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Communicating the Invisible: Communicated Sense-Making (CSM) and the Relational Burden of Autoimmune Illness

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ABSTRACT

Objective: *The main goal of this study is to explore how women in Karachi, Pakistan, perceive relational barriers as they attempt to define and communicate their invisible autoimmune illness with family, friends and health care providers; utilizing Communicated Sense Making (CSM) and Memorable Messages (MMs) to provide insight into these perceived barriers.*

Methods: *Through a qualitative approach, Illness Narratives of women in Karachi, Pakistan were taken. By employing Communicated Sense Making (CSM) and Memorable Messages (MMs) to assess the barriers that existed for participants in articulating their illnesses to others; seven out of twenty respondents were selected through purposive sampling as case studies.*

Results: *The findings supported the notion that although some initial support was evident, it declined over time leaving many of the participants feeling socially isolated and rejected. In addition, it was found that when the participant's invisible suffering failed to be made visible as a result of futile attempts at sense making, it resulted in increased psychological distress.*

Conclusion: *Due to the erratic and often invisible nature of their symptoms, autoimmune diseases create significant relational burdens for those who have them. As they struggle to receive recognition for their suffering as humans, and not simply as patients or sick people. While effective communication and intentional support can be seen as mere addons to medical care, they are critical in lessening the psychosocial trauma experienced by those living with a chronic and invisible illness.*

Keywords: *Autoimmunity, Communicated Sense Making, Invisible, Memorable Messages*

INTRODUCTION

The process of autoimmunity occurs when the host's immune system mistakenly attacks healthy cells and causes both localized and systemic damage to the body. Due to the presence of specific genes, autoimmune conditions disproportionately impact women. Medical literature tends to focus on the biological aspects of these conditions, creating a mystery surrounding the psychological and social traumas experienced by the patient (Angum et al., 2020). The major obstacle for women who suffer from autoimmune conditions is the fact that they do not have visible evidence of their most debilitating symptoms (e.g. fatigue, pain, cognitive dysfunction) because these symptoms cannot be measured using the same methods as those used for measuring the effects of an injury or disease that is apparent through visual means (e.g. a plaster cast, visible lesions) (Dobson, 2021). This lack of measurable evidence forces patients to perform extensive amounts of credibility work to prove to clinicians and relational others that they are indeed experiencing suffering (Samulowitz et al., 2018).

Conditions that result in chronic illness but that lack clear visual indications of the condition are referred to as "invisible disabilities." When an individual has an invisible disability, they will often face social and personal conflicts related to their visibility to others and their own perceptions of self. Clinicians and society tend to operate based upon the assumption that "what you see is what you believe" (Dobson, 2021); therefore, they are less likely to provide sufficient or equitable support to patients whose symptoms are difficult to recognize. Individuals with autoimmune conditions are at a greater risk of developing depression than is the general population (Pryce & Fontana, 2016). Several theories exist regarding why there is an increased prevalence of depression among individuals with autoimmune conditions. Chronic inflammation and chronic pain that occur as a result of the autoimmune condition may create feelings of hopelessness in the individual these feelings may ultimately contribute to the development of depression (Euesden et al., 2017). In addition to the feelings created by chronic pain, the physical limitations and social isolation that occur as a result of having an autoimmune condition may also contribute to the development of depression (Euesden et al., 2017).

The Communicating Sense Making (CSM) is a theoretical model developed by (Kellas & Horstman, 2015) that gives a framework for how individuals process and interpret difficulty, identity, and relationships through communication. The CSM identifies six devices for communicating sense-making which include: accounts, attributions, communicated narrative sense-making, metaphors, memorable messages, and communicated perspective-taking. All six devices provide means for understanding the way in which communication plays a significant role in making sense of the difficulties of "confusing, complex or difficult situations and experiences such as mental health and illness" (Kellas, 2018). That is why CSM provides a relevant framework for analysing the illness narratives and memorable messages of people who are trying to navigate the difficulties caused by autoimmune disease. A study conducted by (Joyce & Jeske, 2020) identified a common metaphor that was employed by patients to communicate their illness experience using war-related language (i.e. attack, battle, fight, kill), which resulted in their invisible illness being perceived as more understandable and relatable 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 (J. Gunning, 2021).

RESEARCH METHODOLOGY

The work on which this paper is based, uses qualitative data from an ethnographic study of the lived experiences of women with autoimmune diseases in Karachi, Pakistan.

Study Design and Participants

Narrative inquiry methodology using the interpretivist paradigm were used to provide emphasis to the subjective world and the socially constructed nature of reality (Pervin & Mokhtar, 2022). The purposeful sampling technique was used to select seven in-depth case studies from a sample of twenty participants selected due to their unique illness narratives.

Data Collection and Analysis

In-depth interviews over a period of six months provided the data for research. An analytical framework of Communicated Sense Making (CSM) and Memorable Messages (MMs) were used to analyse the data. CSM provides a framework for understanding how people process and make sense of difficulty through communication (Leventhal et al., 2016). MMs refer to short, impact-full verbal or non-verbal messages that are recalled over long periods of time and shape identity, beliefs and behaviour about health (CookeJackson & Rubinsky, 2016). Coding of narrative texts, for recurring themes such as communication devices, relational experiences, and the construction of illness identity, were used for analysis.

RESULTS The Phenomenology of Invisible Pain

Depression caused by changes in brain chemistry from an autoimmune disease can be exacerbated further by the stress and emotional burdens of living with a chronic illness (Morris et al., 2015). Depression can exacerbate the symptoms of an autoimmune disease and hinder a person's ability to manage their chronic illness. Therefore, individuals who live with autoimmune diseases must develop comprehensive treatment plans that treat all aspects of their illness, both physical and emotional (Pryce & Fontana, 2016).

One of the most significant challenges women face when they experience Autoimmune Diseases is the "invisibility" of their symptoms. Symptoms of many autoimmune diseases include internal symptoms, i.e., extreme fatigue; pervasive joint pain; and/or psychological distress without the presence of empirically measurable, external evidence, or external indicators of treatments (i.e., chemotherapy). The social recognition of suffering is impacted significantly by the invisibility of these symptoms (Bosco et al., 2025). A respondent shared this challenge, explaining that she felt she had an "invisible handicap situation" compared to visibly ill people, forcing her friends to assume she was "making excuses" when she cancelled plans. She said,

> “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.”

As a result of this invisible suffering, the patient is always carrying the "burden of proof". Due to the reliance on the phrase "seeing is believing" from external observers (i.e., family members; friends; employers; etc.) women often have to continually use emotionally taxing efforts to validate their pain (Firm, 2024). One respondent experienced the ultimate violation of privacy when her school principal demanded she come to work despite a severe flare-up. To justify her absence, she begrudgingly sent a photograph of her painful back, covered up in rashes, illustrating the extent to which women must physically bare their hidden suffering to acquire basic credibility.

She stated, “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... 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. In this condition my principal was forcing me to come to school at all costs. So, I 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?”

This constant need to validate their pain increases feelings of isolation, loneliness, and rejection, especially in cases where relationships do not withstand the chronic nature of the condition. When pain is rejected either clinically or socially, it adds to the physical burden of the condition with relational trauma. In order to facilitate the translation of their internally experienced disruptions into a form that is understandable to external observers, patients must utilize various forms of communication that are studied within the Communicated Sense-Making (CSM) framework, specifically through the use of metaphors (Nicola et al., 2022).

Illness as an Alienation

Irving Zola, a medical sociologist, described illness as an alienation process. He said that when someone gets sick, they can become disassociated from themselves, from other people, and from society as a whole. He felt that being ill could break down interpersonal relationships and cause the person to feel socially disconnected from the world around them. Zola also considered illness as a means of social oppression, through the mechanisms of stigmatizing and excluding individuals who were ill from society. Additionally, he believed that the medical establishment contributes to this alienation by viewing patients as passive recipients of medical care, as opposed to the active participants in their own medical care (Williams, 2008).

In his book, "Illness as a Metaphor," Zola stated that many illnesses, including autoimmune disease, have a number of cultural and social meanings associated with them. For example, he states that diseases such as tuberculosis, cancer, etc. are often used as metaphors for social and/or psychological problems, thus giving the illnesses' cultural and political interpretations that may affect the quality of life of the people who suffer from them. In the case of autoimmune diseases, Zola stated that due to the fact that they are often difficult to understand, and are therefore often misunderstood by others, and therefore stigmatized (Williams, 2008).

Using the CSM framework helps us see the critical relationship between a lack of effective communication and the loss of a patient's ability to act independently. Zola stated that illness is a source of alienation (Williams, 2008). When a woman tries to share her story, but instead receives responses such as "it's just stress" or "you're too unhappy," as were statements that my respondents received, she has had her identity as an ill person delegitimized (Gray, 2018). One of the respondents said,

“I used to think that he (husband) doesn’t take my pain seriously because when my tests used to come out normal, he would say that the pain is all because I don’t try to remain happy. As if my pain was in my control.”

The stigma associated with having an autoimmune disease can create a sense of alienation and isolation from others, which can increase the physical and emotional symptoms of the condition. Zola discussed the influence that cultural factors can have on how researchers and medical professionals develop a greater understanding of autoimmune diseases. He stated that there is a need for a more complex and culturally sensitive understanding of autoimmune disease (Williams, 2008).

As an example of how diseases have been used as metaphors for various social, political, and psychological issues, he pointed out several examples. Tuberculosis was used as a metaphor for moral decay during the Victorian era, as a result of the emphasis placed on sex and hygiene during this time. Cancer was used as a metaphor for environmental pollution, representing the fear of industrialization and the effects that it had on the public health (Dickon & Gonzalez, 2019). Mental illness was used as a metaphor for social and political dissent during times of war, as a result of the fear that dissent represented to the established order. AIDS was used as a metaphor for the perceived moral decay of homosexuals and drug users, as a result of the prejudices against these marginalized groups. This showed how these metaphors contributed to the development of negative stereotypes and justified the exclusion of people with these diseases from society, and can isolate people with these diseases (Armoon et al., 2022).

The most common form of dismissal is unconscious and is based on gender bias and the tendency of clinicians to believe that a woman's suffering is caused psychologically rather than physically (Samulowitz et al., 2018). To continually perform in order to prove that you are sick, is emotionally taxing and increases the anxiety and depression that is already associated with chronic inflammation. The CSM model provides a basis for this type of situation because it emphasizes the importance of an open dialogue and encourages health care practitioners (HCPs) to recognize and respect the patient's voice (Milaneschi et al., 2021).

Memorable Messages and Identity Ambiguity

Social influences impact how women perceive their bodies and themselves. It can affect how they develop their identities, and how much agency they believe they have in the context of both medical practitioners and the environment in which these interactions occur. 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 & Rubinsky, 2023). 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 (J. N. Gunning et al., 2020). 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 (J. Gunning, 2021). A study by (Cooke-Jackson & Rubinsky, 2023) 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.

The process of navigating illness and constructing a new identity is heavily influenced by "Memorable Messages" highly impactful verbal communications received from significant relational others, including family and HCPs. These messages directly shape the patient's self-concept, beliefs about their body, and subsequent health behaviors (Baiocchi-Wagner & Talley, 2013). Negative MMs, unfortunately, are common in many women's lives. A woman I interviewed said that her relatives continued to judge her negatively. They implied she was exaggerating the severity of her pain and manipulating others for sympathy. "She has developed whining as a habit", (*Is ko bus aadat hai haye haye krny ki*), they said. These types of MMs contribute to social disbelief and exacerbate the patient's psychological problems. Additionally, while families and friends typically come to support during crises (acute episodes or hospitalizations), this support will eventually "fade over time" (Rosland et al., 2012) as the patient learns to live with the illness. In this regard, the respondent noted that her children had been very helpful during times when she was extremely ill and fearful of dying, however, once she recovered, they thought she was "fine again", returned to their normal routines and did not appreciate the ongoing psychological cost of her condition. This realization that even her children would ultimately limit their empathy caused her to pray for death with "*the integrity to protect me from the humiliation of having to depend on someone*". Conversely, positive MMs may enable patient agency and help form a resilient identity that refuses to allow the disease to determine what she accomplishes personally. For example, one respondent reported that her cousin told her "*If you cannot move your legs then at least move your fingers and write*." This message empowered the respondent to continue writing despite her inability to walk.

DISCUSSION AND ANALYSIS

One common experience reported by individuals experiencing an autoimmune disease is a sense of being alone with their illness. Many report that initial support from family and friends dissipates over time. It is also common for individuals to report a lack of understanding from those around them regarding the individual's experiences, as well as a reluctance to educate themselves about the individual's disease. This can result in feelings of rejection, and ultimately in increased feelings of isolation and loneliness (Miller, 2023). Additionally, low self-esteem, sadness, and depression are all common emotional responses to the chronic stress of an autoimmune disease. Up to 50% of patients with autoimmune diseases show impaired health related quality of life and exhibit depression like symptoms (Pryce & Fontana, 2016).

Absence of support from their immediate social circle, patients are forced to rely on alternative forms of support, i.e. online forums, Facebook groups, etc., and support groups. Online communities offer opportunities for shared communicative sense making and allow patients to communicate with others who share similar struggles with invisible illnesses. The peer network provides validation of Memorable Messages, mitigates the effects of isolation and provides practical ways to cope with the illness; ways that healthcare providers do not always provide (Armoon et al., 2022). The CSM framework clearly advocates that healthcare providers refer their patients to available support groups and additional sources of community and control (Chung, 2014). The CSM framework clearly outlines the steps to overcome the relationship burden. Healthcare providers can promote patient education and autonomy to transition the patient from a passive, distrusted recipient of care (as described by Zola) to an active, informed participant (Williams, 2008). The CSM model states that healthcare providers will provide patients with means of coping; namely, information and emotional support (Annelie J et al., 2025).

CONCLUSION

The stories of women in Karachi demonstrate that a chronic and invisible autoimmune disease is fundamentally a communication crisis. The loss of support systems combined with the negative memorable messages from social and medical interactions, result in extreme social isolation and significant mental distress. Through the use of the Communicated Sense Making (CSM) framework, this study illustrates the necessity of a systematic approach to the communication provided by healthcare providers, requiring greater empathy, sustained emotional support and the referral of patients to peer based support networks. Communication needs to be collaborative, integrating the patient's subjective understanding (illness story) and the biomedical facts (disease description). Failure to engage in a patient centred communication model contributes to the persistence of higher rates of anxiety and depression (Ee et al., 2020). Finally, to manage an invisible illness, the disease must be visible, and it is through purposeful and respectful communication that the emotional and relational burden on women can begin to be relieved.

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