on a life free from diseases she concluded: "But, maybe this was the only way life was supposed to be."

Upon being asked about the way her life changed due to the disease, she asked clarification on meaning of change. When further probed about her thoughts on difference between life before and after her diagnosis, she didn’t have that distinction, only a clear divide between her life before and after marriage. With a heavy sigh she expressed a sense of nostalgia for the time she lived with her parents, and which can never come back. She again shared that even after her extensive experiences of illness, she doesn’t discuss her disease and pain much and do not want others to give her advice or suggestions on her lifestyle. She doesn’t want anyone to have pity on her, so she has never made discussing her ailments with others a coping mechanism. She only confides in and share her challenges with those people who are dear to her including her family and friends and who sincerely care for her wellbeing. She mentioned a friend, Zahida in particular who was also diagnosed with rheumatoid arthritis around when Khawlah was diagnosed. Their shared experiences created a unique bond between them, and she found comfort in confiding in Zahida, as they both understood each other’s struggles. She shared that what started only as a cursory exchange happening between acquaintances, turned into sharing conversation about the disease, symptoms, and ways to deal with it.

> *“I find myself being more optimist when I have my close group of people around. They make me keep away from being depressive, lethargic, or hopeless. These things make humans drenched in a negative energy. You start having negative perceptions and opinions about everything and they bring out many intrusive thoughts from the deepest part of your brain. I know well enough that hopelessness is a sin in itself. So, with these people I get to find a glimmer of hope. I have meaningful conversations with my friends, where we put a kind of an analytical lens and thoughtful perspective over the state of things rather than only pointing fingers at them. These people make me find something positive from my life that I can share with them instead of wallowing in self-pity.”*

She further praised her friends for having stood by her in the worst of times and with her disease. She shared that when she used to be very sick, they took care of her kids, cooked food, looked after her home and kids if she had to make a visit to the doctors, even accompanied her to take her kids to hospital in case of her husband’s unavailability. Hence, they helped with whatever was the need of the situation with the utmost, well-disposed intent and never made her feel that her parents and siblings were away from her.

> *"My friends completed whatever I lacked in my life. I thought them as my equal, as well as equal to every blood relation that I have. There is a sort of camaraderie and sisterhood, and we share one vision of life. These sisters are my allies and aides in whatever I have achieved in my life and made my aim. We understand each other well and know how to deal with each other."*

She shared that her husband and kids have also stood by her and helped in coping with the adversity that life throws at her way. She also mentioned her brother who helped her immensely. Talking about her husband she shared that when the pain and her condition peaked at a level intolerable, he did all in his capacity to bring her to the doctors who could diagnose her accurately, provided her with medications and the best of health care the country had to offer. She continued:

> *"He has all my medications and prescriptions memorized. I don't have to remember anything because he remembers everything for me. If you would ask him, he would tell you the specific names of medications right off the bat. He also respected my wish to not talk about the matters of my health with others. Once he used the word handicap and it shocked me so much to hear it from such an open-minded person that I have not been able to forget about it."*

Khawlah shared her relationship with Allah that runs deep and that has played a role in her disease. She shared:

> *"When the intensity of pain reaches the brink mixed with dejectedness, it's very hard to bring myself out of it. It takes time. Talking to Allah works like a charm for this because in doing so I make myself positive. I am really not suggesting that my relationship is equal to that of saints and pious people but in the most desperate moments when I find myself the most dejected, I take help from Allah and Quran."*

She shared her feeling of restlessness when she became so ill that she was not even able to get up from bed but just in two days' time she gathered enough strength to teach Quran because she believed it to be the only solution to keep her motivated in the face of lethargy and illness. She shared some contemplative thoughts on her prayers and dua:

> *"The extent of my tolerance has become such that the state of emotions that a person channel for a heartfelt dua, that specific sensation that spurs up in the heart while making a prayer, I have gotten tired from that. I have restricted my heart to immerse itself in that feeling because I don't think I would be able to tolerate it now. It's not like I have stopped praying for my*

health but to get in that zone where it effects my heart, I avoid it completely. While praying I don't let my emotions reach the heightened state and try to conserve as much energy as possible."

To summarize the full extent of her experience that her autoimmune disease has given her she explained:

"I would say that it has been Allah's greatest mercy and blessing on me that at a very young age He revealed to me the real purpose of this life and I understood that I have to be faithful to Him alone. I remember a sentence that depict this devotion as - if you are unable to run on to His path, walk. If you can't walk, then keep standing still. If you are unable to stand then sit or lie down on the path. If you cannot even do that just watch over the path, keep your eyes at it. Meaning that I have to devote myself to such an extent that if I acquire this feeling, I must watch that path leading to Him because that path is that of Allah's. I also want my children to be in the group who have chosen this path. Only then I would have felt that my diseases and hardships of life were worth something."

Analysis

Knowing

In Khoula's case study, a notable aspect emerges whereby the patient has been battling her condition for around 28 years. The individual was diagnosed with her condition in her late twenties and is now 55. The case study of Khoula demonstrates the enduring nature of a patient's sickness. For this particular patient, the experience of marriage was seen as a significant source of stress throughout her adult life stage.

Diagnosing

The individual was now diagnosed with metastatic arthritis, inflammatory bowel disease (IBD), and renal dysfunction. The individual in question exhibits a multitude of bodily ailments and has moreover received a diagnosis of an autoimmune disorder. She was unaware of what she was going through and wasn't even aware of the symptoms. Neither she nor her family were aware of the events unfolding. The individual was diagnosed in the 1900s when awareness of chronic diseases was limited, even within the educated community. It is well recognized that elderly patients diagnosed with chronic diseases have more extended diagnosis periods than contemporary patients, mainly due to limited internet access, inadequate medical knowledge, and other related resources. A significant disparity exists between the elderly patients and the more recent patients of the present era. Elderly individuals have experimented with many alternative approaches and self-care methods due to a lack of comprehension of the symptoms, their underlying causes, and their corresponding references. Ultimately, a local doctor who lived close to the patient's home diagnosed her with an autoimmune condition and advised her to see a rheumatologist. Subsequently, a protracted period of her ailment and well-being ensued. Some waves represent the greatest and lowest life events, putting her in a debate. Additionally, she had complications related to an ulcer. She experienced the conditions above for an extended duration and endured a life characterized by discomfort.

Curing

Khoula was among the sufferers who had come to the understanding that her condition is incurable. Neither allopathic nor homeopathic doctors have been able to provide a treatment for her condition. As previously examined in the example of Summaira, she holds the belief that the use of bandages serves as a means to alleviate the experience of pain. The individual said that they had no recollection of a period in their life when they did not experience physical discomfort. The aforementioned comment has significant weight, since it is from an individual who has endured the burden of a distressing medical condition for a duration spanning 28 years. It is evident from the existing body of research that individuals with chronic diseases have developed a certain level of adaptability in managing their conditions. The individuals in question do not possess recollection of their existence before the onset of the aforementioned ailment. For many individuals, the absence of recollection pertaining to their previous existence is seen as a fortuitous circumstance, leading them to perceive their current state as innate and unaltered from inception. Regarding Khawlah's disease, it is evident that the patient perceives this condition as an integral aspect of their existence, necessitating a choice between disregarding its presence or allowing it to run its course. The individual's response to their suffering is characterized by a desire to promptly alleviate the discomfort. This phenomenon is often seen among women who perceive their familial responsibilities as the primary means through which they define their identity. In these particular case studies, it is evident that the primary focus of the individuals involved was to fulfil their roles as mothers or wives to the greatest extent feasible. I diligently fulfil all of my obligations while experiencing a significant degree of physical discomfort. The experience of this intense emotional state is often seen among women, especially those belonging to certain cultural groups, such as Pakistan. The emotion seen in previous case studies is notably pronounced in this particular case study. The individual in question would make reference to the use of supplementary steroids or steroid injections as a means to alleviate her discomfort, hence facilitating a more manageable winter season.

Coming in terms with illness

Regarding her approach to managing her condition, she adopts a proactive stance by exerting maximum effort to confront it. The individual expresses a sense of community (referred to as "jammat e islami") and acknowledges the consistent support and care provided by this community throughout her hospitalization, benefiting both her and her family.

4.7 Almas

Almas, 27 years old has a skin condition due to an autoimmune response called Vitiligo. In vitiligo, immune system attacks melanin producing cells in skin called melanocytes, due to which different areas of skin lose their pigments and white patches appear on it. People suffering from other autoimmune diseases like lupus, diabetes 1, thyroid disease, rheumatoid are also susceptible of developing vitiligo. White patches usually appear on an area including face, forearms, hands and may or may not spread to other areas. Although a painless condition, emotional distress is common among people suffering from Vitiligo (Vitiligo, 2022).

Almas has graduated in Software engineering and is currently doing her master's in data science from Fast University. She is married and has an eight-month-old baby boy. Her vitiligo started in last trimester of pregnancy, so it has been less than a year since her condition's appearance. Although Almas reported that the skin around neck changed colour during the last trimester, she brushed it off at that time but after her delivery through Caesarean section, the colour grew lighter, and the patches expanded to her face.

The aetiology of Vitiligo, according to the doctors, was the blood loss that happened during her complicated delivery and her iron deficiency. Almas did not have prior knowledge of auto-immune diseases or Vitiligo being one of it. However, much like other interviewees, she associated the onset of her patches with stress and shared that she was under a lot of mental strain in the last months of pregnancy. One of her concerns was her master's degree. She feared that she would not be able to continue her studies after a baby or would not be able to manage both of these responsibilities. She started doing master's before marriage and after her father's death her mother thought it fitting to marry her off during the Masters. Furthermore, Almas always have had a phobia for needles, surgery and IV drips so she was stressed out about C-Section. She shared:

> *"I was constantly terrified of surgery and kept thinking about everything that could go wrong. When I went to the hospital, I was afraid still, but gradually doctors and nurses calmed me down and my family put great effort to put my mind to ease and gave me mental support. My family especially told me that 'logo'n k to 4 4 ho jaatay hain' (women reproduce multiple children), so I should not worry that much. Doctors and staff at the hospital were very supportive and were talking to me in the operating room in a very normal manner which helped me relax considerably."*

Her diagnosis took time because it was her postpartum period, and she was busy with the baby. When her spots became visible enough to draw her full attention, her concern peaked, and she consulted a doctor. At the last months of pregnancy only a little discolouration had happened, and she thought that it must be due to pregnancy, so it will get better on its own. After delivery however, there remained no doubt that her skin around the neck was changing colour so she should consult the doctor. The first time when she observed the spots her first understanding was that her skin was getting dark. She thought that the white skin was the original colour, and the darker part was getting effected. As the scars expanded however, doctors negated this and told her that the white part of the skin is the effected part and gave her the diagnosis of Vitiligo. According to doctors, her condition must have started before the start of pregnancy. For this they conducted no tests, just observed the skin. Firstly, she consulted her gynaecologist and then a skin specialist. The treatment that he gave her was difficult for her to understand and dietary restrictions resulted in weakness in her body. Then she discontinued her medicines in the fear of side-effects.

For Vitiligo, Almas is currently not taking any medication, but she has taken both allopathic and homeopathic treatments. She prefers allopathic treatment over homeopathic medicine because she has found homeopathy to be slow and longwinded, more so when it has not been able to cure her patches. However, the ability of allopathy to provide immediate results has also not worked for Almas and her condition persists. Therefore, she has discontinued her homeopathic treatment for its slow approach to healing and the time commitment it requires and her allopathic treatment for the side-effects that are inevitable in the medicines. She further shared that both allopathy and homeopathy have limited medicines available for Vitiligo but the doctors' main approach of healthcare for this condition is a set of dietary restrictions which she has usually trouble following.

As currently she is not taking any treatment, her future course of healthcare depends upon completing her masters and getting a job because she has found the treatments for vitiligo as quite expensive. Consultation fee of doctors was high, when one time she had paid Rupees 2500 for one session. Furthermore, the medicine is also very expensive, for around 5000 rupees. So, Almas has decided that she should settle down first, and get a job to meet the expenses for the treatment. She has done research on medication for Vitiligo on internet and found that there are only limited number of medicines and even limited lotions available. Almas believes that she will have to resort to these medications because of lack of research on Vitiligo and no prospects for further medication. Doctors also have limited information about the overall healthcare needed for Vitiligo which she came to know from the prescriptions that they gave. She believes that doctors just prescribe medicine and dietary restrictions on pure guessing. For her, the ideal treatment for her will be medicine with no side-effects like weight gain and also which gives at least some kind of improvement. Without any visible improvement she describes herself getting bored which ultimately led her to take medicine sporadically and eventually its discontinuation.

Regarding dietary restrictions, Almas shared that different doctors gave list of foods that more or less encompassed similar things that she was to exclude from her diet. These food items usually included milk, fish and eggs. A doctor even recommended her to stop eating fruit. She shared that one of the most disappointing things was that she actually thought her patches could be cured from abstaining from the foodstuff. She further shared:

> *"The doctors which I consulted were putting restrictions on a lot of food items which are integral in daily life. Some told me not to drink milk or eat eggs. Some told to avoid eating fish. I found it hard to completely abstain from these restrictions when milk and eggs are too common ingredients to avoid even if you try. Take milk for instance. How much can you avoid it when many cultural dishes are made from it? Being a guest in someone's house it becomes very hard to refuse them when they present something to you, like kheer or custard. Even if you stop drinking milk, it is surely used to make tea. And then, I could've kept away from fish but how can you abstain from eggs. When I attempted to follow the dietary limitations at the start of diagnosis, I felt my energy levels going down further when I already had weakness from the delivery. So, my mother just urged me to not listen to the doctors and start eating eggs."*

The difficulty that Almas encountered because of Vitiligo and the patches extended beyond problems related to self-perception or body image, which remained unaffected. Her central challenge that she had to face was reaction from other people and their inquiry after her condition. She stated:

> *"At first, I naturally panicked. My family never gave any bad reaction to the discolouration and they were somewhat prepared for a difficult situation because they knew about the critical condition and the magnitude of the operation I was going to go through. They also knew about the blood loss and iron deficiency, so they thought that it was a sign of weakness. But for me, these patches came as a shock, and I only wanted to get rid of them. I was not prepared at all. And the fact that they were expanding at the time made it very difficult for me to come in terms with it. But eventually I got over it. What kept bothering me immensely was people asking about my skin. They kept asking me the reason for them and what kind of spots were they. After inquiring after it, the other thing that followed used to be home remedies. They would say to do this or stop eating that. I never applied the home remedies from fear of getting a further bad reaction from them. The condition was very new to me. I couldn't have known what was causing them and so wasn't ready to take any further risks."*

Almas told about the advice on home remedies she received from people. Someone suggested her to mix some oils and apply on the patches. Someone told her about a hakeem whose medicine works by applying on the skin and sitting in sunlight. (Interviewer shared her experience where her Vitiligo in the eye got cured by the medicine which she had to apply and sit in the setting sun). Almas told that she has heard that only some people whose melanin are yet to be totally finished gets cured by this medicine. Somebody also told her about a liquid resembling milk to drink. People have also told her that she must have drunk milk after eating fish that caused her patches.

Almas experienced social consequences for Vitiligo and shared that she could decipher that people wanted to keep their distance from her in the fear of contracting the condition. She excluded her family and friends but shared that she experienced this from her neighbours and complete strangers. Her family acted normal and also her friends didn't care about the spots, but Almas felt saddened by attitude of other people but more so when they outright asked about her patches.

"It's just like when someone points out your acne. It's not as if they affect other areas of your life, so you manage to keep them out of your head. But as soon as someone points them out, you get insecure. Same happened with my Vitiligo and that scrutiny of people solely on my patches left me feeling insecure and embarrassed and obviously my confidence also plummeted. During the start of my condition, I also didn't have something that could stop me from getting demotivated at the time. At first, people stare or start discussing with each other. Then, if anyone muster enough strength to ask me about it, I tell them my story. But the way they look at me it clearly shows like they cannot believe me as if I'm lying. It's like nothing you tell them may satisfy them. They assume that this must have happened at birth. Secondly, if some people haven't asked about it, they surely commented on someone else on social media with vitiligo which have revealed very clearly to me what their actual opinion about this disease is."

Therefore, the way Vitiligo subjected Almas to a scrutiny from others, became a source of mental turmoil for her. The way people noticed her whenever she went outside used to leave her discomforted. She described further that instead of seeing the person that she is, she could feel them only seeing the patches, could feel their gazes snagging on to the lightened skin, and could imperceptibly feel pointing or discussing them with each other. Moreover, she told that she never has to worry about any physical problem so if she didn't have to worry about this behaviour of people, she wouldn't have to worry about anything.

"I don't have any fear regarding this disease and the major factor is that there is no disability or some grave complication, and for this I am much grateful. As long as I have healthy and

> *working hands, feet, eyes and other organs I don't have anything to worry about. I can also go anywhere, maintain a social life and freely talk to people so this condition has not limited my life or any activities. I do take caution not to touch anyone because I know that some people can consider the scars as transmissible, and I know they must be taking caution not to touch me or sit with me. But this disease doesn't limit me from enjoying any experience of life. I can delve into studies, can get jobs which I wouldn't have been able to do if there was any major disability to intrude in my life."*

Her self-perception remained unaltered and there were no feelings of inadequacy. However, she remained confident till somebody asked something. By way of example, she told that sometimes it happens during family functions with conversations happening all around when somebody specifically ask about the patches and then she feels attention of other people diverting towards her automatically. Therefore, she believes that even if her self-perception hasn't changed, people's perception towards her has certainly altered. She shared that even if people don't outright tell you this, but just from their attitude and behaviour they convey the message across that they want to keep their distance or show their discomfort towards you.

Almas shared that she has never let anybody show the way their behaviour impacted her and has now made herself strong enough that whatever feelings their behaviour induced in her, she doesn't let them faze her. Her family has foremost helped her with this. She shared that her family has motivated her throughout to accept her disease and that she has gotten full support from her mother, sister and husband. Their behaviour towards her didn't change at all and her patches didn't bother them. She also commended that they never showed any pity towards her and could care less about the scars. For Almas, this has been a great source of comfort. Thinking about her family and their behaviour makes her feel blessed and lighthearted. She feels happy that these people exist in her life who are concerned more about her inherent nature and the person that she is rather than reducing her to her looks or appearance and believes that these people will stick to her in the future too. However, she shared behaviour of her *bhabhi* (sister-in-law) when she pointed out her patches and accused Almas and her family for keeping the disease from her in-laws saying that Almas must have had this condition since before the marriage and kept it as a secret from everybody till now after the baby when it was safe for her to do so. "Firstly, patches like these cannot be concealed for a whole year. Secondly, I do not have a reason to hide them from anyone. My scars are what they are, and I am not ashamed.” When she communicated what her sister-in-law has said by way of taunt to her husband, he supported her and mentioned that he does not care about the appearance.

> *“Although only for a brief period, but a time did come when I felt that nothing in my life would be able to make me happy again. But because I didn’t have to experience any physical pain my family managed to keep me from going into depression. They behaved with me as if there were no patches to begin with and I only remembered them when others pointed them out to me. Otherwise for most part of the disease I really forget about them. Behaviour of my neighbours and sister-in-law did hurt me but sharing them with my husband and mother I got full consolation and support. The solace that I got from my mother was to such an extent that I could actually feel all my problems and tensions getting erased. She gave examples of inspiring individuals like Asifa Bhutto Zardari whose vitiligo didn’t stop her from doing her activism against polio and of Helen Keller, who despite her challenges of deafness and blindness was able to become one of the greatest writers. My mother always motivates me with these examples and tell me to not give up on my goals and aims.”*

Almas shared that by giving examples of people who overcame significant challenges to achieve their goals, her mother motivated her to establish herself on her feet and become an independent individual. She encourages Almas to never give up on her aspirations, to pursue her studies and become a career-oriented, independent woman. She inspires her to remain steadfast in her determination and resilience. Almas shared that her mother’s motivating words instil a confidence in herself and present her the possibility of achieving greatness, despite the obstacles she may face.

Almas also shared other instances where people’s perceptions towards the disease can be analysed. She told about her visit to a parlour where she noticed women working there giving meaningful looks to the woman giving her services as if telling her to not touch her. And so, Almas reported that the worker was careful not to touch those areas of her skin. She didn’t say anything because she knows about the futility of changing people’s mentality which is always informed by long drawn cultural judgements and prejudices. However, Almas herself never held such a belief that Vitiligo could be contagious or that she has to feel apprehensive towards it. She shared that while living in a boarding school during college she was acquainted with a girl who had these patches but it didn’t matter to Almas and she always behaved normally around her. They used to sit together and Almas never thought of keeping away from her. Then when doctors told about the blood loss being the reason for this condition, it confirmed what she already knew. She believes that it is a lack of awareness that incite such response from people. She continued:

> *"I sometimes find myself thinking unconsciously that what would have happened if Vitiligo happened to me before my marriage. People would have really talked and made issue about how will I ever get married. In this sense, I feel really blessed."*

Almas only thinks of people's behaviour when she imagines how different her life would've been if not for Vitiligo. She thinks that the point of view that she presents, people would've paid more attention to it or respected it. She feels that her opinions are not given due respect from people and somehow, they manage to bring the topic of conversation to her condition or outright stare at her. She has felt people talking about her publicly in a party and leave all other topics aside and start asking after her condition. She feels saddened that people had made this her identity and feels perplexed at the urge of strangers to give opinions and cures from up their sleeves as if they have extensive knowledge about it.

She thinks that her condition will only improve if she gets a proper treatment, or a proper guideline and she is hopeful that medical science would at some point reach to that stage. But for now, she thinks that doctors lack information regarding Vitiligo and the only advice they can give is to stop eating certain foods or fruits. Some doctors also give the prospect of grafting skin but her only wish is to get a treatment that incorporates effective medication without harmful side effects. Almas has followed two women on Instagram who have Vitiligo and give awareness to cope up with it. One @thevitiligogirl as her username and second as her own name who is also a model by profession. She does not have any family history of Vitiligo. Almas has shared that she has never complained to Allah, just prays for the skin to return to its normal colour but apart from this, she also prays for a change in society's mentality. According to Almas, if she never got cured but society became more accepting, she'll be satisfied with that too.

Analysis

Knowing:

Almas is the only autoimmune patient who has ever been recorded to exhibit evident characteristics of her ailment, according to the findings of the case study that was done on her. Vitiligo is characterized by white spots appearing in various locations on the patient's body. She is the only person who responded who has evident symptoms of an autoimmune illness. It is abundantly obvious that auto-immune diseases are the source of pain that is invisible to the human sight. There is a widespread prejudice towards those who are afflicted with diseases that may be easily seen. The general population has a tendency to assume that diseases with such blatant symptoms are very contagious. Nobody had the courage to sit near her or talk to her, and they most definitely refrained from touching her. Her husband, mother, and sisters were the only people in her life who were especially friendly to her, therefore this caused difficulties in her social life.

She has a clear recollection of her sister-in-law informing her that her sister-in-law suffered from this illness before to her marriage but that she hid it from everyone. And she only tells us when she's already settled down with a spouse and a child. Almas, on the other hand, thinks that the stress of her pregnancy was the primary factor in the development of her vitiligo. She was preoccupied with her pregnancy and didn't pay much attention to the spots that were starting to appear on her body, so she had no idea what was going on. However, since she had a C-section, her vitiligo spots are more noticeable than they would have been otherwise. She discovered that she had vitiligo after seeing a doctor about her skin condition.

Diagnosis:

Almas's situation was very straightforward and easy to diagnose. Because her illness is readily apparent, she was able to catch it early.w

Curing:

Similar to other autoimmune illnesses, Vitiligo is also considered incurable. However, she encountered a significant amount of stereotyping in comparison to the other participants. Individuals tend to refrain from physical contact with her. The participant relayed her encounter to the researcher, describing her visit to a beauty salon where the beautician refrained from touching areas of her body that had spots, presumably to minimize the risk of contracting any associated diseases. In relation to the treatment for vitiligo, it is important to note that there is now no known cure for this condition, which is believed to be triggered by stress. The medications provided by the physician were deemed too costly, prompting her to explore dietary modifications as an alternative approach. The individual had the belief that medical professionals do not provide sound recommendations, since they advised against the use of dairy products, which she perceives to be very beneficial for maternal health.

Coming to terms with illness:

She has the support of her family, particularly her spouse. The husband shows little concern for his wife's physical deformity. He consistently demonstrates high care for her and develops positive feelings about her physical self.

CHAPTER 5

5. EXPERIENTIAL REALITIES OF AUTOIMMUNE PATIENTS

5.1. Pathway to Cure

5.1.1 Role of Wealth in Access to Good Medical Care

Socioeconomic status is closely linked to good aging and healthy life, with wealthier people having a higher possibility of being healthy. According to the WHO, healthy aging is evolving and prolonging the functional abilities sanctioning good health in old age. Healthy aging limits a person's physical and cognitive capabilities at any stage of life. In addition, healthy aging means living a healthy and active lifestyle, maintaining good physical and mental functionalities, and leading healthy behaviors, and all this can only happen when a person is wealthy or has enough money to take care of himself in old age. As people get older, the "wealth-health" gradient becomes more prominent. (McMaughan, Oloruntoba, & Smith, 2020, p. 9)

The higher one's income, the lesser one's chances of early death and illness. According to studies, Americans with low economic resources are not much healthier than those with higher financial resources. However, it is elementary to understand that health is related to income for both the rich and the poor. The relationship between money and good health is a gradient: they are linked step-by-step at each level of the economic ladder. (Woolf et al., 2015, p. 25)

Wealth can buy good health and longer life. However, wealth is also associated with physical well-being. Consequently, various health status assessments throughout a person's average lifespan strongly correlate with financial resources. Researchers have previously compiled evidence from a wide range of research showing that wealthy people have longer lives, lower rates of chronic illness, and greater levels of function well into their old life.

During research, it was made apparent to the researcher that the individuals who showed characters of wealth, such as, expensive cars, expensive clothing, educational background, and residence (Rokopoulos & Rio, 2018), not only took treatment of their illness more seriously but were open to experimental and expensive treatments. This may be understood because the rich have access to higher-quality housing and medical treatment that helps them avoid illness in the first place and treats it more effectively when it does occur. (Thomas, 2022) Respondents from better financial backgrounds did not complain about the cost of treatments or their medications. They were also less likely to skip their appointments or have to select health care providers according to affordability. While studying the case studies it became clear that respondents with greater financial strength like, Hania and Zunaira were swiftly diagnosed, one due to their own knowledge of medical science and secondly due to access to better medical professionals.

Even though those in poverty have greater healthcare demands, several studies have indicated that those in the middle and upper classes have more opportunities to get medical treatment. Furthermore, even if all financial barriers to accessing health care are removed, access to health care might still be unequal due to other factors, such as a lack of health knowledge and awareness, an uneven distribution of health infrastructure, and different rates of infrastructure development in different areas. (Johar et al., 2018, p. 134-145)

Over 80 distinct autoimmune disorders have been recognized by medical researchers so far. These diseases range from Diabetes Type 1 and Rheumatoid Arthritis to Scleroderma and Multiple Sclerosis. Because of insurance companies, patients with autoimmune diseases have trouble getting the necessary medicines. Experts may agree that patients with autoimmune disorders experience significant challenges due to the high care expense. Nevertheless, they can have different perspectives on whether or not this is the most critical challenge they face. However, everyone acknowledges pharmacists may be vital in easing patients' pharmaceutical access. (Wiley, 2022)

Individuals with more financial resources may be able to consult rheumatologists or immunologists who specialize in treating autoimmune illnesses. Also, they may have access to cutting-edge diagnostic tools that improve patient care. Because of their financial standing, wealthy people often have access to a broader selection of pharmaceuticals, including high-priced treatments for autoimmune disorders. Those with little financial means may be unable to afford these drugs because of their high cost and the possibility that they will not be reimbursed by insurance or public health systems. Respondents with middle class income took more time to reach out to medical professionals and would try to alleviate their issues with alternative remedies. These respondents also found lab tests, doctor's appointments, and expensive medications to be a financial burden. Which, when coupled with the extensive diagnostic time also becomes an emotional burden. Wealthy individuals may have the luxury of devoting more time and energy to treating their autoimmune disorders and having more access to medical specialists, therapies, and drugs. Patients with more financial means may have more options for caring for themselves, such as taking time off work to relax and manage symptoms or hiring assistance with chores and childcare. Socioeconomic status does have a role in the prognosis of autoimmune disorders, but it is not the sole determinant. Autoimmune illnesses have several contributors, including genetics, lifestyle choices, and the environment. Not all autoimmune diseases can be cured. Therefore, individuals with these conditions may have to live the rest of their lives with their needs. No matter how good their medical treatment is. (Madej, et al., 2023, p. 20)

5.1.2. Role of Internet for Patients in Finding Answers

The internet has emerged as a key or at least essential information resource for young people seeking advice on matters of health. One of its many uses is as a platform for online support groups by connecting users with resources that may help them make informed health decisions and preventative care decisions. Even though young people may access such resources online, they will still use them to adopt healthier lifestyles. Young people who participated in targeted Internet-based treatments for weight loss or depression responded better to therapy than those who used Internet-based health education alone. However, gains tended to diminish with time. (Ettel, Nathanson, Ettel, Wilson, & Meola, 2012, p. 35-38) While conducting research, it became apparent that younger respondents, those in their twenties and thirties, used the internet to navigate their lab reports, medical treatments and diagnosis. Some even diagnosed their autoimmune diseases before their health care providers, such as Zunaira, Nida and Sumaira. While older respondents who experienced their illnesses before the internet like Khawlah were in the hands of their doctor's to properly diagnose them.

Patients' research topics include the rationale behind a new treatment plan, issues left unanswered after doctor visits, and how to incorporate dietary and activity modifications into daily life. Patients sometimes prefer looking up their information online rather than relying on their physicians' recommendations. Most individuals who successfully locate their desired data also judge it as high quality and credible. When people looking for health information lack the knowledge and tools to critically assess the data they discover, as might happen when their health literacy is inadequate (Kanthawala,Vermeesch, Given, & Huh, 2016, p. 33). Respondents like Nida shared their frustration that reading too much up on their illness would make them obsessive over the tiniest detail or symptom. They would also find themselves over-diagnosing themselves and getting upset over nothing.

Internet users can access various health resources, including medical journals, mailing lists, publications, government and professional organization websites, and online support groups. People can now locate individuals going through the same experiences using the internet. Patients with chronic diseases, whose main form of treatment is often caring at home, may benefit greatly from building peer support networks through online groups. 23% of people who use the internet with chronic illnesses have looked for information about their conditions online. These folks discovered that it was helpful to seek the guidance and comfort of other patients for both emotional and immediate needs and that doing so was beneficial to them. Because of this, many materials can be found online, some more helpful in some circumstances than others. (Kanthawala, Vermeesch, Given, & Huh, 2016, p. 33) A study shows that even while 45% of persons without chronic illness say they or someone they know has benefited from following medical advice or health information acquired online, just 36% of those with chronic disease share this sentiment. This phenomenon was found during research as well where many young patients found peer groups online, on Facebook and WhatsApp or influencers who shared the same illnesses as them on Instagram or YouTube. These peer groups helped the respondents in understanding their symptoms and learning about their treatments. These groups and influencers would also guide on alternative health practices, natural remedies and lifestyle changes for achieving a better quality of life.

On the other hand, people with autoimmune diseases are much more likely than the general internet population to report that their most recent online health-related search resulted in a change in their health care or how they care for another person. (Fox & Purcell, 2010, p. 67) Blogging and other forms of online health conversation stand out among those with chronic illnesses. The chronic disease makes a person far more likely to utilize the internet, all other things being equal. They could, for example, run a blog, participate in an online support group, or manage a mailing list to aid others in dealing with health or personal difficulties. The number of individuals participating in these activities is often relatively low, but those who do are typically quite enthused about the new perspectives they get. Patients who joined an online support group were better equipped to deal with the challenges of living with a chronic illness. They understood the condition better and learned that their symptoms were not imaginary.

When a person has access to the internet, having a chronic condition is associated with a greater likelihood of using user-generated health resources, such as blogs, hospital reviews, doctor reviews, and podcasts. This is particularly true for those who have internet access at home. With access to these tools, one can do in-depth research on a health-related topic and utilize the internet as a communications medium rather than simply a data dump. (Fox & Purcell, 2010, p. 67)

5.1.3. Role of Stressful Life Events on Autoimmune Patients

Although autoimmune illnesses vary clinically, epidemiologically, and physio-pathologically, they have a similar pathogenetic process that involves activating B and T cells due to immunological self-recognition. In addition, both physical and psychological stresses have been suggested as contributors. The stimulation of the neurological and endocrine systems has been shown in research conducted on human subjects to illustrate that stress affects immunological responses. Specifically, the connection between the active neuroendocrine and immune systems through hormone mediators, neurotransmitters, and cytokines may be a factor in developing autoimmune disorders. Doctors often link stress and autoimmune diseases. Stress has been linked to immune-based conditions, including infection, atopy, and asthma. Stress and autoimmune illnesses have also long been studied. Anxiety and its downstream neuroendocrine modifications may impact immune function, affecting autoimmunity and autoimmune disease. (Porcelli, et al., 2016, p. 325-334)

People disrupted by chronic conditions are more likely to have adverse outcomes due to stressful life events. Chronic illnesses last for an extended period and may significantly influence a person's quality of life. As a result, chronic diseases often call for continuing medical treatment and management. The symptoms of chronic illnesses may be made worse by stressful life events, and it can also be made more difficult for individuals to manage their ailments when these symptoms are present successfully. Stressful life events may influence persons with chronic illnesses in several ways, one of which is causing flare-ups of the symptoms of such diseases. For instance, those who suffer from autoimmune disorders like rheumatoid arthritis or lupus may have joint pain, exhaustion, and other symptoms if they are under a lot of pressure. This might make it more difficult for individuals to manage their diseases successfully, and it can also interfere with the activities they typically enjoy doing and the quality of their life. (Salleh, 2008, p. 9-18) During research it was similarly found that patients felt stressful events more intensely after their illness had struck and in some cases the illnesses showed face during stressful life events for them. In cases like Nida, Khawla, Shazia, and Almas their autoimmune issues showed face after or during stressful life events. For Nida it was COVID and Sciatica, for Khawalah it was difficulty adjusting to married life and miscarriages, for Shazia it was a difficult pregnancy and for Almas it was the same. Others, like Sumaira and Zunaira however found themselves in debilitating pains after minor events like, bead hitting the knee for Sumaira and walking back home in the rain for Zunaira. It was common for all respondents, however, to experience pain not just physical but emotional pain caused by their illnesses. They felt and expressed themselves to be emotionally traumatized by the paralysis their lives experienced due to the illness.

Stressful life events may make it more difficult for persons with chronic conditions to stick to the treatment programs laid out for them. (Muscatell, Slavich, Monroe, & Gotlib, 2009, p. 154-160) This was experienced by most of the respondents who felt the slow and sometimes unnoticeable progression of their treatments to be exhausting and would often times quit their treatment plans.

In addition to the adverse effects of stressful life events on a person's physical health, the exact circumstances can also substantially influence a person's mental health. In times of stress, people suffering from chronic illnesses may be more prone to anxiety, depression, or other mental health difficulties. These may further worsen their symptoms and make it more difficult for them to manage their conditions successfully. (Cohen, Murphy, & Prather, 2019, p. 577-597) All of the respondents experienced some kind of mental health issues before, during, and/or after their diagnosis. These mental health issues came not just internally but also due to their external environments which sometimes became too stressful to handle.

5.1.4 Role of Faith

Since the dawn of recorded history, all human populations have shared a connection between religion, medicine, and healthcare. These therapeutic modalities were combined for a long time until recently. The history of religion, medicine, and healthcare in Western industrialized nations is intriguing. (Koenig, 2012, p. 33) A woman's struggle against an autoimmune illness may be fraught with hardship and difficulty. The autoimmune illness causes several types of tiredness. Some signs of an autoimmune illness include persistent tiredness, discomfort, and inflammation. Fatigue is complex and generally characterized, making its origins in particular autoimmune illnesses challenging. Fatigue is characterized by chronic weariness and incapacity to accomplish tasks. The degree of functional impairment and other factors may be used to classify fatigue. These changes may be connected to the condition's afflicted tissues/organs, cell types, brain regions, and molecular and physiological pathways. These symptoms may tax a woman's body and mind, making it hard for her to have a happy attitude. (Zielinski, Systrom, & Rose, 2019)

Religion has always dealt with life, death, and suffering. Life is a holy gift in many faiths. Religion addresses daily life as well as the darker side of human existence. At the same time, faith's promise to help humanity deal with sorrow and death is one of its most enticing qualities. People seek to avoid, alleviate, and accept pain and death. People have prayed to divine powers when faced with starvation, human violence, pestilence, and illness. Faith in a higher power may be a massive blessing in helping people face and overcome these obstacles. Faith, for many, is a source of strength and meaning in the face of adversity, especially while coping with a long-term medical condition. If someone has faith, they trust that everything occurs for a purpose and that there is a greater force in the universe. (Cummings & Pargament, 2010, p. 28-53) If someone suffers from a chronic disease, knowing that their hardships are meaningful and integral to a more excellent plan may be a tremendous source of solace. Religion may give women community, belonging, hope, and life purpose. When a person has faith, they typically feel connected to other believers. (Villani, Sorgente, Iannello, & Antonietti, 2019) If a woman suffers from a chronic disease, having support from others may make a world of difference in her ability to cope. Connected people are more inclined to ask for and accept assistance when needed, especially when managing a chronic condition. The significance and perspective provided by one's faith may be invaluable for anybody living with a long-term condition. When someone has faith, they are more likely to think their hardships are working for the greater good. When coping with a chronic disease, this may benefit women immensely by giving them a sense of purpose and helping them to see their hardships in the context of a more significant journey. Furthermore, religion may give women a sense of perspective that might aid them in gaining a new understanding of their difficulties. One of the hallmarks of a person of faith is a conviction that their existence has a spiritual dimension beyond the mere material. Suppose women with chronic illnesses can put their hardships in a broader perspective and discover acceptance and serenity. In that case, it may affect how they cope with their condition. (Arrey, Bilsen, Lacor, & Deschepper, 2016) Respondents during research had different views of their illnesses; some viewed it as a divine test, others saw it as a product of lifestyle issues, while others just saw it as a part of life.

In conclusion, women's religion may be a powerful resource in the fight against autoimmune illnesses. When coping with a chronic disease, having a feeling of hope, purpose, connection to others, meaning, and perspective is beneficial. Faith may not be able to reverse the effects of autoimmunity, but it may be a beneficial resource for managing the symptoms.

5.2. Youth and Autoimmune Disease

Autoimmune disease develops when the immune reaction destroys tissues in the body and is characterized by the affected organ, tissue, or system. The condition may appear in the second decade of life but peaks in the third to sixth. Infectious agents and environmental factors are the most prevalent causes. ADs are chronic, start at a young age, and have palliative treatments. Thus, they are a substantial personal and financial burden to people and their families. Approximately 3% to 8% of Americans have autoimmune diseases (ADs), a diverse group of 70 to 80 inflammatory conditions. The frequency of autoimmune disease (14.7 to 23.5 million persons) is rising. (Dube, et al., 2009, p. 243–250)

Young people with autoimmune disorders may struggle not just with the physical manifestations of their illness but also with their condition's psychological and social effects. For instance, they may feel isolated or different from their peers due to the symptoms they are experiencing or the therapy they must undergo. As a result of their disease, they could also suffer feelings of worry or sadness. (Oliveira Ribas, Ribeiro, Nunes Cat, & França, 2021, p. 1-6) Illness in general can cause alienation for the individual suffering from the said illness. Like when someone catches the flu, people tend to avoid them. Almas had similar experiences with her vitiligo, where people outside her circle would refrain from sitting next to her, avoid touching her or sharing a space with her. This causes a form of alienation as also discussed by Ervin Zola (Williams, 1996). For others among the respondents, as most were diagnosed in their younger years the alienation came from family, friends, and health care providers. Shazia, for example, felt alienated by her children and family who, according to her, did not understand her pain. This was common among all other respondents as well, they felt like they were ostracized for skipping events and setting boundaries due to their illnesses.

Young individuals with autoimmune disorders may have emotional and social repercussions if they do not take proper care of their health and the medical ramifications of not taking care of their health. For instance, because of their symptoms or therapy needs, individuals may experience isolation or be different from their social circle. This might result in feelings of isolation, despair, or anxiety, which can negatively influence the individual's general health and well-being. In addition, if young individuals with autoimmune disorders do not care for their health, they may be at extreme risk for problems connected to their condition. They may, for instance, be more prone to infections, which may be especially hazardous for those whose immune systems are already compromised. (Dube, et al., 2009, p. 243–250) This was seen during research as well, where respondents found themselves finding it difficult to manage an active youthful life filled with experiences, mistakes, and carefree days. Most young respondents felt like they had to start taking care of their health earlier than their peers, which was both a blessing and a difficult task.

5.3. Female Experiences During Fertility

Due to gender differences in immunological response, a study suggests that 80% of autoimmune patients are women. Women produce more antibodies than males in response to illness, immunization, or trauma. Glucocorticoids reduce cell-based Th1-type immunity in response to severe stress, which may explain differences in gender in autoimmune disease. Females' glucocorticoid levels are transcriptionally increased by estrogen, whereas males' levels are decreased by testosterone. (Dube, et al., 2009, p. 243–250)

Autoimmune illnesses can potentially adversely affect women throughout their fertile years. The most prevalent autoimmune disorder that may affect fertility and it can impair women's reproductive health. One of the most well-known autoimmune illnesses is lupus, which affects women more often than males. Lupus is one of the most well-known autoimmune disorders. Lupus can potentially have a wide-ranging impact on the women's body's organs and tissues, including skin, joints, and internal organs. Joint pain, rashes, and weariness are some of the more typical symptoms that may be caused by lupus in women. Lupus can also produce a variety of other symptoms. It is possible that having lupus may affect a woman's ability to become pregnant and increase the likelihood that she'll have complications throughout her pregnancy. Both of these aspects of a woman's fertility can be affected by the disease. For instance, women who suffer from lupus may have an increased chance of having a miscarriage, giving birth prematurely, and developing hypertension. Rheumatoid arthritis (RA) is another autoimmune condition that may affect a woman's ability to conceive. Rheumatoid arthritis (RA) is a long-lasting inflammatory condition primarily affecting the joints. In addition to weariness and maybe other symptoms, rheumatoid arthritis (RA) can cause women to have pain, stiffness in their joints, and swelling. (Tabarkiewicz, Selvan, & Cools, 2018, p. 3)

Autoimmune disease may have many different effects on a woman's fertility in various ways. Autoimmune disorders may make it more challenging for women to conceive a child, putting them at a greater risk of experiencing difficulties while pregnant. Regarding a woman's capacity to create a child and her likelihood of experiencing problems during pregnancy, Rheumatoid arthritis (RA) may negatively influence both aspects of a woman's fertility. Women with Rheumatoid arthritis (RA), for instance, may have more chances of having a premature delivery and a baby with low birth weight. In addition to rheumatoid arthritis (RA), there are a significant number of other autoimmune disorders that may have an effect on a woman's fertility. For instance, women with celiac disease may have difficulty conceiving children and have an increased chance of miscarrying existing pregnancies. (Tabarkiewicz, Selvan, & Cools, 2018, p. 3)

Hormonal and physical changes occur in females during pregnancy and last at least one year after that. Changes like this cause autoimmune disorders. Pregnancy causes physiological changes such as weight growth, higher basal metabolic rate, and lipid levels. Pregnancy alters hormone levels such as estriol, progesterone, and prolactin. The mother's immune system is suppressed by the fetus's foreign antigens. This reduces fetal rejection but suppresses the immune system, possibly leading to autoimmune illnesses. Post-partum hormonal changes might raise the risk of inflammatory diseases like rheumatoid arthritis. In the 24 months following birth, rheumatoid arthritis increases by 1:7. Rheumatoid arthritis and SLE afflict more women over 40. (Pillay, Catherine, Tolppanen, Mebazaa, & Tolppanen, 2016, p. 89-94)

Several autoimmune illnesses have been connected to unfavorable results in reproductive health. Even before an autoimmune condition emerges clinically, researchers have shown that women with autoimmune disorders have a lower fertility rate than those with no autoimmune disease. In addition, women with autoimmune illnesses have a higher risk of experiencing infertility, recurrent pregnancy loss, and other obstetric issues such as premature birth; however, the processes by which these ailments may affect reproduction are not well known. Given that autoimmune diseases may harm reproduction and tend to run in families, there is a need to understand whether a family history of autoimmunity imparts a greater risk of poor reproductive outcomes. This is because family members of individuals with autoimmune disease may be more likely to exhibit abnormal immunologic features, have a subclinical autoimmune disease, or have an overt autoimmune disease that has not yet been diagnosed. (Plowden et al., 2020, p. 5)

5.4. Life in Laboratories

Examination of patients for suspected autoimmune diseases is complex due to the absence of a straightforward diagnostic laboratory test. Examples of tests under this category include blood tests, metabolic panels, and biopsies. The tests might be used to check for particular antibodies or other signs of inflammation or disease activity, although this depends on the autoimmune illness being investigated. The results of these examinations may lighten the prognosis of a patient with an autoimmune disease or reveal the extent to which a particular organ has been damaged. (Castro & Gourley, 2010, p. 238-247)

The diagnosis and treatment of autoimmune diseases may be difficult at times, and this is especially true for female patients. In developing autoimmune disorders, women have a higher risk than men and sometimes have to wait longer for a diagnosis than men. This may be very aggravating and challenging since many autoimmune diseases can produce symptoms that can be difficult to assign to one particular issue. (Blum, 2022) A woman with an autoimmune disorder may undergo several diagnostic procedures before her condition is appropriately identified and treated. Women with autoimmune diseases may have a rich hospital and laboratory history besides the tests. They may consult with various medical professionals, such as rheumatologists, endocrinologists, and gynecologists. It might be difficult and unpleasant for them to deal with the insurance and billing processes. (Castro & Gourley, 2010, p. 238-247)

There are several autoimmune diseases, and 20% of the world's population has at least one. Women are disproportionately impacted by more than a hundred distinct autoimmune illnesses. Over 80% of those who suffer from an autoimmune disease are women. Sjogren's syndrome is a form of autoimmune disease characterized by the inability to produce enough tears and saliva, leading to persistent dryness of the eyes and mouth. It is nine times more common in women than in men. (Angum, Khan, Kaler, Siddiqui, & Hussain, 2020, p. 10)

Women who suffer from autoimmune diseases may have a variety of exposure to clinical and research settings. Because of the complexity of diagnosing and treating individual conditions, it is essential to collaborate with a healthcare physician who has experience with your specific issue. Healthcare practitioners may learn a lot about the course of the illness and its effects on a patient's life from the order in which events occur in the medical records of patients with autoimmune disorders. The development of symptoms, when a diagnosis is made, and how well a patient responds to therapy are all examples of such life events. (Angum, Khan, Kaler, Siddiqui, & Hussain, 2020, p. 10)

A chronology of life events, as documented in medical reports of women with autoimmune disorders, may be an effective tool for healthcare practitioners to assess the disease's evolution and its effect on the patient's life. These life events might encompass a range of elements, including the beginning of symptoms, the timing of diagnosis, and the patient's reaction to therapy, among others. When women with autoimmune disorders go to the doctor, they may have to go through several different testing and diagnostic procedures for the doctors to discover the underlying source of their symptoms. Blood tests, imaging investigations, and biopsy procedures are a few instances of what could fall under this category of examinations.

In general, the chronology of life events documented in medical reports of women with autoimmune disorders may be a valuable tool in understanding the disease's evolution and influence on the patient's life. Women who suffer from autoimmune disorders can have the best possible care and therapy provided for them if they collaborate with a healthcare professional who is familiar with their condition and has access to their medical data. (Kronzer, Bridges, & Davis, 2021, p. 629-633)

5.5. CSM Sense Making

The CSM framework is a way of thinking about healthcare that prioritizes freedom of communication and cooperation between patients and medical professionals. Patients are the foremost authorities on their conditions, and this paradigm acknowledges the importance of considering patients' views and viewpoints when making healthcare choices. The CSM framework assumes that good communication is crucial to grasping complicated topics because it is how individuals construct meaning about their reality. This framework has several applications, such as in times of crisis, during negotiations, and while implementing structural changes in an organization. The CSM framework stresses the need for open dialogue, attentive listening, and teamwork to understand complex problems. It's a helpful resource for anybody attempting to understand complex issues and the world. (Castle, 2015) Women with autoimmune disorders may find the CSM (Communication and Sensemaking) helpful framework. Diseases of the immune system are chronic disorders that may produce various symptoms. As a result, it may be difficult for women to have a happy attitude while experiencing these symptoms. The CSM framework is helpful for women with autoimmune disorders since it accounts for their specific struggles. Women with these disorders typically struggle between the time and energy required to manage their symptoms and their obligations to work, family, and other commitments. They may also have to deal with prejudice and stigma because of their illnesses. Women living with an autoimmune condition might benefit from the CSM framework as they try to make sense of their experiences and develop coping mechanisms. The CSM framework is predicated on the premise that communication is how we interpret our environment. The CSM framework recognizes the significance of clear communication, active listening, and cooperation in making sense of complicated challenges and bases its recommendations on these tenets. The CSM framework supports several important outcomes for women with autoimmune illnesses. (Mamykina, Smaldone, & Bakken, 2015, p. 406-417)

By focusing on open lines of communication and teamwork, this method acknowledges the specific difficulties these women experience. There are several ways in which the CSM framework might aid women dealing with autoimmune disorders. It stresses the need for healthcare practitioners to actively engage with patients to learn about their needs and goals and then craft an individual treatment strategy together. This may aid in giving each patient the individualized attention they need. The CSM framework also acknowledges the value of emotional support for patients with chronic diseases. Due to their illnesses, women suffering from autoimmune disorders are at increased risk for developing anxiety, depression, and other mental health issues. The CSM framework recommends that medical professionals talk to their patients about these problems and provide them with coping mechanisms, including information and emotional support. Third, the CSM framework stresses the value of patient education and autonomy. Some women with autoimmune disorders may feel lost when confronted with the plethora of therapy choices and the intricacy of their symptoms. Using the CSM framework, medical professionals are urged to educate patients about their problems and invite them to participate in treatment choices.

Finally, the CSM framework acknowledges the value of social networks in helping those with long-term illnesses. Having supportive relationships with other women also dealing with autoimmune disorders might be helpful. The CSM framework strongly urges providers to direct their patients toward available support groups and other avenues for gaining a sense of community and control over their health and well-being. Overall, the CSM framework has the potential to be a helpful resource for helping women who are dealing with autoimmune disorders (Mamykina, Smaldone, & Bakken, 2015, p. 406-417).

CHAPTER 6

6. SUMMARY AND CONCLUSION

Autoimmune diseases are chronic conditions characterized by an abnormal immune system response targeting organs or tissues. Females have a higher susceptibility to some conditions due to their two X chromosomes, leading to a duplication of genes on the X chromosome. Chronic illnesses can persist for an extended period, leading to feelings of isolation and marginalization. This study aims to examine the personal accounts of women diagnosed with chronic or moderate autoimmune diseases using sickness narratives. The research employs theoretical frameworks such as Communicated Sense Making (CSM) and Memorable Messages to gain insight into the experienced reality of women diagnosed with autoimmune illnesses.

Arthur Kleinman's book "Illness Narratives" emphasizes the importance of understanding the cultural and personal meanings of an illness to shape an individual's experience and response to treatment. Marian Burchardt's framework for analyzing illness narratives consists of three key elements: the illness story, illness identity, and illness biography. By analyzing these three elements, researchers can gain a deeper understanding of how individuals make sense of their illness and how it shapes their lives. Existentialism, a philosophy emphasizing the individual's freedom, choice, and responsibility for their existence and the meaning of their life, can be applied to the study of illness narratives. Albert Piette, a French anthropologist, argues that existential anthropology emphasizes the individual's subjective experience of the world and Heidegger's concept of "Dasein," which refers to the unique way an individual exists in the world. The sick role theory, developed by Talcott Parsons in 1951, is a sociological model that explains how individuals with illnesses behave within society and interact with the healthcare system. It has been widely studied and applied in medical sociology, with authors like Conrad, Zola, and Kleinman contributing to the field.

Autoimmune diseases are characterized by their chronic nature, where the immune system generates antibodies that target and destruct healthy bodily tissues, posing challenges in diagnosis. There are over eighty autoimmune disorders, with symptoms such as weariness, joint discomfort, fever, dizziness, and cyclical exacerbations of heightened disease activity. These illnesses result in negative physical and emotional consequences, disruptions in identity and relationships, and necessitates a reassessment of personal priorities, values, and belief systems. Diagnosing autoimmune diseases is challenging due to lack of clear criteria, healthcare provider understanding, and prevalence in women. The existing body of research on vulnerability within the healthcare sector highlights many facets of this phenomenon. Depression is a common co-occurring condition in individuals with autoimmune diseases, which causes the immune system to mistakenly attack healthy cells. Memorable messages are impactful verbal messages that shape individuals' identity, values, beliefs, and behaviors. Research on memorable messages in long-term difficulty and illness has mainly focused on breast cancer prevention and detection behaviors. Understanding these messages is crucial for health professionals in long-term illness prevention and detection outreach.

The research focused on illness narratives of women with diagnosis of autoimmune diseases with the prime focus on the subjective experiences of these patients. The narratives revolved around the patients’ own understanding of their illness, the treatment, stigmatization, vulnerabilities, and realities within the realm of their own subjective reality. With some input from particular family members or caretakers of these patients. The research focused on oral accounts of events, diagnosis and treatments in addition to blood test results, x-rays, and the doctor’s prescriptions that the patients shared with the researcher. Methodologically speaking, the research was conducted exclusively in the interpretivist paradigm using qualitative measures focusing on narrative studies and oral histories. Purposive sampling was used to select a set of candidates for narrating illness narratives of autoimmune patients while others were generally added into the research understanding.

The research explored the experiential realities of female autoimmune patients and how they experienced their illnesses throughout the process of pre-diagnosis, diagnosis and post-diagnosis. These experiences revolved around physical spaces such clinics, hospitals and homes; in non-physical spaces such as doctor-patient relationships family relationships, friendships, the internet and most importantly the ‘self’. The researcher learned that wealth, access to the internet, stressful life events, faith and faith-based communities, youth, and challenges with fertility all shaped the nature and intensity of the patients’ experiences. They live a life in laboratories and have their stories attached to each test result and each prescription. There are memorable messages all around them which shape the way they (patients) see themselves as individuals and as functioning or dysfunctional people. In its essence the research discovered that there is the ‘disease’ in its bio-medical form affecting the molecular structure of the individuals’ body and then there is the ‘illness’ which goes beyond the chemicals and the molecules and exists in the social structures. The disease becomes harrowing if the patient finds their relationships failing them or if they feel misunderstood by their health care professionals and family. Treatment of the illness becomes not just taking medicines but also in creating a supportive and loving environment for the patient.

6.1 Limitations and Recommendations

All research has limits, and this particular research is limited to the patients personal experiences. Research focused on all the participants of an illness, that being the patients, their loved ones and the health care professionals would present a better picture of autoimmune illnesses and how they affect people and how they can be treated better. The research also focused on only the female patients because women are more prone to these conditions, but it does occur in men also and would be interesting to learn the male experience and how if differs with the female experience. The researcher would recommend future research done in this domain to also include longitudinal study on these patients following them as they experience their illness in real time.

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8. ANNEXURE

8.1 Glossary

Qameez: Long shirt worn most.

Danzen: A type of medicine that is used to reduce pain and inflammation in conditions in rheumatoid arthritis, ankylosing spondylitis, and osteoarthritis.

Demard: Disease-modifying anti-rheumatic drugs

Deltacortril: Deltacortril Enteric is used in the treatment of allergic and inflammatory disease and immune reactions.

PRP Therapy: Platelet-rich plasma therapy uses injections of a concentration of a patient's own platelets to accelerate the healing of injured tendons, ligaments, muscles, and joints.

Lefora Tablet: LefOra Tablet is used in the treatment of rheumatoid arthritis and psoriatic arthritis.

Omega 3: Omega-3 fatty acids help your heart in several ways. They curb inflammation in the blood vessels (and the rest of your body). At high doses they also make abnormal heart rhythms less likely and lower your level of blood fats called triglycerides.

Hadees: Hadith, Arabic Ḥadīth (“News” or “Story”), corpus of the sayings or traditions of the Prophet Muhammad, revered by Muslims as a major source of religious law and more guidance. It comprises many reports of varying length and authenticity. The individual reports are also called hadith (plural: hadiths)

Roti: Round flatbread common in South Asia

Hiatal hernia: Another digestive tract condition

Sciatica: Sciatica occurs when the sciatic nerve becomes pinched. The cause is usually herniated disk in the spine or an overgrowth of bone, sometimes called bone spur, form on the spinal bones.

Malabsorption: Malabsorption refers to impaired nutrient absorption at any point where nutrients are absorbed, and maldigestion refers to impaired nutrient digestion with intestinal lumen or at the brush border.

Celiac: Celiac disease is a chronic digestive and immune disorder that damages the small intestine.

Bichari kha nhi sakti: Poor girl, can’t eat.

Hashimoto disease: An autoimmune disease. It occurs when your body makes antibodies that attack the cells in your thyroid.

PCOS: PCOS is a very common hormone problem for women of childbearing age. Women with PCOS may not ovulate, have high levels of androgens, and have many small cysts on the Ovaries.

Hypothyroidism: It is an autoimmune condition where thyroid gland produces thyroid hormone. In such low amount that it remains unable to meet energy needed for normal functioning of body organs.

Khala: Mother’s sister

Maida: Refined wheat flour

Namaz: A worship performed by Muslims.

Hijama: An ancient, holistic method for the treatment of a variety of diseases.

Iss ko bs adat hai haye haye krny ki: She has made whining her habit.

Haddi jor: Chiropractor/physiotherapist

Maalishi: Masseuse/orthopaedic

Bhabhi: Sister-in-law

Tum achi ho tum chali jao, aur tum chali jao gi: You are nice, you should leave, and you will leave.

Exploring Illness Narratives

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