THE PSYCHOSOCIAL IMPACT OF RECEIVING AND COPING WITH A CHRONIC
ILLNESS DIAGNOSIS AMONGST YOUNG ADULTS

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ILLNESS DIAGNOSIS AMONGST YOUNG ADULTS

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TITLE: The Psychosocial Impact of Receiving and Coping with a Chronic Illness Diagnosis

Amongst Young Adults

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ABSTRACT

The psychosocial implications of chronic illnesses (CIs) are an apparent issue as exemplified through the extensive literature put forth on the matter. However, the primary focus of this literature is typically the aging population, and researchers have given less consideration to the experiences of youth. At this point in their life, young adults are already experiencing self-discovery, pursuing anticipated milestones, and defining one's worth/purpose, therefore, being diagnosed and living with a CI only complicates these matters. Investigating how CIs impact young adults' mental health (MH) is imperative when trying to understand the various intersecting forces that influence one's ability to achieve optimal health and well being. This research explores the psychosocial effect of receiving a CI diagnosis using a qualitative, interpretive phenomenological approach (Van Menen's viewpoint) in which 12 semi-structured interviews were conducted with university students. Interviews were recorded and transcribed for thematic analysis. Findings indicate that the onset of CIs among young adults adds/perpetuates various types of psychosocial distress, ultimately impacting one's MH based on their exposure towards such stressors and ability to cope. Irrespective of individualized experiences, all participants unilaterally echoed the need for MH support post diagnosis. Such a finding warrants evaluation of the existing treatment and management of CIs, suggesting that interventions ought to be more holistically designed to include greater MH support.

Keywords: Psychological, Emotional, Mental Health, Social, Psychosocial, Distress, Quality of Life, Health and Welling, Social Determinants, Young Adults

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Above all, I would like to thank God, who has granted me the knowledge, fortitude, desire, and opportunities to bring this thesis research towards fruition.

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List of Abbreviations

Cl: Chronic Illness

Cls: Chronic Illnesses

EDI: Equity Diversity Inclusion

HRQoL: Health Related Quality of Life

LGBTQ: Lesbian Gay Bisexual Transgender Queer

MCID: Medical chronic illness diagnosis

MH: Mental health

QoL: QoL

SD: Social Determinants

Social Determinants of Health : SDoH

SES: Socioeconomic Status

WHO: World Health Organization

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DECLARATION OF ACADEMIC ACHIEVEMENT

I, Jonathan Ramdawar, declare this Master's thesis dissertation to be my own work. All ideas that are not my own have been both directly and indirectly cited and using APA formant. No other formal research work has been submitted as part of completing this thesis. To date, no part of this research has been submitted for publication or as partial completion for degree requirements at another institution.

To the best of my knowledge and abilities, this dissertation does not infringe on any other publication's copyright.

My supervisor, Dr. Mat Savelli, has provided me guidance and editorial assistance throughout the entire research and writing process. I am the sole researcher and writer for this thesis, thus, all data collection, analysis, and synthesis of conclusion for the manuscript were my responsibility.

INTRODUCTION

A chronic illness (CI) can be defined as any prolonged medical condition with persistent effects/limitations towards daily life, both functionally and socially. The onset of receiving a medical chronic illness diagnosis (MCID) can often (but not always) be described as a harrowing experience, leaving individuals with a plethora of unanswered questions and an instantaneous sense of uncertainty. Irrespective of the specific illness being diagnosed, enduring such a potentially life altering event can provoke feelings of emotional distress once the term "chronic" is attached. When the trajectory of the illness and consequentially one's life is rendered ambiguous, decision making becomes significantly more complex. The immediate reaction towards receiving a MCID typically varies depending on its severity, one's social determinants of health (SDoH), and health literacy amongst other factors (Shantz & Elliott, 2021). CIs demand psychological and social adaptation to prevent negative mental health (MH) outcomes and foster resilience (Revenson et al., 2022). Cultivating a reflexive mindset requires learning how to pivot when faced with the resistance of life unexpectantly changing, which propels individuals to overcome adversity. Moreover, in terms of living with a newly diagnosed CI, the individual's perceived sense of independence, feeling of helplessness or agency, emotional reactivity, and coping efficacy must be considered when employing management strategies (Gignac et al., 2000).

What is Mental Health?

Mental health (MH) is state of emotional, psychological, and social well being – all of which affect how we think, feel and act (CDC, 2021; WHO, 2022). One's MH can determine how they handle situations, cope with stress, and relate to others. Enshrined within the concept of health and well being the right to MH (access to care and freedom from discrimination)

underpins both individual and collective abilities to shape the world, therefore it is vital to personal, community and socioeconomic development (WHO, 2022). When seeking intervention, it is crucial to understand that there is no single determinant for the onset of negative MH problems, acknowledging that a range of diverse life experiences, such as trauma or abuse, addiction, ongoing medical conditions, and prolonged feelings of loneliness/isolation, can all impact one's mental well being (CDC, 2021).

Traditionally, health has been largely determined from a biomedical perspective, which has viewed the mind and body as separate entities (Kalla et al., 2020). Healthcare has been fixated on achieving the absence of illness, disease, injury, or infirmity, while negating other encompassing aspects of well being, such as one's MH (WHO, 2021). The maintenance of the biomedical approach (which historically deprioritized psychosocial factors) has privileged one factor over another (physical over mental), and as a result, achieving optimal health has paradoxically become more difficult (Carbonell et al., 2020). Along with various external contributing factors, the added pressure of coping with a CI can have severe psychological ramifications if not dealt with effectively (Compas et al., 2011). More specifically, experiencing a sudden shift in one's health may be life altering event. Thus, ensuring the transition towards independence and self-management post-diagnosis requires a holistic approach that goes far beyond mitigating physical suffering (Barskova & Oesterreich, 2009; Sezgin et al., 2020).

Quality of Life

As defined by the World Health Organization (WHO), quality of life (QoL) refers to the individuals' "perceptions of their position in life in the context of the culture and value systems in which they live, in relation to their goals, expectations, standards and concerns" (CDC, 2022). QoL is also the feeling of "life satisfaction, as determined by the mentally alert individual whose

life is being evaluated" (Megari, 2013, p.141). More specifically, health related Quality of Life (HRQoL) is a multidimensional construct with physical, psychological, and social functioning as the three main domains – all of which are likely to be affected by CI (CDC, 2022). Most chronic diseases can potentially worsen the overall health of people by reducing their capacity to live well and limiting their functional capabilities (such as mobility or mental alertness) due to increased pain and/or fatigue. According to Watson et al., the number of young adults being diagnosed with chronic diseases is increasing (2019), therefore, it is imperative that they understand how to gain an optimal QoL (Megari, 2013). While an extensive amount of research has been conducted on the psychological ramifications of living with a CI, these findings are typically drawn from an older population (Hopman et al., 2009). Several QoL issues (social seclusion, engaging in risky behaviours, increased distress etc.) for young adults with CIs are linked to coping with the illness itself, and the psychosocial problems generated by the interaction between the illness, the person, and their immediate environment (Sawyer et al., 2007).

Why Study Young Adults?

Diagnoses of chronic conditions are typically received at a later stage in life, where older adults often do not experience distinct ruptures in identity because they already anticipate increasing physical limitation when thinking about the trajectory of their lives (Engman, 2019). Yet for young adults this is rarely the case seeing that anticipations regarding one's identity are often explored through a period of self discovery – which is already a process in itself, and receiving a CI diagnosis only aggravates the matter. Given that being relatively healthy within a western society is the cultural norm for a young adult, straying from that can provoke "worries about the perceptions of others and [the desire to seek] validation through social endorsement"

(Wicks et al., 2019, p.47). Young adulthood comprises a time in which gaining independence, establishing a career, pursuing romantic relationships, and forming a sense of identity are expected milestones. For individuals with chronic conditions, achieving such milestones may be delayed or prevented (Wilson & Stock, 2019).

Biographical Disruption

The basis for Michael Bury's 1982 theoretical framework argues that the onset of CI represents a "biographical disruption" that fundamentally ruptures the fabric of everyday life. This results in a challenging alteration of the narratives people create about the future to understand the trajectory of their lives (Bury, 1982). This concept has become paradigmatic in that it describes why CI is experienced the way it is. People have an idea of the way their life is going to be (a biographical plan) but then something happens (a disruption) that changes the way they thought their life would have played out. Biographical disruption can also be explained as a "disruption at the level of one's embodied orientation towards the world, that is, as a disruption at the level of the habitual behaviours that govern daily life" (Engman, 2019). Knowing this, the ramifications of CI extend far beyond some level of deterioration in the capabilities of the body. Biographical disruption encompasses just how fragile one's perceived reality is when the narratives people use to understand themselves and their lives can change within an instant. Part of the biographical disruption process entails reconfiguring those narratives as people begin to integrate the shift of having a CI and contemplate how that impacts one's self-perception/ life trajectories. The concept of biographical disruption also illuminates the relationship between CIs and important social bonds (Engman, 2019, p.120). When a life-altering moment such as a CI diagnosis occurs, the most significant support is typically found from the closest relationships.

Goals and Outcomes

In Bury's framework, receiving a CI diagnosis may disrupt the course of one's life, forcing them to pivot from pre-existing expectations towards new ones. Aside from attempting to mitigate physical suffering and promote optimal health and well being, learning to live with a CI demands a strong sense of psychological reflexivity, seeing that individuals must adapt to new norms. While Bury's work with biographical disruption begins to unravel the complexities within CIs, it ignores the extent in which demographic characteristics influence perceived experiences. Reactions to the onset of CIs are often contingent upon other aspects of life (Delbene, 2011). To account for such a discrepancy within the phenomenon, this project uses the concept of biographical disruption as a foundational theoretical framework while considering social determinants (specially age, amongst others) as a varying factor that impacts one's experience of being diagnosed with a CI. Specifically, this study investigates the psychosocial effects of receiving a CI related medical diagnosis amongst young adults aged 18-25. From analyzing participants' lived experiences, along with assessing their current healthcare (accessibility, delivery, and rollout of treatments), it is apparent that the pursuit for optimal health is a challenging one, especially when receiving and coping with a CI. This study highlights the multiple barriers, complexities with social support, and emotional distress that impact one's mental well being and QoL.

REVIEW OF THE EXISTING LITERATURE

The Emergence of Mental Health

For most of the 20th century, health was recognized predominantly as the absence of disease from a biomedical view. Within this medical standpoint, deviations from the biological norm (anything that appeared not healthy) were typically attributed to either a chemical or

physical occurrence (Kalla et al., 2020). As discoveries and new perspectives emerged, the notion of health itself became more holistic and encompassing of mental, psychological, and social aspects.

In terms of MH, the ability to thrive lies within one's emotional state of well being, often characterized by mood and behavior (Perry et al., 2010). The idea of flourishing can be described as a state of experiencing positive emotions and being equipped to function well, both psychologically and socially, whereas languishing refers to a feeling of emptiness and stagnation in which individuals perceive their life as one of despair (Keyes, 2002). Undergoing a CI diagnosis can possibly shift an individual's outlook in which flourishing becomes harder and if not dealt with effectively, feelings of languish can arise.

In terms of CIs, the connection between MH and physical health appears intertwined. Those diagnosed with CIs are susceptible to engaging in risky externalizing behaviours as poor coping choices, especially if psychological issues are internalized (Gubelmann et al., 2018). Such behaviours include, but are not limited to, withdrawing from social engagements, physical inactivity, smoking, drinking, and insufficient sleep. Moreover, engaging in activities that promote positive MH is associated with improved health outcomes and health perceptions (Perry et al., 2010, Sezgin et al., 2020). Knowing this, intentional choices that preserve/improve one's MH are ultimately beneficial despite potentially appearing as an additional distress from the illness itself or burdensome.

When receiving a CI diagnosis, far more than just the patient and the healthcare professional are involved. Friends, family, and other forms of social support all influence one's personal experience with being diagnosed. CIs are exemplified by fluctuating tendencies inside and out of clinical settings, both of which are contingent upon time and intersubjectively

experienced within one's environment (Walker, 2010; Vijayasingham et al., 2018). In essence, even if two individuals received the exact same diagnosis, their experience could vary drastically. Furthermore, the sociocultural context (one's environment) can also be viewed as a means of providing the blueprint for adaptation to diseases, when considering how illness is defined, what factors give meaning to illness events, which coping strategies are best suited, and how decisions are made (Revenson & Hoyt, 2016).

Despite not following a universal trajectory (given that CIs differ from one another), most carry psychosocial burdens that can ultimately impact one's self-perception. CIs can present themselves in a variety of ways: acute phases, being degenerative, remissive, oscillating/episodic, or lifelong. These illnesses are often multifaceted in both causality and impact – posing physical, emotional, psychosocial, and economic burdens (Walker, 2010; Revenson & Hoyt, 2016; Kalla et al., 2020). When taking a psychological approach towards defining CI, the process becomes more complex. CIs exist within many varying dimensions, "including: the rapidity of onset; ambiguity of symptoms and thus treatment plan; predictability of the course of the illness; degree to which the illness is life-threatening; whether pain and other symptoms are constant, recurring and/or disabling; rapidity of disease progression; availability and effectiveness of medical treatment; degree of daily life disruptions from symptoms and treatment; and degree of self-management" (Revenson & Hoyt, 2016)

Studies have revealed that individuals living with CIs place almost as high a value on their MH as their physical health and are keen on pursuing treatments that mitigate the presence of depressive or anxious symptoms (Shih & Simon, 2008; Ballew et al., 2012). If not included as part of a comprehensive approach to healthcare, psychiatric comorbidities can exacerbate the

already formidable obstacles that often hinder the successful management of chronic diseases (Shih & Simon, 2008).

Mental and Emotional Effects of Chronic illnesses

Social support is the "perceived or received functions or provisions afforded by social ties, including emotional support, tangible or instrumental support, esteem support, and belongingness" (Revenson & Hoyt, 2016). When diagnosed and living with a CI, one's social supports are likely to be met with new responsibilities as they may provide various levels of care. However, such reliance can consequentially leave chronically ill individuals in fear of receiving compassion to avoid feelings of being a burden and/or loss of autonomy. Such fears act as psychological captivities that emotionally oppress oneself from being socially supported (Baanders & Heijmans, 2007). As chronically ill individuals typically have lower levels of independence, they often experience a decrease in quality of interpersonal relationships, feelings of being misunderstood, feelings of helplessness and isolation (Baanders & Heijmans, 2007; Taylor, 2006). Symptoms of isolation and loneliness such as loss of appetite, sleep issues, and decreased energy are critical signs that alert the connection between health behaviours and depression.

The relationship between CI and psychological well being is exemplified through the presence of depressive symptoms and level of life satisfaction (Ballew et al., 2012). As individuals grapple with their newly found reality (receiving a CI diagnosis), various barriers may prevent them from reaching the highest possible QoL. When minimizing the impact of CI amongst young adults, approaches towards acceptance, understanding, and management requires understanding the various determinants of one's CI and how to account for them (Ballew et al., 2012; Vijayasingham et al., 2018).

According to Revenson & Hoyt (2016), many living with CIs experience symptoms of depression, anxiety, and grief to some degree, especially when first diagnosed. In the past, while researchers worked to identify the root causes for psychological disorders, the emphasis largely focused on mitigating negative MH outcomes. However, current perspectives suggest MH is far more that the absence of psychopathology, and recent scholars have placed a greater emphasis on strengths and life satisfaction for those adjusting to life with CI. "Adjusting" or "adapting" to illness are broad terms used to denote the "process of coping with illness and its outcome, including intrapersonal and interpersonal domains, with cognitive, emotional, physical, and behavioral components. Adjustment to illness is not static but represents a process that unfolds over time and within particular medical and social contexts" (Revenson & Hoyt, 2016, pg. 284). Adjustment is contextual by nature, with determining factors differentiating one person's experience from another. Adjustment outcomes can be positive, negative, or even simultaneously exhibit both positive and negative aspects. For instance, a person may endure feelings of anxiousness or depression while still unearthing a greater appreciation for life (negative and positive co-existing).

Coping can be described as the cognitive, behavioral, or emotional efforts put forth in attempts to manage or eliminate stress/emotional distress and can be conceptualized as one's pursuit towards managing an array of difficult demands (Revenson & Hoyt, 2016; White et al., 2018). Coping strategies vary depending on the individual's lived experience and SDH; therefore, how one pursues ways of adjusting to their new normal when faced with life changing news such as a CI is highly circumstantial (White et al., 2018; De Rider et al., 2008). Ensuring that healthy coping mechanisms for those enduring a CI diagnosis is imperative in stabilizing the psychosocial adaptation process that occurs during unprecedented and stressful times. Losing a

specific state of health/image and being triggered into grieving/mourning the life that once was (life before being diagnosed) can perpetuate feelings of not being in control and powerlessness, for which coping skills are required. Given that CIs can change with time or be episodic in nature, the process of coping is rarely about returning to a pre-illness state, but rather forging sustainable ways to continually adapt and pivot, birthing a new sense of self, multiple times if needed.

Another emotionally taxing ramification of CI is the inherent fear of the unknown. Varying levels of uncertainty, combined with potentially facing discrimination and stigma, makes recently diagnosed individuals susceptible to feelings of isolation and being ostracized (De Rider et al., 2008; Compas et al., 2011, Trindade et al., 2018). Such experiences can leave individuals more prone to feelings of shame surrounding their illness and symptomatology. Shame is described as a self-conscious emotion, inflicting pain, and functions as a signal, alerting the risk of being excluded or rejected by one's social group (Gilbert, 1998). Shame is often triggered from situations where someone perceives their existence (past, present, or potential future) as different, unattractive, inferior, or inadequate. These perceptions often arise when one's personal characteristics (e.g., an illness, physical appearance, personality) deviate from the societal norm or is deemed as inappropriate, garnering criticism or rejection (Gilbert, 1998; Tangney & Fischer, 1995).

Social Determinants of Health

Chronic diseases are not communicable and therefore, are not transmissible, nor do they stem from infection such as bacteria or virus (Shantz and Elliott, 2021). Unlike infectious diseases, whose origins can be easily deduced, CIs are complex and multifactorial in nature. Despite the onset of most CIs being preventable (to some degree) with behavioral/lifestyle and

environmental modifications, various social determinants must be considered when understanding the intricacies that promote chronic conditions (Shantz and Elliott, 2020). The SDoH can be described as the nonclinical factors influencing health and well being. This perspective highlights the way health and ill-health are framed by considering the areas and conditions in which people are born, grow, live, and use for recreation (WHO, 2021). As emphasized by this framework, obtaining optimal health and well being is an iterative process predicated on dynamic, yet balanced, relationships between individuals and their respective environments. One's environment influences their behaviours, and one's behaviours influence their health; thus, modifications to the environment can subsequentially impact health behaviours and outcomes. (Wilkinson and Marmot, 2008).

The onset of CIs is complex in nature and develop through a combination of "biological and biochemical processes, sensitive to multiple risk factors and determinants", including genetics, psychological, sociocultural, lifestyle, socioeconomic, and environmental factors (Ballew et al., 2012; Vijayasingham et al., 2018). While the prevention or mitigation of several CIs can occur through lifestyle and/or environmental changes, some illnesses are hereditary in acquisition, and the causative origins of others are left unclear.

Accumulated research has reinforced the associations between social factors such as poverty, racial injustice, SES, gender inequality, education, access to care, and health outcomes. Educational level, employment status, marital status, having children or not, gender, and sex all influence one's ability to successfully manage a CI (Baanders & Heijmans, 2007; Knapp & Hall, 2018). When reducing health inequalities, it is imperative that institutional-level economic factors (government, healthcare, social services, education) be considered, acknowledging the impact negative social factors have towards the promotion of optimal health for all. Failure to do

so compromises the integrity of human rights (access to healthcare), where some individuals are privileged to acquire the resources needed for effective CI management at the expense of others.

Individuals of lower SES are predisposed to more psychosocial risks, often experiencing more stressful events, all whilst having fewer resources, which inevitably makes adversity greater (Gallo & Mathews, 2003; Shih & Simon, 2008). Those living in poverty are often forced to cope with illnesses through a weakened context, one that is usually pervaded with a deep sense of helplessness and hopelessness. Furthermore, the psychological adjustment needed to effectively cope for racial/ethnic minority groups, who are disproportionately exposed to health disparities, is often that of a greater intensity. The reason being, the associated barriers presented with CIs (mental distress, access to care, stigma, etc.) are compounded with racism, discrimination, and social exclusion (Mays et al., 2007). That is not to say individuals within majority groups are exempt from facing discrimination or social exclusion, however, such experiences are often exacerbated for minority groups.

Several conceptual frameworks have outlined the various determinants of health and risk factors, which could increase the probability of a person developing a CI or impede the management of existing conditions. A person's physical and psychological basis, coupled with determining risk factors such as health behaviors, SES, cultural awareness, and biomedical factors, can affect the onset and progression of CIs (Kalla et al., 2020). Specifically, culture plays a significant role in the onset, awareness, and acceptability of CIs. Given that some cultures integrate health promotion more than others, a person's cultural context can be considered beneficial or detrimental. Culture also influences the ability to understand and accept the diagnosis, one's comfortability with emotional expression (e.g., anger, sadness, frustration, grief), and health beliefs regarding various concepts such as fatalism (Revenson & Hoyt, 2016).

Depending on where someone is situated, their responses towards receiving a CI diagnosis and coping may vary.

When the conditions that individuals live within contribute towards the likelihood of developing chronic and mental illnesses, those with lower SES are more likely to be left socially vulnerable while suffering from anxiety, depression, and mental distress. The unequal distribution of the SDoH (e.g., low educational attainment, poor quality education/educational inequalities, poor housing quality/instability, and unemployment/underemployment/job insecurity) is a pivotal contributor to health inequalities. (Prokosch et al., 2022). Those with poor SDoH unjustly bare the burden of existing in a society designed for others to thrive, as the impact of the external world can greatly affect people's predispositions to both chronic and/or mental illnesses.

How Living with a Chronic Illness Affects Daily Life

For most individuals whose lives are impacted by CIs, they must grapple with various issues such as how illness impacts their work lives, the ambiguity of how their illness will progress, how to critically negotiate the disclosing of their illness, the impending choice to stay or leave in their current situation (work, school, relationships, communal associations), reduced salary/job security, and how their illness affects those around them (Walker, 2010; Vijayasingham et al., 2018). Given that work and education are favored over other attributes (religion, location, race/ethnicity, sexual orientation, attractiveness etc.) within modern western society, its dominance in forming individuals' identities is painstakingly evident (Walker, 2010). With copious amounts of time, energy, resources, and education/training devoted to one's career, the importance of one's occupational success progressively contributes towards the construction of a person's identity (Walker, 2010). When life changing events such as the onset of a CI,

complicates someone's ability to effectively complete day-to-day tasks (such as education or employment), their independence and self-worth may be questioned. Often times people's perceived identity stems from where they feel they most belong; and given that enduring a CI is typically a very isolating experience, some may struggle to feel valued within their communities.

The psychological distress that inevitably comes with CIs is associated with decreased HRQoL. People's perceived level of life satisfaction often cascades when under prolonged periods of stress, in which obtaining optimal health and well being becomes more difficult and seemingly out of touch for some (Shih & Simon, 2008). Given the increasing prevalence of CIs, affected persons may benefit from targeted approaches that jointly manage both the physical and mental aspects of chronic diseases. Mitigating or managing daily psychological distress is imperative when treating chronic conditions, in which the goal of treatment is not necessarily to cure the disease, but rather prevent further disability and improve one's MH, ultimately improving the HRQoL (Shih & Simon, 2008; Megari, 2013).

Coping and Management Strategies

Despite CIs being attached to complexities that seemingly make life more difficult, living with such challenges has been shown to have benefits (Park et al., 2009). Some chronically ill people have reported a greater appreciation of life, improved personal relationships when mutual trust and support is accepted, and spiritual growth (Park et al., 2009). Spirituality has steadily served as a coping mechanism that moderates the impact of illness. Having a positive effect on one's mental and physical health, spirituality can be considered an imperative element towards managing one's CI. Spiritual coping works to diminish feelings of suffering such as anxiety, fear, or death by engaging in spiritual practices (praying, meditation, yoga, connecting with nature, attending spiritual or religious services) (Ballew et al., 2012). Evidence has indicated

that perceiving one's illness as having a positive effect and engaging in benefit-finding

behaviours can influence disease outcomes, promoting individuals to not only survive, but thrive,

through the mediation of negative psychological effects (Ballew et al., 2012; Revenson & Hoyt,

2016).

In terms of making sense of their illness, people with chronic conditions often seek out

causal attributions for illness. Attributions are the reconstruction of basic assumptions in order to

provide a means to explain the world and why something occurred (Roesch & Weiner, 2001;

Revenson & Hoyt, 2016). In doing so, the impending question of "why me?" can be explored in

a way that fits the illness into an existing worldview, helping individuals to regain a sense of

mastery, even if the sense of control is merely an illusion. The types of causal attributions made

can impact the effectiveness of one's psychological adjustment efforts. For example, those with

optimistic attributions adjust better to CIs than those with pessimistic purviews (Roesch &

Weiner, 2001). Similarly, chronically ill people can promote optimism and preserve their self-

esteem by drawing downwards comparisons. These comparisons rely on a person who

sympathetically views less fortunate situations in attempts to enhance their subjective well being

by feeling grateful (Revenson & Hoyt, 2016). Causal attributions and downwards comparisons

are both mechanisms used to help understand and cope with one's reality.

From a cognitive standpoint, appraisals are another means of psychological adjustment

used to help individuals cope with stressful situations or life crises such as CIs. The process of

creating an appraisal involves evaluating potentially stressful events in attempts to discover its

meaning or significance (Carpenter, 2016; Revenson & Hoyt, 2016). The methods by which

individuals appraise stressful events impacts their overall health in several dimensions – mental,

social, emotional, and physical. These appraisals only come to fruition when an adverse situation

is determined stressful, thus, appraisals are contextually bound to one's perceptions and environment. Furthermore, appraisals can be split into two subtypes, where the primary appraisal requires identifying if an event poses some sort of threat/harm to one's well being, and the secondary one assesses if someone possesses the necessary resources to cope with that stressor (Revenson & Hoyt, 2016).

Additionally, forgiveness therapy (with or without religious overtones) from both psychologists and pastoral counselors may also serve as a form of treatment/management that allows those living with psychosocial dysfunctions to cope more effectively (Elliot, 2011). Often times, individuals will blame themselves for the onset of their CI, in which the role of forgiveness therapy may aid in forgiving themselves and healing the burdensome consequences of early adverse experiences such as living with CI (Elliot, 2011; Friedberg et al., 2015). In order for the treatment to be rendered effective, people follow two essential steps. First, they must eliminate the resentment they are experiencing such as negative or uncomfortable feelings/thoughts/behaviors associated with a specific situation. Secondly, individuals must intentionally work towards experiencing an increase in positive reactions and emotions such as joy or compassion. As people come to terms with what once was and gain acceptance, their current situation can be deemed through a perspective enshrined with understanding and empathy, ultimately laying the past to rest, and finding inner peace (Borris, 2003).

Upon investigating the current literature, it is evident that CIs impact the mental and physical well being of those affected in numerous ways. Specifically, young adults living with CIs often wrestle with fear of the unknown, regaining independence, achieving life goals, and finding self-worth. With that being said, the psychosocial effect of receiving a CI diagnosis may vary from one individual to another based on a magnitude of factors such as social determinants,

changes to daily life, ability to understand and accept the illness, and exposure/adherence to coping mechanisms. Moreover, when forging effective management solutions, understanding the role CIs play within one's identity is imperative. Learning to accept changes within expected life trajectories and reconstruct one's narratives is a complicated but vital part of the healing process – as without it, efforts towards managing any CI are unsustainable. While the literature illuminates many aspects of CIs independently, there are discrepancies when trying to identify the intersectionality between SD, MH, and CI. Unearthing these intersecting forces could reveal why some individuals are disproportionally affected, but more importantly, how to compensate for such disparities.

METHODOLOGY

Research Question(s)

The main research question guiding this study is: how does receiving a chronic medical diagnosis impact young adults' overall MH? Attempting to answer this question would illuminate the social, emotional, and psychological implications of being diagnosed and living with a CI. A secondary question guiding the research surrounds identifying what factors (such as social determinants and support) influence the impact of CIs and one's ability to cope.

Philosophical Orientation

This study falls within a constructivist philosophical orientation, in which multiple existing truths exist, but are dependent on one's perspective. A constructivist approach focuses on theory building and exploration, in which new concepts, mechanisms, and processes can be discovered to help explain social reality (Chandra & Shang, 2020). This study attempts to understand the complexities (truths) that reside within the lives of those diagnosed with a CI. This research undertakes a qualitative approach to explain one's personal

mental/social/emotional experience with receiving a medical diagnosis. The landscape of this study is largely humanistic in that the findings are based on people's interpretations of their experience. Rather than seeking to quantify those phenomena, this study used open-ended questions that generate observations, shared experiences, and non-numerical data.
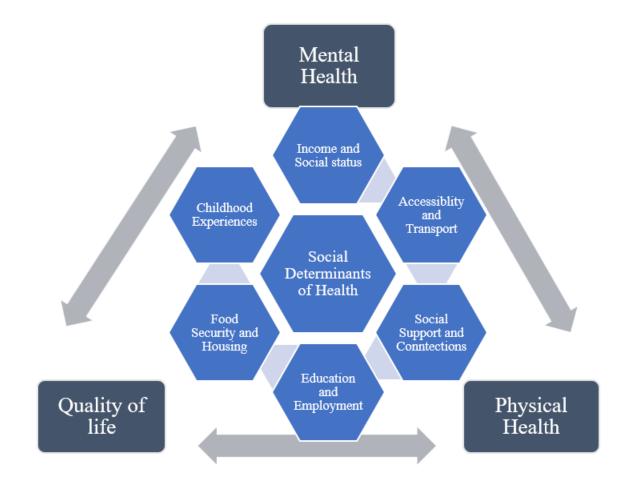
Conceptual framework

Those living with a CI could experience biographical disruption that could potentially change an individual's self identity comparatively pre and post diagnosis. The concept of disruption involves redefining one's self worth and identity, along with rewriting the narratives for their projected life. This study uses Bury's concept as a foundational framework when analyzing the experiences of participants. However, this framework does not address the extent in which one's experience with a biographical disruption varies based on demographic characteristics. In attempts to account for these discrepancies, this study also considers how social determinants affect one's experience with receiving a CI diagnosis, and the intersections that exist between MH, physical health, and QoL.

For this study, the conceptual framework (refer to Figure 1) provides a guiding basis by employing various aspects of existing frameworks to unravel the interconnected intricacies within CI. The outer triangular diagram (with arrows) highlights the parallels between MH and physical health, and how those two contribute towards one's overall QoL (Akinyemi et al., 2014). Given that a person's QoL affects their MH and so forth, the double ended arrows in the figure represent how the process is iterative. Moreover, the inner hexagonal diagram highlights the social determinants as they dictate the outcomes of the outer forces of the physical health, MH, and QoL (Knapp & Hall, 2018). Both inner and outer parts of the diagram (which make up

the framework) are interconnected and must be considered when addressing coping mechanisms for living with CIs.

Figure 1: Conceptual Framework

Study Setting

The study took place within Hamilton Ontario, Canada. This setting was chosen as it encompasses the Canadian population, having a diverse range of people with regards to ethnicity, gender, socioeconomic status (SES), and age (Government of Canada, 2021). According to Public Health Ontario (2021), chronic conditions such as various cancers, cardiovascular diseases, respiratory diseases, autoimmune diseases, and diabetes cause about two-thirds of all deaths in Ontario. Using a major city like Hamilton provided adequate

participants given that urban centers often carry heavier burdens of diseases. For the purposes of convenience sampling, participants were recruited at McMaster University.

Study Design and Procedure

This study used a phenomenological approach to explore one's experience with receiving a CI diagnosis. This method of inquiry is an approach that explores a bounded system/experience in detail. Phenomenological inquiry is accomplished by studying the experiences of people through phenomena in real-world situations (Giorgi, 1985). More specifically, phenomenology renders explanations of experiences unconstrained by explanations or presupposed theories. The aim of using a phenomenological approach is to understand the psychosocial phenomenon of a CI by illuminating participants' lived experiences and analyzing any influencing factors. Such experiences are characterized by the individuals' awareness, consciousness, and interaction with the situation (van Manen, 1997). The purpose of the study is to understand the individual, relational, psychological, and social experiences related to one's diagnosis. Given that the data collected is complex and experiential/personal, a phenomenological approach promotes the in-depth gathering of information for each circumstance necessary for comparative review.

The qualitative method of phenomenology allows researchers to flexibly engage within activities to better understand and describe complex ordeals that surround the human social experience (Alhazmi & Kaufmann, 2022). Trying to encapsulate the human experience of a given phenomenon can be a tricky task given the complexity of human nature, as well as individuals' experiences being largely multidimensional (psychologically, culturally, and socially structured). Phenomenology allows the firsthand privilege of readers being able to experience the perceptions of participants vicariously. Aside from questioning the meaning of life with the hopes of identifying how people live it, phenomenological informed research aims

to mitigate prior experiences or presuppositions that can potentially cause biases in order to witness the phenomenon impartially (Van Manen, 2014).

Phenomenology analyzes experiences to inductively describe the common essence of a phenomenon, where the relationship between objectivity and subjectivity is explored while illuminating significant invariant aspects that lead to generalizability. Within the philosophy of phenomenology, there are two methodologies: descriptive and interpretive. For the purposes of this research, interpretive phenomenology (also known as hermeneutic phenomenology) was used to understand the experiences/phenomena by co-constructing the data with the participants as understandings are achieved continually throughout participants descriptions/recollections. Van Menen's approach towards phenomenology was taken, as it is indicative of descriptive and interpretive elements, while refraining from bracketing and challenging scientific naturalism (Fuster Guillen, 2019). This specific approach (hermeneutical phenomenology) is oriented towards the description of fundamental structures as well as creating an interpretation of the lived experience that discloses deeper meanings with various underlying factors. Given this, constructivism and existentialism are the epistemologies informing this research. Therefore, this research is predicated on the notion that personal knowledge is constructed as opposed to discovered – where researchers are gatherers and interpreters in which they report their construction of reality or knowledge.

For the purposes of this study, an interpretive phenomenological analysis (IPA) was used to inform the case studies. As opposed to the concept of bracketing (sidelining preconceptions to be self-aware and not intrude on the essential aspects of participants' accounts), the role of the researcher is more involved for IPA. Smith (2009) refers to this concept as a "double

hermeneutic" in which participants are trying to make sense of their experiences, and the researcher is trying to make sense of the participants' perceptions.

Within this study, it would simply be impossible to unearth the psychosocial implications of receiving a diagnosis of a CI without considering the context in which the experience exists. In terms of data extraction, semi structured personal interviews were chosen, given the sensitivity of the topics being discussed. Having personal interviews as opposed to focus groups allowed for maximum confidentiality, privacy, and expression without fear of judgment. Face-to-face interviews also allowed for the expression of non-verbal cues, pauses, and physical patterns, in which the researcher was able to better gauge the situation (DeLiberto, 2021).

Data was collected through semi-structured interviews held during the period from July 6 to August 5 of 2022. A semi-structured interview process was employed for the use of intentional questions (refer to appendix A) while also allowing for spontaneity within the conversation – an aspect that is imperative in phenomenological inquiry (Giorgi, 1985). Interviews were audio recorded and transcribed for further analysis. Given the Covid situation at the time of recruitment, interviews were held virtually through Microsoft Teams (video calling platform) for convenience and safety purposes. To mitigate the issue of intimidating power dynamics, a fellow student researcher (myself) conducted the interviews in hopes of creating a more comfortable dynamic between the interviewee and interviewer.

Interviews were recorded and transcribed for later analysis using thematic exploration. The process of qualitative coding systematically categorizes excerpts within the data to later find themes and patterns (refer to table 1). It makes the analysis more systematic and rigorous, thus providing transparency and reflexivity towards the research and others. Coding increases the validity of the findings while also decreasing bias. The process involves reading through the data

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several times, applying codes to excerpts, grouping codes according to themes, and making interpretations for final research findings (Nowell et al., 2017).

Study Population and Sampling Strategy

The targeted study population for this research is young adults aged 18-25, both male and female participants of various ethnic/racial backgrounds and socioeconomic statuses. Recruitment posters stated that participants would be asked about any mental/emotional/social challenges that arose as a result of being diagnosed with a CI and how that experience impacted their ability to live life and obtain optimal health/wellbeing. Not having exclusion criteria regarding one's SDoH or CI type provided insight as to how variations within these determinants impact one's experience with being diagnosed and coping, while allowing the data to encapsulate a diverse array of illnesses, severity, and symptoms. Prospective participants inquired further details from recruitment posters via social media direct messages or email.

Non-probability sampling was used to garner participants for this study. Specifically, purposive sampling was used so that the most impactful cases would be highlighted within the research. This type of sampling allows for intentional choices so that certain characteristics can be represented. Upon receiving nearly 30 prospective individuals, final participants were selected based on who had the most to share regarding their experience and mental health struggles. This type of sampling is also known as judgment sampling and is often employed to generate theories or gain a wider understanding of the social implications embedded within the topic of interests (Keilmann et al., 2012). It should be noted that this methodology does not account for all potential experiences of receiving a CI diagnosis seeing that not everyone with a CI diagnosis is psychosocially impacted greatly. Thus, any comparative conclusions drawn aim can only be

generalizable to the perspectives of those that do identify as experiencing psychosocial distress post CI diagnosis.

The sampling is smaller and more purposeful (12 participants) rather than being indicative of a large population. One strength of this analysis is that it is geared towards being inductive, seeing that new perspectives are revealed as opposed to strictly deducing existing ones (Neiswiadomy, 2012). Given the qualitative nature of this research, a smaller sample size is used to support the depth that case-oriented analyses require. These cases are purposive, therefore by virtue they demand more time and effort towards providing rich information that is relevant to the phenomenon under investigation (Vasileiou et al., 2018). This study continued until saturation was reached (Saunders et al., 2018). When no new additional data was found, analysis of the properties within a given category took place.

For the purposes of this research, a CI is defined as any medical disorder or disease type that impacts one's functional status (impairment of vision, hearing, activities of daily living etc.) and/or causes limitations in socially defined roles (school, work etc.). Chronic health conditions have a biological, psychological, or cognitive basis, and have lasted or are expected to last for at least 1 year (Sawyer et al., 2007). A CI must produce one or more of the following: (A) limitation of function, activities, or social role in comparison with healthy peers in the general areas of physical, cognitive, emotional, and social growth and development; (B) dependency on one of the following to compensate or minimize limitations: medications, special diet, medical technology, assistive device, personal assistance; (C) need for medical care or related services, psychological services, educational services, special ongoing treatment, or interventions (Sawyer et al., 2007). The checklist for this study includes mental, behavioural, and cognitive disorders – seeing that they too are chronic conditions. Having a noncategorical approach towards evaluating

the psychological impact of a CI allows for the focus to remain on the immediate reaction towards a life altering event (the diagnosis itself) and the ability to cope, rather than the implications of a specific disease or disorder.

For this study, the inclusion criteria requires that all participants be living within Canada for at least 4 years, be of age 18-25, received a chronic medical diagnosis within the last 5 years, and speak English. Such eligibility ensures that participants' experiences are conducive towards the goals and implications of the study. Participants' age ranged from 18-25 and age of diagnoses ranged from 15-23, with the following CIs: enclosing spondylitis, diabetes, eating disorders, ADHD, anxiety and depression, fibromyalgia, pots, asthma, epilepsy, TMJ, Meniere's, auto immune, metabolic, psoriasis, OCD, Crohn's, and scoliosis. To recruit participants, advertisements were made public using social media platforms (refer to appendix B). Furthermore, participants were compensated as a token of appreciation.

Ethical Considerations

Seeing that qualitative research study designs are centered on building authentic relationships with participants, ethical concerns such as respect for privacy and the establishment of honest interactions was considered within this research. This study also considered anonymity, confidentiality, and informed consent. Defining what confidentiality means to both the researcher and participants occurred to omit any confusions and miscommunications. The goal of establishing confidentiality from the researcher is to "minimize the possibility of intrusion into the autonomy of study participants by all means" (Sanjari et al., 2014).

Another ethical factor that was considered was that of informed consent, which often entails the researcher specifying in advance what data will be collected and how it will later be

used. According to Sanjari et al., (2014) the basis of informed consent reiterates the researcher's responsibility to fully make participants aware of the different aspects within the study, in language that is applicable to their level of understanding. Thus, the informed consent provided clarification towards questions surrounding the nature of the study, what the participants' roles are, allocation of financial resources (funding), the identity and background of the researcher, and why/how the research will be used and published (Sanjari et al., 2014). Moreover, informed consent should be an ongoing facilitation that serves to establish a coherent mutual understanding amongst all parties. Knowing this, informed consent occurred two times within the study (refer to appendix C). Furthermore, seeing as the researcher is the person who inevitably controls the interview, it is their job to uphold a given Code of Ethics. For the purposes of this study, the Code of Ethics from the Hamilton Integrated Ethics Board (HIREB) was upheld (refer to appendix D).

FINDINGS AND RESULTS

Based on the data collected within this study, the psychosocial impact of receiving a diagnosis can be seen and categorized into the three main overarching domains. The first being barriers or facilitators (structural SDoH) depending on the circumstances, whether it be systemic, institutional, and/or physical. Secondly, the lack or abundance of social support (relational SDoH) effected individuals' experience with CI. Thirdly, various emotional/mental strains were noted to have exacerbated the psychosocial distress amongst participants. The first two themes can be utilized to analyze what structures influence the psychosocial implications of a CI diagnosis, whereas the third theme explores the psychosocial implications themselves (emotional and mental reactions). In other words, the outcomes listed in theme three are contingent upon the circumstances listed within the first two themes.

Each of these main themes/domains consist of several factors as highlighted below (refer to figure 2). The impact of receiving a diagnosis is not bound to the very moment it occurs, but rather the understanding, acceptance, and ability to cope comes with time. As exemplified through participants' experiences, being diagnosed with a CI can place individuals in a stressful mental state, where various questions surrounding their identity and future arise. These immediate concerns largely depend upon one's ability to understand and cope. Therefore, how one lives and copes with their CI is influenced by associated factors which either promote or hinder good mental health.

BARRIERS AND FACILITATORS

Socio Economic Status

SES and the ability to acquire the necessary financial resources to pursue treatment proved to be a challenging ordeal for many participants when trying to effectively manage their CI. Irrespective of accessibility, if the treatments and solutions needed to alleviate/manage the burden of CIs are not economically feasible, their proximity and tangibility are irrelevant, as described by participants' experiences below.

> "Yeah, definitely went [to get treatment] and during the process of like trying to get approval for this medication, it wasn't even necessarily just the coverage, like it [the fact that] even if you can have [access to] this medication, you have to pay for it. [regardless of being] approved to take this medication… at that point I was like shoot, I can't afford it" (B1-3).

> "I am seeking out therapy but it's extremely hard, and when you find an actual therapist in real life, it's like over $200 a session. Like, who has money like that? Like, I don't. I don't have $200 to give my paycheck for one session a week. Like, it's just not worth it.

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So, it is really difficult. I don't think there's enough resources for people who do really want therapy" (B1-7).

"Like right now, like I'm paying $75 for 45 minutes. Like, that's insane. And I have no coverage either, which is super expensive. And so, I just was kind of like oh well, I can't afford it so I'm not going to do it. I was on Ozempic, and I was on it for about two months. I lost a little bit of weight, but the problem was it was so expensive [and] I wasn't covered" (B1-10).

Participants noted that despite being made aware of potential treatments and actively pursuing them, not being able to afford them was a debilitating realization, prompting feelings of hopelessness for some. One participant stated that "because of my SES at the time, I couldn't really receive help, which further exacerbated my [physical and psychosocial distress]" (B1-1). Such findings reinforce the SDoH (SDOH) framework in which individuals of low SES are disproportionally exposed to various barriers, preventing them from achieving optimal health and well being.

Access to Healthcare and Treatment

Given that CIs last for prolonged periods, reoccurred episodically, or are lifelong, they demand sustainable methods of management to ensure a sense of fulfillment and longevity of one's life. However, insufficient access to care and treatment makes managing CIs extremely difficult and obtaining such care/treatment becomes an additional psychological stressor, often barring one's road to recovery.

As described in one participant's experience, having exposure to potential treatments is not really helpful when accessing them through insurance becomes rather difficult: "there are

specific and very expensive equipment or procedures that you can get, for example, like a

molded mouth guard so that your face and head wouldn't just hurt all day. But the thing is dental

things aren't really covered by OHIP" (B2-1).

Another participant described their experience in trying to access care as very

demoralizing, with having to prove a need for treatment as mentally exhausting:

> "It was difficult to kind of get approved for the treatment because you're constantly doing
>
> these surveys where they, you know, assess your pain and your ability to do specific like
>
> tasks during the day, like walk up the stairs without any assistance or put on your pants or
>
> something. And then it was definitely invalidating because I'm like, these are not
>
> reflecting what I'm actually going through like, you know" (B2-3).

Access to care often becomes challenging when certain types of treatments are harder to

obtain. MH support, such as a licenced psychotherapist or counsellor, are not primarily offered

as a first line of response towards chronic health issues, despite copious amounts of research

indicating the synergies that exists between mental and physical health (Perry et al., 2010). One

participant described their desire to have mental support along with their struggles to obtain

prescribed medication:

> "I wish they did, but they didn't [give any resources for MH services] … I was diagnosed
>
> when I was institutionalized for a suicide attempt. I finally found out that I did have
>
> ADHD … I definitely don't like that I haven't received any therapy or any other social
>
> supports for my ADHD other than [when I was] institutionalized. I would also go back to
>
> the medication. I think one of the main barriers that I had when being diagnosed is that

unfortunately … I had a doctor who refused to give me a refill on my medication unless I physically came in to see him during COVID (B2-7).

Even if treatments appear to be accessible, they are not necessarily useful unless they are tailored and specifically geared towards addressing the needs of the individual patient. General methods of practitioner provided care do not always account for the specific issues that hinder patients from overcoming their illness. Given that, the efficacy and benefits of care must also be considered when evaluating its accessibility. One participant described their struggles with finding useful treatment:

"They're like these free counselors that you can talk to. Kind of a waste of my time. Like I would much rather be medicated than sit here and because the sessions were… about 30 minutes and she just kind of assigned me homework and that was it. And I was like how is this supposed to help me not feel like not wanting to get up in the morning like how is this helpful at all and like I don't know if that's just protocol, I don't know but it wasn't helpful at all" (B2-10).

On the other hand, having reliable access to healthcare greatly enhanced the process of being diagnosed and then having to cope with newly found CIs for some participants. After not feeling like their needs were met from one healthcare practitioner, a participant was able to pursue care/treatment near their university, as "the first thing [they] did [was go] to the Student Wellness Center and… booked an appointment with a different doctor" (B2-2). Another participant described their experience with feeling supported by their doctor in that MH services were suggested. From this, the participant was able to seek treatment that was accessible via their educational institution as well:

"When I came back from the hospital, that it was my neurologist that told me to talk, talk

to a counselor and to get some support. Just because he understands how traumatic it

might be for me, going through Insulitis, losing my memory, stuff like that. So, I did go

to [my university's] MH services and I did talk to [people there]" (B2-9).

Education

Amongst the various social determinants, education is one of the forces that influences

people's ability to obtain the skills, resources, knowledge, access, and connections needed to

pursue optimal health. Just having the privilege of being able to afford post-secondary education

provides individuals with access to resources, as highlighted by one participant who "had the

means to pursue my psychiatric diagnosis. I moved to university [and was able to] seek

counseling … which helped" (B3-1).

For many whose lives have suddenly shifted upon the onset of CIs, pursuing formal

education can become more difficult. Along with physical changes or ailments, there are

numerous social, emotional, and mental impacts that can induce stress, consequently affecting

one's ability to thrive while completing their schooling. As described by one participant:

"… so, the education system really isn't built for people with chronic illnesses. There was

a lot of challenges this past year, especially with COVID, about us not going back in

person and the implications of that. You can tell that their accommodations process is

very much for acute or short term, like, oh, I broke my arm or, oh, I'm sick today versus I

have a chronic illness. I need a little bit of flexibility long term. And so, I think that's a

huge barrier just in terms of the way we think about education and what we expect of our

students without realizing that" (B3-2).

On the flip side, participants described how having formal education was immensely useful towards navigating such a challenging time in their lives (being diagnosed and learning to cope), reinforcing the significant that role social determinants such as education play. Gaining knowledge and having exposure to prolonged periods of stress, such as those experienced at school, may equip individuals with the tools needed to overcome the psychosocial hurdles of CI. One participant explains the leverage educations provides:

> "You know, being somebody who's like in the educational system [and having that] understanding, you kind of have that that little bit of knowledge required to process the diagnosis given to you, [unlike] someone who you know might not know anything of the sort. They would really bother them because it's just like fear of the unknown" (B3-4).

Other participants shared similar sentiments, explaining how their education allowed them to grasp their reality better in comparison to others:

> "I feel like if I wasn't in science, I would feel a lot more like helpless about it because I know where to look for more information and I know how to get more information. So, if I have a question, I can go find the answer, but I feel like if I didn't have that background in science, specifically biology, I would just be so confused as to what's going on" (B3-6).

> "So, when the doctor's explained it to me, I did understand, mostly because I am like a science major and like I, I get that kind of stuff" (B3-8).

> "I can't forget everything I learned in university. [The therapists] just gave me a bunch of homework to do and some of it worked given my existing knowledge of CBT … [which was acquired when I] took MH and addiction [courses] (B3-7).

From participants' varying experiences with education being a barrier, benefit, or both, it is apparent that one's SES influences their health. In terms of young adults specifically, education has the power to equip people with the necessary knowledge and skills needed to obtain and understand information regarding their CI diagnosis. In other words, education leverages certain individuals to thrive when faced with a CI by increasing their health literacy.

Lack of Awareness

There are many misconceptions and stigma attached to CIs. When insufficient, inadequate, or poorly implemented science is communicated, misinformation occurs, which furthers the lack of awareness by creating false narratives that hinder the dissemination of science (Goldstein et al, 2020). For many dealing with CIs, "the lack of research and resources available is pretty frustrating" in that understanding the onset, possible outcomes, treatments available, and ways to cope/live becomes a difficult and grueling ordeal (B4-1). One participant explained how their initial diagnosis felt:

> "Very overwhelming, and it felt very frustrating because it was something that I barely knew anything about and that now I just kind of have to keep living with for the rest of my life. There's no clear answer to like fixing this problem because there's no solution. It was just kind of…I was told all of these things could make it worse, so try and limit them as much as possible" (B4-6).

In one participant's view, there is a "misunderstanding in perceptions when it comes to psychological issues, people often think it's at your own expenditure. You can kind of, you know, control these things, whereas you can't" (B4-1). Despite CIs being partially preventable through lifestyle and environment (albeit highly dependant on the specific illness), there are

several other determining factors. Therefore, when people assume an individual is solely responsible for the onset of their CI, such assumptions can induce feelings of shame and guilt, and chronically ill individuals may refrain from "divulging certain parts of [their] life because [they] don't want to be coddled or … treated like a child. [They] just want to be accepted as a peer, as an equal – though often that isn't the case" (B4-2).

Uninformed assumptions can also be made by patients themselves, causing forms of psychological and emotional distress such as self doubt or overthinking. Such a notion was made evident through one participant's recollection of being diagnosed, in which they questioned "why [they were] stuck with this or what could [they] have done differently. [But] now [working] in health care, [they] know that [they] couldn't have done anything differently … and that the beginning was kind of just like beating [themselves] up a lot" (B4-10).

Even aside from participants and the general public, a lack of awareness within the healthcare realm seems to impact patients' experiences, as described below:

> "I think because these three conditions aren't very well understood, a lot of doctors don't even know about them. That concerns me about, OK, what is like long term care going to look like for me?" (B4-2).

> "That the hardest thing is getting that initial diagnosis because there's so much ambiguity in the process. None of the symptoms are like extreme outliers which meant various doctors couldn't make a clear diagnosis" (B4-9).

Employment

Knowing that one's career/employment often makes up a significant portion of their identity, understanding that one's work life may be impacted can potentially trigger chronically

ill individuals to indirectly reflect upon their lives pre and post diagnosis. Many participants shared their concerns for the future and what that would look like, specifically, being able to work:

> "I'm literally experiencing these horrible symptoms. I'm not gonna be able to work. I'm not gonna be able to get through school with this. Like, if I was just thinking … I mean, I was just thinking about my career. If I randomly flare up for I two weeks at a time, no one's gonna keep me as their employee. If I'm out for like 2 weeks, right? Like that was what was going through. My head is like, even if I get a job, how am I even gonna work and make a living" (B5-3).

> "If I want to be an ER nurse and there's a lot of stress and a lot of sleep deprivation and a lot of, I guess just like the high stakes of that kind of job, I feel like that's a barrier. I can't really do that job because when it comes to my health, that might induce more seizures versus if I take a more relaxed nursing role like a public health nurse, that is something I'm able to do, but it would be nice to have all the options and not always think like, oh, I can't do that because of my epilepsy" (B5-5).

> "For example, I…like…the employment that I want to pursue in the future might be limited by having to constantly go see a doctor like every six months or so, and also having to take constant medication (B5-8).

Lack of Organization and Time

When initially diagnosed with a CI, several changes may need to be employed in order to adjust to one's circumstances, however, if these changes are not attainable in the long run, other solutions will be required. Knowing this, time management and planning becomes imperative

when promoting a sustainable approach towards living life post diagnosis. Whether it's managing treatments or medications, following up on medicals appointments, or balancing day-to-day activities with social engagements, all require active planning. In a world where the impacts of CIs are uncertain, effective time management allows individuals to regain a sense of stability. Initially, it may be hard for people with CIs to manage their time, given that "they don't really have that understanding of their own limits, which can sometimes be a difficult thing to grapple with… you know, identifying what I can and cannot do. [It] would mainly be a very mental thing that each person has to figure out" (B6-5).

The onset of a CI can be emotionally and mentally taxing, leaving individuals unable to organize their time well. This is where social support comes into play, as exemplified from one participant who relied on their family members, seeing that "especially at that time [they weren't] good with you know, making appointments or doing things for [themselves], or figuring things out like it" (B6-3).

Given that CIs may be episodic in nature, with symptoms appearing at random moments, participants described their coping as akin to always having to have their guard up. In a sense, chronically ill people always have to be concerned with their circumstances and environments, constantly having to consider the ramifications of their actions (more than the average person), which can become psychologically and physically exhausting. One participant described how "these symptoms … doesn't really give you a warning like when the flare ups would happen. So, what would happen [is] I would be out for like a couple weeks, right, [and then unexpectedly] a flare up would occur" (B6-3).

When individuals learn to effectively manage their time, they may even find a new sense of independence, improving their MH. As one participant shared, planning is "allowing me to

give myself more balance. So, am I going out and doing all this more social stuff or more school? No. I'm able to do more. But I'm also easier on myself when it comes to my limits" (B6-2). Another participant realized that:

> "I'm very organized now because I have to take my medications at specific time. If I'm not feeling right, I've definitely learned the art of communication just because in order to help my doctors properly diagnose me, I need to be able to tell what I'm feeling. I would journal things down and in terms of an overall person, I would say this disease has made me a better person. It's made me work harder. It's made me put life into perspective, and it's made me [who I am today]" (B6-9).

Health Literacy and Communication

Health literacy can be described as the ability to not only obtain medical/healthcare information, but also comprehend and use that information when making decisions regarding one's personal health (or decisions for others when caretaking). Knowing this, healthcare professionals must communicate effectively so that patients are left equipped to make informed decisions. Failure to do so leaves room for misunderstanding and ambiguity, in which individuals become frustrated and psychologically distressed, as noted in various participants' experiences. One participant asked their doctor "hey, is this gonna be like a chronic thing? They're like, 'maybe no, we don't know, we just have to see years from now'… [Hearing that,] anxiety arose from a lack of understanding what you've been diagnosed with" (B7-1).

Another issue that seemed to pervade much of participants' experiences was the lack of trust and comfort to communicate their concerns, along with frustrations in not obtaining definitive answers by healthcare professionals, as highlighted below:

"That's a thing like seeing some of those specialists. If they ask me if I had any MH concerns, I just wouldn't tell them because I knew the moment I said I had some anxiety… that's immediately what they would put it on. And so, the fact that I had to lie by omission to these physicians to get help from my physical pain is just completely unacceptable. And I think the other main barrier is just like the lack of medical knowledge, you know, I've had people, you know, like, I think one of the rheumatologists and one of the cardiologists, like, they told me information about my conditions, that it's just, it's just purely false" (B7-2).

"So initially [I did] not really [feel cared for] because they really didn't know what to do with me because they had no idea what was going on. I think initially it was a lot of me just shutting down … I don't know what to do at this point because it was communication between two people and it wasn't like clear communication, I'd say because it's not" (B7-3).

"I don't really trust my doctor sometimes with what he says because it just seems like he overlooks what I say. Like, I'll say like, oh, this is what I did. I'll be very honest with him, and he'll be like, '[don't worry,] children take those over-the-counter pills to sleep on airplanes.' I'm like, no, they don't take an adult dose of four capsules though. That's ridiculous. But he's like, yeah, no, it's not a problem. But, I mean, if I woke up in the ER having taken too many it is" (B7-5).

"I wasn't really told that there was a possibility that I could develop a resistance to the cream. So, I found that out by myself and I have been very, very skeptical of using it since then. It gets frustrating when you're asking your doctor. Like, what does this mean? And like, how does this happen in my body? And they tell you some people think it's

because of this and other people think it's because of this and we don't really have an answer. It's a big debate" (B7-6).

Although trusting the healthcare system is not always intuitively easy when fears and doubts run rampant, medical professionals remain highly skilled, knowledgeable, and dependable. And while getting definitive answers from physicians is preferred, it is rarely the case and an unrealistic expectation that should not hinder one's healthcare advice receptibility .

Oftentimes, people with CIs do not feel like they are being treated appropriately, respected, or understood. When this occurs, one's independence and sense of autonomy is further dismantled, weakening their ability to voice concerns: "A lot of the times [communication] is negated because healthcare providers often take on a very paternalistic role, which undermines you as a person and your individual ability to be your own advocate" (B7-5).

One participant explained the importance of having social support whose health literacy skills is sufficient, even if they themselves cannot understand medical information accurately.

"Another thing is having someone that is in science or has an understanding of science just because if you try doing your own research through Google, you will be terrified like doing that research. Even for me, I'm a business kid. I didn't understand anything. But if you go through Google, it's terrifying but fortunate enough that my sisters were able to explain to me like this is what it's doing to your body" (B7-9).

Strong communication between patients and their healthcare providers requires finding a solution to an issue that addresses their individual needs. Unfortunately, treatments and care are not always tailored, often leaving patients feeling neglected when the "care was generalized

instead of personalized… and because of that, [they feel like] their needs are not attended to" (B7-10).

Day to Day Life and Activities

Part of what makes enduring CIs psychologically challenging is how it affects day-to-day life. When individuals are faced with the jarring reality that things they once used to do so freely have now become more complicated, their perceived independence diminishes. One participant even described feelings of shame with regards to her reduced mobility as a result of having a CI: "I'd say physically it impacted my ability to go to school and stuff like I was on crutches for a while. I [wasn't] be able to walk properly which was embarrassing" (B8-3).

Feelings of resentment towards one's CI for its impact on pursuing daily activities was a common sentiment shared by participants, as exemplified below:

"I was pretty cynical about it. I figured like all of these things that are making my life enjoyable, like going into the pool or things that I can't help, like being stressed or making this worse. So, like, what's the point of even trying? Even though it might not be directly posing a critical threat to your health, it's preventing you from doing things that make your life enjoyable" (B8-6).

Aside from current struggles, those with CIs often live in fear that their disease/illness may prevent them from doing things in their day-to-day lives that they hoped for. This type of psychological distress can easily spiral out of control if not managed properly, derailing both physical and mental progress towards optimal health and well being, as highlighted from one participant's experience:

"Like it was really starting to impact my studies because I would spend so much time, you know, in the bathroom or getting stressed out? I'm thinking like, you know, why can't I do this within the same amount of time other people were doing? I would mentally stress myself out" (B8-4).

Social well being is an integral part of overall health, though having CIs can make the social aspect of a person's life rather difficult. Whether it be physical barriers, mentally feeling ostracized or isolated from others, or even emotionally overwhelmed, overcoming such hurdles demands intentional choices to ensure social engagement is achieved.

"Well, it has changed a great deal, especially my social life. Right now, I can't go out with friends as I used to, you know, because I'm afraid that maybe there are some triggers out there and I'll have to go home early, or that they'll have to call an ambulance. So, that's one thing my social life has been affected greatly and it's something I'm working on" (B8-12).

Taking on a positive perspective, CIs may indeed promote individuals to adopt health-conscious behaviours, as noted from one participant who said "I feel more rigid with like a healthier lifestyle for sure, because I had this underlying condition and it's just more motivation for me to take better care of myself. So, I exercise quite regularly. I try my best to sleep as like 8 hours a night" (B8-8). CIs often compel people to educate themselves and become more informed on achieving optimal health, and in doing so, such newly found awareness can yield a deeper appreciation for life.

SOCIAL SUPPORT

Family Pressure

One of the most crucial elements towards effective coping when dealing with CIs is having a strong sense of social support (Compas et al, 2012). Aside from others being able to physically help those with CIs, carers are able to alleviate some of the emotional and mental burdens. Intuitively, family members would appear as the strongest form of social support, though that isn't always the case, as exemplified by various participants. One participant revealed how they could not "really share anything outside of the physical chronic conditions [they had], so [their parents] didn't really know that [they were] diagnosed with [mental] things. And that's kind of resigned to the fact that [their parents] will only know a little bit about [them] (S1-1). The same participant shared how their home failed to provide a safe environment to confide in their parents. Rather than feeling unconditionally loved and supported, the participant described their relationship with their parents as transactional, where the environment was "emotionally abusive. And now it's more of a financial abuse kind of thing, where it's like I'm pursuing Med school, which is very expensive, but they have money. So, if I want their money to help me, that means I gotta shut up about all of this. (S1-1)

Other participants revealed how a lack of knowledge and awareness regarding CIs caused their parents to downplay the severity of the issues and/or create skepticism, resulting in a lack of support, as shown below:

> "I think I didn't really have any support from my family because they were just trusting my family doctor. They didn't know any better. It was 'oh, you know, take a Tylenol,' or 'go lie down' and not really understanding or trying to seek out a diagnosis" (S1-2).

"I think my mom [doubted me], especially because she didn't want to believe that I had OCD. So, she's like, 'oh no, you don't have this.' But I did" (S1-4).

"I was still living with my mom at the time, but I don't think she fully understood it. And I think she still to this day kind of blows off some of my symptoms as like not being pertaining towards ADHD and just me kind of using it as like an excuse (S1-7).

"My mom and I kind of just laugh about it and she's like 'oh yeah, it's such a you [thing] to have this major disease but it's not affecting you at all.' It's like something in the back seat. You know, … it's just taking medications, just something to … it's not a big deal type of thing" (S1-8).

Surprisingly, one participant described how their parents were knowledgeable in terms of understanding the CI at hand, and therefore, they "would have expected more support – just because [their parents] have gone through it and knew what it was like" (S1-10).

Moreover, one participant shared how despite their family being well acquainted with scientific information and being very supportive, they downplayed the severity of the issues as shown below:

"Everyone in my family has somewhat of a science background. My dad's studied pharmacology. My mom was a lab technician. My oldest sister is a paramedic, and my other older sister is a nurse. So, in terms of understanding medical conditions, they have a pretty good grasp on that. Yeah, as soon as I got the formal diagnosis, my parents were able to validate [the condition itself].... but [prior to that] like the biggest thing was the disconnect [in understanding my feelings.] I was in an insane amount of pain, but from them based off the symptoms, they didn't really think it was that serious. So, once they

had the formal diagnosis, they could do their own research and understand [and ask how] do we proceed from here (S1-9)?

Community and Friends' Support

Finding social support is not always the easiest thing one can do. On top of having to navigate life with a newly diagnosed CI and mentally cope with constant adjustments, feeling indifferent only adds to psychological distress. Often times individuals may even find "it's very hard to pursue help because [they have] not been supported" (S2-1). One participant even had to "to cut someone off because [they] were having a meltdown or panic attack at something, and [the friend shamefully asked if they] could stop that right now (S2-1)? When situations like this occur it leaves individuals feeling betrayed in that they "show[ed] symptoms to people you think you can trust, but you can't" (S2-1). Luckily for this participant they relied on the "encouragement of [other] friends [which urged them] to take that step of seeking help despite how convoluted the process can be" (S2-1). Similarly, another participant revealed that their friends were extremely supportive and encouraged them to seek help, stating "that push from peers and friends my age was really what helped me get that diagnosis" (S2-2).

For one participant, they explained how enduring the diagnosis left them distraught and highly irritable, yet their friends were understanding and supportive even if that meant they were "less likely to go out and have fun with… [Therefore, their] relationships didn't really suffer, they just become a little less engaged" (S2-6).

Other participants shared their experiences with finding social support online from social media (Facebook, Instagram, Twitter, YouTube, Tik Tok, Discord) as a means of connecting

with others who lived through similar experiences and could provide insight and a sense of reassurance, as shown below:

"They've made like group chats, Discord pages, and Instagram DM chats where people just share their experiences and share tips. And I think that's been really validating just to hear people talk about, you know, their weird experiences" (S2-2).

"I went back to those content creators, and I think even YouTube has been great. Like, they're just people sitting down and talking about their experience, like talking about their diagnostic experience, talking about, you know, tips and tricks for how they manage their pain" (S2-8).

"I didn't have time for a more formal way [to connect with others.] Whereas with Facebook and Tik Tok, its so convenient because just reading other people's stories was like therapeutic for me. Like if I read other people's stories and I hear how bad things are, it gives me a huge perspective on my own life" (S2-5).

Medical/Professional Support

When receiving a CI diagnosis, the first line of support is typically provided from the medical professional who gives the diagnosis. However, for many participants, their perceived experiences stray far from feeling supported or even shown compassion and empathy from their clinicians. While some professionals catered towards personalized care by supporting their patients and equipping them with sufficient knowledge/resources to manage their illness, others did not. One physician went as far as even accusing the participant of "faking it," which led to a very "tumultuous relationship where you kind of need this person, but at the same time, they're undermining you" (S3-2).

Despite MH support that is offered, the effectiveness or sustainability may not suffice, as exemplified through one participant's experience: "So being the fact that I was institutionalized at the time, I did have therapists that … supported me through the diagnosis. But I would say that I did handle and deal with a lot of [my struggles] by myself" (S3-7).

Similarly, another participant described how their doctor failed to address the MH issues (depression and anxiety) that arose as a result of having a CI:

"That's the only thing they care about, is your physical health. They're like, oh, here's medications, you're fine now. But they're not caring about. I've been dealing with this for so long and … they're not caring about the mental effect that it's had on me for that long. Like, what about those symptoms? What about that aspect of my health that's still 100% part of my health and part of my everyday life (S3-3)?

For others, the emotional support and extended support (resources shared) from physicians was completely overlooked. Mental healthcare "wasn't something that they provided, but it was something that [participants] had to receive [for themselves]" (S3-3). Even if medical professionals shared some of their knowledge, it was not "enough to fully [understand] what's happening, which is … frustrating" (S3-1). Such a notion leads to a greater conversation in which:

"You would think that going to a health care practitioner, they would have those resources available to guide you, even if it's beyond the scope of their practice, because you know, for physical suffering everyone gets referred to a different specialist when your health care provider can't do it themselves. But when it comes to mental issues, nobody really cares to go that extra mile of giving you such kind of support" (S3-7).

Furthermore, support in terms of healthcare and access to treatment also proved to be challenging for some participants, seeing that "the process of … trying to obtain the healthcare coverage was a bit invalidating because it's almost as if they were questioning the validity of your experience" (S3-3).

Conversely, some participants had rather positive experiences with their healthcare professionals, leading to greater recoveries and sustainable management practices of one's CI as noted:

"I had very good doctors on my side in terms of giving me a sense of direction and walking me through not only what the condition is, but the steps taken that I need to focus on in order to kind of make this disease work. You know it always helps and is very validating when your healthcare professionals actually are attentive, and you know they want to help. Sometimes it's easy for people to just brush away the symptoms and treat you like just the number [instead of] a patient" (S3-9).

"So, it was the first time where I've actually received something that kind of made sense. And she also explained everything as to what was going on. It gives me a sense of like she believes in me, and she cared enough to sit with me and make this plan with me, where it's worth a try. And I've never been so dedicated to something like this" (S3-10).

Misconceptions and Differing Perspectives

Social support does not always derive from personal relationships but can also be derived from a wider perspective. People can feel socially supported from the communities they live in, the workplace or school environment they exist within, or even congregations of faith. However, various misconceptions (along with differing perspectives and/or disagreements) among groups

can leave certain individuals feeling alienated, despite those very individuals searching for acceptance. In terms of CIs, the spread of misinformation often reinforces existing misconceptions, consequentially hindering one's sense of being seen and understood. One participant described their classroom peers as "understanding on a cognitive level ('this research says you have this, these are the symptoms etc.'), but they don't really feel it unless they also have the same conditions" (S4-1).

Various participants echoed the sentiment put forth by one interviewee: "it's pretty astonishing to see just how many stereotypes [about] this information exists in society" (S4-2). Just mentioning the term "chronic illness" can invoke judgments that perpetuate "negative stereotypes... in which a lot of people often believe [someone with a chronic illness] is going to die… or must live really unhealthy" (S4-6). Another misconception that creates social fear is that CIs are contagious. Such assumptions can disparage those living with CIs. As one participant shared, "I feel worse because people immediately assume that, you know, I would give them a disease" (S5-6).

One participant shared their experience with differing perspectives between generations and the various levels of acceptance for concepts such as MH:

"Like, even like to this day, I still have conversations with older people, and they definitely don't understand why there's so much mental health in the world now. And like, they don't understand that … we're like talking about it more and that there's more recognition about mental health versus like when they were younger, there was nobody talking about it. So, I think that they just blow it off because … when [they] were younger, these symptoms didn't pertain to a mental health disorder" (S4-7).

Stigma and Shame

Feelings of being inferior or even shame are a reality for many individuals living with a CI. Misconceptions and differing perspectives, amalgamated with people's biases, creates stigmas. Differences in one's social situation can drastically impact their experience of being shamed. Even if "its not necessarily intentional judgment, [people with CIs] feel like they are being treated differently" (S5-3). Given this, many individuals are left perplexed as to whether to disclose their illness with others. One participant stated that "I definitely don't keep [my CI] away from others, I feel that it's part of my identity just because it's chronic and it can't be treated really. I'm just more selective of who I tell" (S5-8).

In a society that glorifies hyper-independence, pursuing help of any kind is a rather humbling experience, especially having to admit you cannot make it on your own. Social support and encouragement can empower people to take action and seek help where needed, although when the opposite occurs and someone feels shamed, it can deter their willingness to do so. For one participant who was already reluctant towards interventions, the therapists embarrassed them by saying "well, I'm sorry I can't really help you with that. It seems like you just don't have the money to do that, huh? This is way too serious. And honestly, you should seek more professional help because I just can't help you" (S5-1). Such assumptions and condescending remarks left the participant feeling personally attacked and helpless.

One participant shared their frustrations with the disparities that hinder disability from being recognized as being on par with other forms of marginalization within the EDI movement, within which they perceived some groups being prioritized over others:

Equity seems to be important, like apparently, I learned for the first time this year that July is for disability, a month after Pride Month. Though no one knows about it or celebrates it, like its just always forgotten. Even … my school for example, when they're talking about equity seeking groups and equity action, they'll mention race or gender or LGBTQ plus, or SES, and disability always just seems to be forgotten. [I got] this e-mail saying there was … a professor [who] used this racist microaggression or said something to a student in the LGBTQ community, and [the university] will not stand for that. [Yet] there have been several disability microaggressions that [I] will raise to administration, but it goes dismissed. So, it just seems to be a little bit of a double standard" (S5-2).

Moreover, one participant described their experience with feeling embarrassed or too ashamed to even discuss or reveal their CI due to misconceptions and stigma towards their specific illness. The participant held back from saying anything because:

"There is kind of like a stigma with people who are [living with this condition] and people will just assume 'oh, like you're just fat, you just eat whatever you want, you're a pig and that's why.' And so, I never even wanted to say anything because I didn't want anybody to think of me like that and be like … I just simply downplayed it. And so that was like a big barrier" (S5-10).

MENTAL AND EMOTIONAL DISTRESS

Fear of the Unknown

Receiving a medical chronic illness diagnosis can be a scary ordeal. Irrespective of the nature of the disease or severity, not knowing what the future holds or how to proceed can become mentally exhausting. For one participant, "seeking help is already so daunting that when you put that onto someone [who is] already intimidated by change and being vulnerable, it's a

lot" (M1-1). The participant expressed how pursuing treatment can sometimes be a risk when the outcome or results are not guaranteed. For another participant, fear of the unknown became painstakingly apparent when they realized they are "going to have to deal with this, and it kind of sank in … this means that there really isn't a great treatment, so what are the options now" (M1-2). Similarly, concerns regarding the future of one's school and work arose:

> "The realization that this [is] chronic and something I'm gonna probably have to live with was difficult. You know, is there even any point of going to school anymore? Am I even gonna be able to do my job in like 5-10 years from now? And if it does eventually affect me, then you know that's what happens. But I'm not in control of what happens to me in the future, especially in regard to this, because I'm doing what I can to treat it. But for now, I shouldn't let that stop me from living my life the way I want to" (M1-3).

> "And you know at that time, for me, the biggest fear that I had was I didn't want to pull out of school. Fear was my biggest barrier cause like the fear of [having to potentially] drop out of school was real [because] I actually had a co-op opportunity lined up, so the stakes were high. But then the interview was when I was in the hospital, so I felt like I felt regret. I'm like, because of this condition I could have been working at [a great place], but I didn't have that opportunity. Like I was kicked out of [my university's] internship program because I had to drop this semester off. Like for me I felt like I missed out. The fear of missing out, yeah" (M1-9).

When it comes to being diagnosed and living with CIs, varying levels of uncertainty pervade people's newly found reality. Part of effective coping is learning how to preserve or increase one's mental health by not allowing such fears to trigger prolonged periods of mental distress.

Depression and Anxiety

For many, coping with the onset of a CI can result in mental distress where feelings of being depressed or anxious are experienced. Not being able to understand why something bad (negatively impacting) is occurring can leave individuals confused and distraught as exemplified below:

"I think my anxiety increased around getting sick more than it was already because now there was that additional fear of this could potentially get worse" (M3-2).

"It's related to your visible health … so once you feel strong mentally, you're able to get through so much more than you think and having, you know, feeling depressed or feeling low" (M3-3).

"I was dealing with depression because they're CI or they feel like everything's going downhill like I felt like that a lot" (M3-5).

"I knew I was an anxious person, and I just couldn't help the anxiety. So, it felt like I was in a never-ending loop of making myself worse and worse just because of something that I was feeling. Which it sucks because you're looking at your body and you just see your chronic illness manifesting itself, and then you get anxious about it" (M3-6).

One participant shared their experience with how the symptoms they were experiencing, along with the diagnosis and lack of medical understanding or support from physicians led to depression:

"Then in terms of the depression, when I was diagnosed it was like my breaking point. I had never talked to a doctor about symptoms. It was just my family physician, and she

didn't really ask those types of questions. I would always say I'm so tired and never want to do anything, how I'm not really motivated to do anything, but she kind of just brushed it off … So, the being diagnosed and being overweight as I was, it was 100% a core reason for being diagnosed with depression" (M3-10).

As exemplified by participants, dealing with a CI can induce various negative psychological outcomes such as depression, thus, including mental health support as part of holistic treatment plans is critical for optimal health and well being to be achieved.

Loneliness and Isolation

Having to deal with a CI at a young age can be a rather isolating experience when most of the people around you are relatively healthy. Aside from drawing constant comparisons to others, those diagnosed and living with a CI may often feel lonely in that no one around them understands because "they wouldn't really go through the same experiences" (M4-1). A participant shared how they "definitely feel isolated sometimes actually … but never realized it until now because [they've] always been a pretty disciplined person [given] the nature of the [career] goals … which kind of added into the isolation" (M4-8).

One participant described their struggles with wanting to be more social but having their CI be a hinderance, which left them lonely: "I mean, it's really hard you know, you want to go out with your friends, and you have to cancel last minute, and they don't understand why, it's really hard to explain" (M4-2). Similarly, another participant revealed that despite being engaged with others at social events, "there's still a form of exclusion when you didn't necessarily feel like you fit in with everybody else, because you can't do everything" (M4-3).

Even with having loved ones physically near, the failure to empathize or educate oneself on the matter (the CI) often leaves individuals feeling isolated, as highlighted below:

"Maybe having a chronic illness such as ADHD has left me feeling ostracized or like isolated because not a lot of people might experience what you have to live with? Like at first [you think you] have a great group of friends, but like, none of them have ADHD. My boyfriend doesn't have ADHD. My parents and my sister don't have any ADHD. I feel isolated because like I can't look at them and be like, you understand it because you deal with it on the day-to-day basis as well and trying to explain to them how my mind works is like near impossible. So, they kind of either have to just like agree to disagree or … try to understand how I'm feeling" (M4-7).

Being surrounded with people does not necessarily exclude an individual from feeling lonely. Part of having a strong social support is cultivating a network of quality relationships over quantity, where those closest have the capacity to provide support.

Self Perception and Comparing to Others

Young adults are already faced with several challenges related to one's sense of identity, and having to cope with a CI only further complicates the matter, as expressed by almost all participants within the study. At an age where self discovery is usually taking place, it is hard not to compare oneself with others when a life altering moment (such as being diagnosed with a CI) occurs. One participant described how their sense of self-worth deteriorated via constant comparisons to others because they "just wanted to be treated like everybody else like" (M5-3). Another participant shared that "you have to learn how to compartmentalize your own self and identity, which means deciding what aspects to share and what aspects do you suppress.

Learning how to do that effectively is a skill, but at the same time it's something we shouldn't need to do" (M5-1). Furthermore, similar sentiments revealed that:

> "When you get hit with such a thing as a diagnosis, it's very overwhelming because you look around and you're like, well, other people seem fine yet I'm not. I'm not even old. Like, why do I have to carry this problem? And then your kind of just feel a bit ostracized because you might not necessarily have anyone else in your personal social support that can understand your experience" (M5-3)?

Self perception has the ability to change under the influence of others, therefore, one's environment and who they choose to align themselves with matters. When people decide to care for someone, they must have the capacity to do so, otherwise such efforts could potentially exacerbate the problem.

> "If people aren't necessarily equipped with the knowledge and understanding or lived experience to fully conceptualize what you're going through, it's kind of like blindly supporting. At times you might even feel a bit parentified in that … people are kind of coddling you or giving you unnecessary sympathy, making you feel a bit like childish. (M5-7)

For some participants, their own doctors negatively impacted their mental stability by undermining their intelligence and/or refraining from showing compassion, as noted:

> "I never knew anybody with who was my age [with this CI], I've never heard of it. Usually, you hear about people who are 40's or 50's, so just felt like I'm the only one and the doctor didn't make it any better because he kind of alluded to the fact that like it was very abnormal and so and like there was something really wrong with me" (M5-10)

"I definitely see how that experience [with my doctor] was in a sense, taking away my autonomy and very much undermining my own thought process. Which is kind of like ironic because with chronic illness, you know, the hope is to equip … individuals with the ability to be self-sufficient and not have to rely on others' opinions but make conscious decisions for themselves" (M5-7).

Looking at things more optimistically, several participants shared how being diagnosed with a CI has changed their self-awareness for the better, giving them perspective and lived experience with overcoming adversity.

"Overall, I've always just put the idea that [my symptoms] kind of small things in my life and the only things that I'm really concerned with is my relationship with people. [Asking myself] am I acting morally good, and the [CI] is not a reflection of my moral goodness. So, I've always seen it as just a little thing to work on. It's just about perspective and like, you're widening that perspective to [realize that yes] this happened, but in regard to everything else in my life, does it really take that much importance" (M5-4).

"Like looking back, maybe this was a positive experience in a way because I made that mistake with few consequences. And now I know going forward, I would never do that again and I can educate other people to not experiment [with over-the-counter medication] because this is what happens. I'm trying to take the positive and look at well, things could have been much worse, and I could have been in a whole situation, but I'm still the same person … I'm using that perspective" (M5-5).

"In a way it was self discovery and understanding what's important … This disease really taught me what's important in terms of learning and what makes you happy. Because if

you're not content with what you have, your body is going to show it first, right? Like if I'm stressed out, my body is going to make everything very bad, so managing my own emotions is one thing. But being able to shift perspectives and take opportunities to kind of make yourself be in control your own story and work with the cards that you've [been] dealt, this disease has definitely helped me mature in that aspect and showed me not only how to regulate myself, but to build a team around me that can help support me" (M5-9).

Regardless of the circumstances, CIs inevitably alter individuals' realities in which they must adapt and reset expectations. Nevertheless, CIs do not have to be defining characteristics of one's worth even if they change one's identity. As exemplified by participants, the ability to embrace a newly found identity and rewrite one's life narrative is a matter of perspective.

Frustration and Anger

The absence of knowledge and lack of certain coping skills needed to fully understand/accept one's diagnosis can leave individuals "rather disappointed and really frustrated" (M6-1). When people typically think of sickness, there is an associated remedy or cure to feel better, but what happens when they are told the sickness is not going away any time soon or at all? Processing such news can invoke feelings of frustration and anger, especially when coming to the realization that one's life has changed, as shown:

"Once that medication started working, I felt terrible mentally because … I suffered physically for 11 years and here was this one simple treatment that could have made things so much better, right. Like that was really frustrating to have to go through all that for no reason. Like you're allowed to be mad. You're allowed to be mad at the world and then you'll move on" (M6-2).

"[Getting the diagnosis] definitely did have a mental toll on me and I'm like, I just kind of felt stuck. Definitely debilitating when you can't go places and all. Its so frustrating and quiet. You know, why is this happening to me" (M6-3)?

"I was getting really frustrated because I had no answers and we kept on thinking it was different conditions. And finally, I got the diagnosis. I was happy that I had an answer as to what it was, but I was also really frustrated because the answer to most of my problems just seemed to be it's gonna stay like this for the rest of your life" (M6-6).

"It's that frustration of it all, like why was it me that ended up with this or why did it take so long to figure this out" (M6-12).

Shock

While social determinants often help to structure how people handle situations, it is reasonable to assume that being in a state of shock is a typical human response when it comes to receiving a CI (depending on the CI an/or severity). Whether people have been experiencing symptoms and actively looking for answers or getting a diagnosis was completely unexpected, most participants were shocked when receiving the news, as noted:

"Very much of a shock because number one, I have never heard of this" (M7-1).

"And at that point, like your mind's not really in a place to seek out your own help. You are kind of just like trying to process what's happened" (M7-3).

"A bit of like a shock, I guess, because like nobody wants to obviously hear that they have to live with something that is debilitating in some sort of sense. It was a little bit of a shock because even though I knew it was a possibility, I didn't want it to be true" (M7-6).

"I was really shocked because I didn't have any symptoms at all. But it was still really shocking for it to happen to me because I'm a health-conscious person" (M7-8).

"… So of course, my first reaction was a lot of shock and confusion" (M7-9).

"I really found that like in that moment, like I was like, wow I can't believe this is happening" (M7-10).

The realization that one is experiencing something outside of the norm or anticipated trajectory often creates a plethora of unanswered questions in which an individual is taken back by surprise. Especially when it comes to young adults, the feeling of shock is apparent given that CIs are not typically seen within such a demographic.

Helplessness

When no clear solution is in sight, the trajectory of one's life looks uncertain, and the reality of what has occurred (getting a diagnosis) finally sinks in, people may feel helpless. Many participants shared feelings of being helpless during the onset of their CI:

"Just feeling helpless like, I think that lack of control is a huge thing with anxiety. And so, the fact that you just have this random someone telling you it's nothing, and you know it's not nothing, but you don't know if it's something really serious" (M8-2).

"When you're faced with the fact that you know it's something that will stay with you for the rest of your life, you start to ~~look~~ spiral a little bit and you wonder, like, could this have been stopped? … knowing that it can cause many other conditions in the future … really made me feel a little bit hopeless because looking at the list of conditions that

you're more susceptible to when you already have [a CI]. I feel really like hopeless I can't stop it and I can't really do anything to make it that much better" (M8-6).

"Things were out of my hands, and it made me feel really helpless at the time" (M8-8).

"The ambiguity really hit me because I'm like, at this point, what do I do with my life? Like there's one medication. That was my one [which didn't work]. Hope no longer works" (M8-9).

Some participants also shared their frustrations with trying to obtain treatment/help, in which failure to adequately do so resulted in feelings of helplessness:

"Reflecting on my mental health and how I could get through this, it was just me trying to survive. And if somebody else had provided me, you know, referred me to someone that I definitely think that I would have gotten over helped. (M8-3)

"The whole thing was very almost like traumatizing in a sense, because it's like you're trying to get the help, but then the help that you're getting isn't really useful because you can't, you know, accessibly access it in the right way because of the chronic illness you're enduring" (M8-7).

When someone believes that they have no control over their situation and that nothing can be done to improve one's situation, feelings of helplessness arise. However, by educating someone and equipping them with the necessary skills/resources to navigate their circumstances, such helpless feelings can be mitigated.

Sense of Relief and Being Validated

While receiving a CI diagnosis can be psychologically debilitating at times, it can also provide a sense of relief to those who have been experiencing symptoms and can now attribute their suffering towards something identifiable, as expressed through participants:

"It was really honestly validating to receive those diagnoses because finally I'm not making this up and it was it like I have the means to communicate what's wrong with me now … Like it's hard to do that (come to terms with the CI) but [the diagnosis] was validating my own experiences like knowing that none of it was my fault" (M2-1).

"It was weird, like the second I got into my car. It was like a I told you so moment like it was a very almost like a celebratory [because it's] validating that this is not in your head, but we just don't know what it is" (M2-2).

"When I initially got the diagnosis, I was relieved because I've been experiencing these symptoms and I didn't know what it was, and nobody was able to tell me what it was. So finally, when I figured it out, I was just relieved that OK, now they know what it is, and we can treat it" (M2-3).

"The initial diagnosis was a huge sense of relief. Just knowing what it was" (M2-5).

"Then it took me a while to realize that it wasn't my fault. It was just something that happens and it's just something that you have to learn to live with" (M2-6).

"I would say the experience was very relieving to me because I always wanted that diagnosis, but just never had the courage to … seek it out myself with doctors and stuff. When they told me I had the diagnosis, I was … not shocked at all, and I was just

thankful, like finally, finally, somebody's diagnosed me with this. And I can get all

medication and actually start my recovery process with [my chronic condition] instead of

just dealing with it, struggling with it, and having bad connotations against it" (M2-7).

While being diagnosed can pose several psychosocial challenges in terms of overcoming various barriers, ruptured identities, and/or changing the trajectory of one's anticipated life narrative, it can also benefit individuals by alleviating some of their uncertainty. From participants' experiences, even if the course of their CI is unclear, just being diagnosed validates them to the point where prior doubts and skepticism surrounding the legitimacy of their struggles are dismantled. The idea that one's issues are real and have a name attached to them allows individuals to regain both the mental stability and reassurance needed to pursue treatment/help. When this occurs, individuals are empowered to regain a sense of direction in which they can actively rewrite the next steps within their lives.

SUMMARY OF RESULTS

Figure 2: summary of results

Overall, the findings of this study suggest that participants' lived experiences and age, amongst other social determinants, play a key role in shaping their psychosocial health and perceived well being post-diagnosis. The findings indicate that while receiving a MCID may be intentional/pursued rather than unexpected for some, all participants who initially identified with having mental distress and/or relief while receiving the diagnosis echoed sentiments of frustration while accepting their new reality. Upon thematically analyzing participants' experiences, three main psychosocial impacts of receiving a CI diagnosis were apparent: various barriers/facilitators, types of social support, and emotional/mental hardships – all of which

complicates the acceptance and management of one's illness, which, in turn affects one's ability to successfully achieve optimal health and well being.

The findings of this study indicate that the types of barriers participants face are highly contingent upon social determinants to the point where such aspects can serve as facilitators in promoting health depending on one's circumstances. Even one's ability to process and accept their diagnosis is influenced by social determinants such as education, access to care, and economic stability. Similarly, the findings highlight the importance of having a social community in terms of feeling supported and empowered to navigate obstacles such as a CI diagnosis.

At the same time, participants also shared some similar emotional/mental distress irrespective of differing social determinants. For participants whose diagnosis itself resulted in mental distress, their initial experiences suggest that feelings of fear, being overwhelmed, and complications with reconstructing one's sense of identity are common reactions to receiving a CI diagnosis. It should be noted that such findings are not indicative of everyone's experience with CI and those who did not struggle with receiving their diagnosis may not experience these psychosocial impacts. With that being said, participants' ability to effectively cope after the 'initial shock' of being diagnosed is influenced by their personal experiences with exposure to CI education, sense of faith/outlook on life, and representation within society (ability to identify with others who shared the same struggle).

In addition, the willingness of each participant to seek treatment and MH support appears to play a role in influencing their recovery. For many participants, life returning to what once was may never be an option, but the idea of regaining a healthy state is a plausible goal. Those who deemed that their illness helped develop a sense of perspective, aiming to be more

intentional with life, were far more equipped to overcome mental challenges and manage their illness.

DISCUSSION

As exemplified through the experiences of participants within this study and the literature, receiving a medical CI diagnosis impacts young adults' MH by causing and/or exacerbating psychological distress in multiple ways (Shih & Simon, 2008; Wicks et al., 2019). The implications of being diagnosed with a CI (and learning to cope while accepting the diagnosis) differentially impacted participants based on influencing factors such as exposure to barriers/facilitators and type of social support. Moreover, despite participants' experiences varying based on types of CIs, severity of illness, underlying SES etc., all participants reflected similar challenges with their emotional, psychological, social, and physical well being. Differences in both one's SDoH and the types of psychosocial distress endured can be used as a basis to better understand the MH of young adults diagnosed with a CI, as well as why discrepancies exist within the literature. The following section will discuss how young adults' experiences with receiving a CI diagnosis compare to the literature and will explore its psychosocial implications.

One of the predominant negative MH outcomes of being diagnosed with a CI is its impact on one's identity. Due to a biographical disruption (CI), young adults mourn the loss of their former self, forcibly birthing the creation of a new identity – though this identity forms with restrictions that must be accepted (Wilson & Stock, 2019). Findings from this study reinforced arguments put forth by scholars, suggesting that anticipated life plans often change with the onset on CIs, resulting in a loss of coherence in the narratives individuals created for themselves, ultimately shifting one's sense of worth and identity (Wicks et al., 2019). Acceptance has been

described as a fundamental component towards improving MH and emotional functioning, where being at peace with the limitations and losses associated with one's condition allows for the formation a new identity (Walker, 2010; Wilson & Stock, 2019). Almost all participants shared experiences with their personal struggles of coming to terms with their newly found reality and accepting their diagnosis. In terms of identity issues, the question of 'why me' and the perceived notion that CIs are typically for the aging were thoughts participants grappled with. Achieving a better quality of health appeared to be more attainable only when participants first gained a true sense of understanding and acceptance for their CI, in which they were able to embody optimism.

As mentioned, when biographical disruption occurs, the identity reconstruction process is arguably more convoluted and psychologically damaging for younger adults in comparison to their older counterparts. Given that young adults' chronic conditions occur outside of expected developmental contexts, they particularly struggle with the integration of their experiences (receiving the diagnosis) towards the formation of a new identity (Wilson & Stock, 2019). In line with the experiences of participants, CIs amongst young adults disrupt day-to-day activities, intended plans for the future, and one's overall MH. The process of being diagnosed may initially be a relief, but sooner after induces anxieties as individuals grasp their new reality. The biographical disruption of receiving a CI diagnosis prompts individuals to examine their life, past, present, and future – where they must learn to let go of prior desires (if no longer attainable), and redefine their identity based on new expectations (Charmaz, 1995). With that being said, constant comparisons to one's former self, others, or the expected norm, makes adjusting one's life anticipations rather difficult, as exemplified by participants' experiences. Furthermore, the present findings reinforce Bury's concept of biographical disruption that

encompasses ruptured identities as a result of grappling with one's reality pre and post diagnosis. Contingent upon one's perspective, as chronically ill individuals grieve the loss of former aspects of their identity, new characteristics may also emerge, both positive and negative.

Similarly, the constant stress of adjusting to life after a disruption (the diagnosis) that inevitably changes the trajectory of one's life can be emotionally and mentally taxing. Having to cope with a newly diagnosed CI can antagonize individuals to the point of being more likely to experience mental issues, such as anxiety and/or depression (Revenson & Hoyt, 2016). Participants described the onset of their CIs as a tumultuous experience, seeing that letting go of their former lives and learning to embrace their newly found realities were difficult. While some participants expected the diagnosis, and others were taken back by it, all reiterated feelings associated with depression and anxiety to some degree. Such MH issues (despair and anxiety) were often triggered by encountering barriers that hindered effective coping. Despite research suggesting that young adults with chronic conditions are more likely to partake in risky behaviors such as binge drinking, smoking, and physical inactivity when emotionally triggered, results of this study suggest otherwise (Watson et al., 2019). Dependent upon sociodemographic characteristics, participants had access to care, higher levels of health literacy as a result of post secondary education, and some level of social support – all of which likely contributed to their success in abstaining from risky behaviours.

Various barriers, issues with social support, and emotional/mental distress all complicate one's ability to effectively manage their CI and pursue an optimal HRQoL (Shih & Simon, 2008). The ramifications of CIs often portray a circular effect (refer to figure 1), causing distress both directly and indirectly, which diminishes the ability to enjoy optimal health, subsequentially causing more distress. Participants within this study noted several obstacles they faced while

coming to terms with their CI. Along with traditional social determinants hindering one's ability to overcome hurdles, struggles with day-to-day activities and time management were reported from participants. Participants also attributed lack of awareness and health literacy communication as barriers towards managing their CI, in which feelings of frustration, stress and helplessness arose. Such findings reinforce the need for health professionals to evaluate management/coping strategies so that solutions can be holistic. Moreover, CIs demand daily attention, seeing that a 'cure' is not always possible, where adequate management aims to reduce the disease burden of the condition (Baumann & Dang, 2012). Being able to provide self-care is a necessary component towards effective CI management; thus, health education combined with lifestyle skills must be provided when creating personalized treatment plans.

Literature has already explored the impact of receiving a CI diagnosis (biographical disruption) and the psychosocial implications of living with a chronic condition, though identifying the factors which elicit similar responses towards diagnosis reactions and coping strategies are rarely explored. With that, participants' experiences highlighted how the overall emotional aspect of the diagnosis process trickles down into their lives as they cope with their illness. Self-management is a crucial component of care for those with CIs and goes far beyond adhering to a regimen, but rather starts with collecting one's emotions and thoughts (Audulv, 2013). Based on one's experiences and social determinants, various factors can serve as barriers or facilitators towards the promotion of MH and QoL/well being. Transitional self-management of CIs often takes place before an understanding and acceptance of one's diagnosis occurs. Adhering to appointments, treatments, medications, lifestyle changes etc. can start the day someone gets diagnosed, whereas fully coming to terms with one's newly found reality (adjustment) takes time (de Ridder et al., 2008). As reinforced from results within the study, the

skills and resources required to overcome the psychological stress of receiving a diagnosis are also needed as individuals begin to navigate their new life and learn to cope with a CI.

Limitations and Strengths

From reviewing the extant literature and analyzing participants' lived experiences, this study has attempted to explore the psychosocial impact of being diagnosed with a CI. However, the findings should be interpreted with caution for several reasons. First, the aim of this study was to determine the psychological impact of being diagnosed with any CI, meaning that the focus was geared towards how receiving such life-altering news affects one's MH. As such, the study does not account for the experiences of those with little to no emotional/mental impact or variations in symptomology, severity, mortality, or any other specifications relating to a particular CI. Secondly, despite participants providing rich information that aided in understanding about the mental impact of CIs, the sample size was small and may not be generalizable to other populations.

Another limitation within this study surrounds the recruitment methods. Participants being recruited from universities creates an unfair advantage in which their health literacy levels may not be indicative of all young adults, such as those who cannot attend post secondary education or access the health resources that are provided within such establishments. Also, the choice to employ purposive sampling may unintentionally create biases within the research, shifting the lens from objective to subjective. In order to choose participants with purposive sampling the researcher makes subjective assumptions, therefore such findings cannot be extrapolated towards the public, but instead, the findings are indicative of those within certain parameters. Given this, any generalizability from findings is only indicative of those who admit to psychosocially struggling with things such as acceptance and coping.

Future Work

The influence of receiving and having to cope with a CI on young adults' MH was explored within this study, with participants indicating that they would greatly benefit from MH and social support services. Such services could alleviate the burden of coping, recognize depressive symptoms, and mitigate feeling of helplessness or frustration that often arise while adapting (NIMH, 2021). With the aid of emotional and behavioural interventions for effective adjustment via cognitive-behavioural, mindfulness, and forgiveness therapies, the enhancement of one's MH may be achieved (Revenson & Hoyt, 2016). Future work may want to assess the current healthcare delivery practices with respect to CI treatments and incorporate mental services as part of effective treatment. Health professionals along with public/global health agencies should focus on mitigating the negative MH consequences of CIs to improve one's overall QoL. Young adults have identified several targeted areas of professional MH support that should be considered: promotion of positive thinking, understanding biographical disruption/learning to reconstruct one's identity, and acceptance of limitations and losses (Wilson & Stock, 2019). Furthermore, while this study explores participants' QoL, it does not account for influencing factors such as gender, type of CI, severity of illness, or culture. Such factors should be considered when evaluating the psychosocial impact of receiving a CI.

Conclusion

In conclusion, results from this study indicate that being diagnosed with a CI can impact young adults' MH (emotionally, psychologically, spiritually, physically) by causing and/or exacerbating various types of distress. Whether these distressing burdens are experienced vastly or not depends on an individual's personal experience that is based on various factors such as social determinants and perception of reality. Results from the study suggests that while the

nature of one's CI and lived experience may differ drastically, similar themes such as uncertainty, feelings of anxiety and depression, reconfiguring one's self-identity, overcoming barriers, and obtaining social support emerged for those who initially struggled mentally. Those who were able to psychologically adapt to their new norm (accepting their diagnosis and effectively coping) mitigated the ramifications of their CI onset.

Irrespective of treatments and management solutions being available, a plethora of systematic, physical, social, and mental barriers exists when attempting to obtain them. Given that, ensuring the accessibility of such treatments must take precedence when evaluating the efficacy and tangibility of current healthcare practices relating to CIs. As exemplified through participants' lived experiences, MH services should be considered equally as important in relation to other combined treatments; thus, healthcare professionals should seek to provide such resources. Furthermore, ensuring individuals are emotionally and mentally equipped to handle the hardships of living with a CI is imperative towards minimizing the deleterious effects long-term conditions have on one's QoL. Those living with CIs must strive towards regaining their independence, sense of worth, identity, positive perspective, and social engagement, should one strive for optimal health and well being.

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Table 1: Thematic Analysis Codes

THEME	CODE	DESCRIPTION
Barriers	B1	Socio economic status
	B2	Access to healthcare / treatment
	B3	Education
	B4	Lack of awareness
	B5	Employment
	B6	Lack of organization / time
	B7	Health literacy / communication
	B8	Day to day life and activities
Social support	S1	Family pressure
	S2	Social support / friends
	S3	Medical/professional support
	S4	Misconceptions
	S5	Stigma and shame
	S6	Community and culture
Mental and emotional distress	M1	Fear of the unknown
	M2	Sense of relief / validation
	M3	Depression / anxiety
	M4	Loneliness / isolation
	M5	Self perception/Comparing to others
	M6	Frustration / stress / anger
	M7	Shock
	M8	Helplessness

GUIDING QUESTIONS FOR CASE STUDIES

Psychosocial Impact of Receiving a Medical Diagnose(s) towards mental health and overall quality of life amongst young adults

Student Investigator: Jonathan Ramdawar, Department of Health Sciences (Global Health), McMaster University

1. What chronic illness were you diagnosed with, and when did you receive your diagnosis?

2. What was your immediate reaction to receiving the diagnosis?

3. Did you have any emotional or social support when receiving your diagnosis?

4. Did your healthcare provider equip you with secondary/other resources to handle your chronic illness or provide you with guidance towards finding mental/social/emotional support services?

5. How has your life changed since receiving your diagnosis?

6. What barriers exists that prevent you from living the most optimal life possible (challenges with QoL)?

7. Have you noticed and changes in your mental health since being diagnosed?

8. That treatments/services were offered to you upon diagnosis, and were you given informed options?

9. Have you consulted or used any sort of mental health service since being diagnosed to cope with your chronic illness? If no, what factors have hindered you from doing so?

10. What advice would you give to someone who has just been diagnosed with your chronic illness?

Version 2 | April 23, 2022

Participants Needed!

We are looking for volunteers (male and female) to take part in a research study looking at how receiving a medical diagnosis for a chronic illness psychologically impacts young adults' mental health.

We are looking for participants between the age of 18-25 who have been diagnosed and living with a chronic illness.

You will be interviewed about your experience with receiving such a diagnosis, and how you've coped with that diagnosis in terms of pursuing optimal health (socially, mentally, physically, emotionally).

The total time commitment is 1 hour, and you will receive a $20 gift card compensation for your time.

For More information about this study, or to volunteer for this study, please contact:
Jonathan Ramdawar
McMaster Global Health Department
Email: ramdawaj@mcmaster.ca

This study has been reviewed and by the Hamilton Integrated Research Ethics Board under Project 14595

Version 3 | May 12, 2022

Appendix C: Informed Consent Form

LETTER OF INFORMATION / CONSENT

Psychological Impact of Receiving a Chronic Medical Diagnose(s) amongst young adults

Investigators:

Local Principal Investigator:
Dr. Mat Savelli
Department of Health, Aging & society
McMaster University
Hamilton, ON, Canada
(905) 525-9140 ext. 24166
E-mail: savellm@mcmaster.ca

Student Investigator:
Jonathan Ramdawar
Department of Health Sciences (Global Health)
McMaster University
Hamilton, ON, Canada
905-409-3180
E-mail: Ramdawaj@mcmaster.ca

Purpose of the Study

This study seeks to investigate how receiving a chronic medical diagnosis impacts young adults' aged 18-25 MH (psychological effects). Attempting to answer this question would illuminate the social, emotional, and psychological implications of being diagnosed and living with a CI (along with the physical barriers). The study would explore what resources/coping methods are currently available. Given that developed countries generally have higher rates of CIs as opposed to communicable diseases, this study seeks to address such an issue by yielding participants within Ontario Canada. Such research could reveal connections towards how mental and physical health are connected. By critically analyzing the current state of healthcare infrastructure, gaps situated within post diagnoses management could be identified. Rather than trying to quantify results, this study seeks to understand human nature by unearthing the complexities (truths) that reside within coping strategies for people living with CIs.

You are invited to take part in this study anytime between June– august of 2022. I want to interview you about your experience with being diagnosed and living with a CI. I am hoping to learn about the psychological impacts (emotional, mental, social) of receiving such a diagnosis. I also hope to find out what post-care services are being provided to those coping with CIs.

Procedures involved in the Research
During the study you will be interviewed on a personal/private basis. Being asked a series of open-ended questions regards their own experiences. The interview will be semi-structured, meaning that there is room for conversation beyond the pre-determined questions. Answers towards these questions will be recorded and stored for further analysis.

Interviews will be conducted either in person on McMaster University campus or virtually through video calling (depending on the Covid situation). You will need to allot approximately 1 hour of your time towards the interview on the date and time of your choice (date must be confirmed and suitable with the interviewer). During the case study, you will be personally interviewed about your experience. The study is looking to interview a total of 8-12 participants, in which your answers will be compared with others'

responses. Digital notes will be made through a laptop and saved in a secure folder drive with your permission.

Possible questions could be:
1.   What CI were you diagnosed with, and when did you receive your diagnosis?

2.   What was your immediate reaction to receiving the diagnosis?

3.   Did you have any emotional or social support when receiving your diagnosis?

I will be asking you questions about the nature of your diagnosis with regards to MH. Seeing how you handled that experience and if you had any support. I will also ask you for some demographic/background information like your age, gender, education, job status etc. to identify how various SDoH contribute towards coping with a CI, and the ability to achieve optimal well-being.

Potential Harms, Risks or Discomforts:

The risks involved in participating in this study are minimal. You may feel uncomfortable with sharing such personal experiences. You may find it stressful and even traumatic to recall such a life-altering event.

You do not need to answer questions that you do not want to answer or that make you feel uncomfortable…. And you can stop to take a break. You can withdraw (stop taking part) at any time. I describe below the steps I am taking to protect your privacy.

Potential Benefits

The research will not benefit you directly although it can be therapeutic to talk about your experiences and share them. Seeing that the pressure of coping with a CI can have severe psychological ramifications if not dealt with effectively, I hope to learn more about the barriers (social, physical, emotional) towards living a fulfilled and healthy life that arise from managing a CI. Given that experiencing a sudden shift in one's health is a life altering event, even traumatizing, exploring what social/emotional/mental impact and support services are available to people receiving medical diagnoses is critical towards diagnosis management. In doing so, the intersectionality that exists between the onset of a CI and feelings of loneliness/isolation with regards to MH could be illuminated.

Payment or Reimbursement
Participants will be provided with a gift card via email as a thank you for their time and effort.

Confidentiality

Every effort will be made to protect your confidentiality and privacy. I will not use your name or any information that would allow you to be identified. However, we are often identifiable through the stories we tell. Any personal information that could identify you will be removed or changed before files are shared with other researchers or results are made public. Though I will report direct quotations from the interview, you will be given a pseudonym, and all identifying information will be removed from our report

The information/data you provide along with audio recordings will be kept on a computer will be protected by a password. Identifying information will be kept until the thesis dissertation is completed and defended. Once the study is complete data will be archived without identifying information for future research and publishing purposes. Only I will have access and analyze the audio recordings. Participants are reminded to not make their own personal recordings of the interview.

For the purposes of ensuring the proper monitoring of the research study, it is possible that a member of the Hamilton Integrated Research Ethics Board may consult your research data. By signing this consent

form, you authorize such access.

This study will use Microsoft Teams (McMaster's access) platform to collect data, which is an externally hosted cloud-based service. A link to their privacy policy is available here (https://office365.mcmaster.ca/privacy-in-microsoft-teams/). While the Hamilton Integrated Research Ethics Board has approved using the platform to collect data for this study, there is a small risk of a privacy breach for data collected on external servers.

If you are concerned about this, we would be happy to make alternative arrangements for you to participate, perhaps via telephone. Please talk to the researcher if you have any concerns.

By participating in this study, you do not waive any rights to which you may be entitled under the law

Participation and Withdrawal

Your participation in this study is voluntary and it is your choice to be part of the study or not. If you decide to be part of the study, you can decide to stop (withdraw) at any time by notifying me (verbally or in writing). You can withdraw even after signing the consent form or part-way through the study. If you decide to withdraw, there will be no consequences to you. You have the option of removing your data from the study. If you do not want to answer some of the questions you do not have to, but you can still be in the study.

Information about the Study Results
[*Alternate wording:* **How do I find out what was learned in this study?**]

I expect to have this study completed by approximately *November 2022.* If you would like a brief summary of the results, please let me know how you would like it sent to you.

Questions about the Study

If you have questions or need more information about the study itself, please contact me at: ramdawaj@mcmaster.ca or 905-409-3180*.*

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HiREB). The HiREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the Chair, HiREB, at 905.521.2100 x 42013.

CONSENT

I have read the information presented in the information letter about a study being conducted by Jonathan Ramdawar*,* of McMaster University.
I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.
I understand that if I agree to participate in this study, I may withdraw from the study at any time. I will be given a signed copy of this form. I agree to participate in the study.

_____   _____   _____

Name of Participant (Printed)   Signature   Date

Consent form explained in person by:

_____   _____   _____
Name and Role (Printed)   Signature   Date

Appendix D: Hamilton Integrated Research Ethics Board Letter of Approval

Hamilton Integrated Research Ethics Board

Jun-01-2022

Project Number: 14595

Project Title: Psychological Impact of Receiving a Chronic Medical Diagnose(s) Amongst Young Adults

Student Principal Investigator:

Local Principal Investigator: Mr. Mat Savelli

We have completed our review of your study and are pleased to issue our final approval. You may now begin your study.

The following documents have been approved on both ethical and scientific grounds:

Document Name	Document Date	Document Version
Data collection sheet CLEAN COPY	May-12-2022	2
email correspondance scripts version 2 CLEAN COPY	Apr-23-2022	2
guiding questions for interviews CLEAN COPY	Apr-23-2022	2
Informed Consent form CLEAN COPY	May-12-2022	3
Participant recruitment poster version 2 CLEAN COPY	May-12-2022	2
STUDY KEY version 2 CLEAN COPY	May-12-2022	2
Research Proposal Study protocol VERSION 3- CLEAN COPY	May-08-2022	3

The following documents have been acknowledged:

Document Name	Document Date	Document Version
Savelli HIREB tcps2-eptc2-certificate	Jan-19-2021	1
cover letter for provisional approval version 2	May-30-2022	2
Cover letter for provisional approval revisions	May-13-2022	Version 1

In light of the current COVID-19 pandemic, while HiREB has reviewed and approved this application, the research must be conducted in accordance with institutional and/or public health requirements.

Any changes to this study must be submitted with an Amendment Request Form before they can be implemented.

This approval is effective for 12 months from the date of this letter. Upon completion of your study please submit a **Study Completion Form**.

If you require more time to complete your study, you must request an extension in writing before this approval expires. Please submit an **Annual Review Form** with your request.

PLEASE QUOTE THE ABOVE REFERENCED PROJECT NUMBER ON ALL FUTURE CORRESPONDENCE

Good luck with your research,

Kristina Trim, PhD, RSW
Chair, HiREB Student Research Committee

The Hamilton Integrated Research Ethics Board (HiREB) represents the institutions of Hamilton Health Sciences, St. Joseph's Healthcare Hamilton, Research St. Joseph's-Hamilton, the Faculty of Health Sciences at McMaster University, and Niagara Health and operates in compliance with and is constituted in accordance with the requirements of: The Tri-Council Policy Statement on Ethical Conduct of Research Involving Humans; The International Conference on Harmonization of Good Clinical Practice Guideline (ICH GCP); Part C Division 5 of the Food and Drug Regulations of Health Canada, Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act 2004 and its applicable Regulations. For studies conducted at St. Joseph's Healthcare Hamilton, HiREB complies with the Health Ethics Guide of the Catholic Alliance of Canada.