

**ILLNESS IDENTITY AND PREFERENCES FOR GROUP THERAPY IN
ADULTS WITH CHRONIC ILLNESS**

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DEDICATION

This thesis is dedicated to many remarkable people in my life: to my grandmother, Elenore Kubik, who never let chronic pain or chronic illness stop her from living life to the fullest; to my partner, who has provided his unconditional love and support (since day one); and to my friends and family, who have encouraged and inspired me through every stage.

ABSTRACT

This thesis explored, through an online survey, the illness perceptions and group therapy preferences of 213 adults with chronic health conditions. This research study was the first to introduce the concept of illness identity to the context of group therapy and filled significant gaps within the literature regarding the firsthand preferences of this population. The participants were recruited through a variety of social media platforms, including chronic illness support groups on Facebook. Descriptive and nonparametric statistics were used to explore: (a) what adults with chronic illness want from group therapy, (b) how illness identity was characterized in this transdiagnostic sample, and (c) how illness identity relates to preferences for group therapy. The data demonstrated that illness identity significantly related to preferences regarding the characteristics of group leaders, elements of group structure, and topics to address in group. Future directions for research and practice recommendations for group therapists are provided.

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TABLE OF CONTENTS

DEDICATION.....	iii
ABSTRACT.....	iv
ACKNOWLEDGEMENTS.....	v
TABLE OF CONTENTS.....	vi
LIST OF TABLES.....	x
CHAPTER 1: Chronic Illness Identity and Group Therapy.....	1
<i>Chronic Illness and Illness Identity</i>	1
<i>Psychological Support for Chronic Illness</i>	2
<i>Group Therapy for Chronic Illness</i>	3
<i>Research Question</i>	5
<i>Contribution of this Thesis</i>	5
<i>My Personal Interest in this Topic</i>	6
<i>Thesis Overview</i>	11
CHAPTER 2: Chronic Illness.....	13
<i>Defining Chronic Illness</i>	13
<i>Psychological Wellbeing and Quality of Life</i>	15
<i>Coping with Chronic Illness</i>	18
<i>Professional Mental Health Support</i>	22
<i>Collaborative Care</i>	24
<i>Limitations in Mental Health Support</i>	25
<i>Illness Identity</i>	29
<i>The Four States of Illness Identity</i>	31
<i>Illness Identity and Counselling Practice</i>	34
<i>Factors Shaping Illness Identity</i>	35
<i>Social Support</i>	38
<i>Chapter Summary</i>	41
CHAPTER 3: Group Therapy for Chronic Illness.....	42

<i>Overview of Group Counselling</i>	42
<i>Advantages of Group Therapy</i>	43
<i>Types of Groups</i>	44
<i>Therapeutic Factors in Group Therapy</i>	49
<i>Mechanics of Group Therapy</i>	55
<i>Group Therapy Preferences of Individuals with Chronic Conditions</i>	61
<i>Illness Identity and Preferences for Group Therapy</i>	63
<i>Chapter Summary</i>	65
CHAPTER 4: Client Preferences	66
<i>Importance of Client Perspectives</i>	66
<i>Exploring Client Preferences</i>	68
<i>Chapter Summary</i>	71
CHAPTER 5: Synthesis of Research Question	72
<i>Invite the Perspectives of Individuals with Chronic Illness on Group Therapy</i>	72
<i>Characterize Illness Identity in a Transdiagnostic Sample</i>	73
<i>Explore Whether Illness Identity Relates to Preferences for Group Therapy</i>	74
<i>Contribution of Thesis Study</i>	75
CHAPTER 6: Methods	76
<i>Participants</i>	76
<i>Measures</i>	77
<i>Chronic Illness Survey Items</i>	77
<i>Illness Identity Questionnaire (IIQ)</i>	80
<i>Group Therapy Preferences Survey Items</i>	84
<i>Demographic Information</i>	86
<i>Procedure</i>	87
<i>Informal Miniature Pilot Testing</i>	88
<i>Recruitment Strategies</i>	89
<i>Online Survey</i>	91
<i>Data Analysis Strategy</i>	95

<i>Data Preparation</i>	96
<i>Normality Diagnostics</i>	97
<i>Somers' D</i>	97
<i>Invite the Perspectives of Individuals with Chronic Illness on Group Therapy</i>	98
<i>Characterize Illness Identity in a Transdiagnostic Population</i>	98
<i>Explore Whether Illness Identity Relates to Preferences for Group Therapy</i>	99
<i>Demographic Data</i>	100
<i>Qualitative Responses</i>	100
<i>Permissions</i>	100
<i>Chapter Summary</i>	101
CHAPTER 7: Results	102
<i>Demographic Information</i>	102
<i>Research Question</i>	106
<i>Invite the Perspectives of Individuals with Chronic Illness on Group Therapy</i>	106
<i>Characterize Illness Identity in a Transdiagnostic Sample</i>	117
<i>Explore Whether Illness Identity Relates to Preferences for Group Therapy</i>	131
<i>Chapter Summary</i>	143
CHAPTER 8: Discussion.....	144
<i>Discussion of Results</i>	144
<i>Demographic Information</i>	144
<i>What Do Adults with Chronic Illness Want from Group Therapy?</i>	144
<i>How was Illness Identity Characterized in this Transdiagnostic Sample?</i>	145
<i>How Does Illness Identity Relate to Preferences for Group Therapy?</i>	146
<i>Strengths</i>	147
<i>Limitations</i>	149
<i>Future Directions and Treatment Implications</i>	156
<i>Additional Areas for Future Research</i>	156
<i>Recommendations for Group Therapists</i>	160
<i>Reflection</i>	164
<i>Conclusion</i>	166

References.....	167
Appendix A: The Four States of Illness Identity	190
Appendix B: Requests for Permission	191
<i>Permission to use Illness Identity Questionnaire (IIQ)</i>	191
<i>Permission to adapt Illness Identity Questionnaire (IIQ)</i>	192
<i>Permission to adapt Support Group Perceptions Questionnaire</i>	193
<i>Permission to share survey: Chronic Illness Support (Facebook)</i>	194
<i>Permission to share survey: Coping with Chronic Illness and Chronic Pain</i>	195
<i>Permission to share survey: Science-Based Chronic Illness Support</i>	196
<i>Survey Sharing Groups</i>	197
Appendix C: Survey Invitations.....	200
<i>Survey Invitation Graphic</i>	200
<i>Survey Invitation: Chronic Illness Support (Facebook)</i>	201
<i>Survey Invitation: Coping with Chronic Illness and Chronic Pain (Facebook)</i>	202
<i>Survey Invitation: Science-Based Chronic Illness Support (Facebook)</i>	203
<i>Survey Invitation: Survey Sharing Groups (Facebook and LinkedIn)</i>	204
<i>Survey Invitation: Personal Social Media Pages</i>	205
Appendix D: Informed Consent.....	206
Appendix E: Survey	212
Appendix F: Human Research Ethics Approval Form	227
Appendix G: Chronic Conditions Reported by Participants.....	228

LIST OF TABLES

Table 1: Age and Gender Identity of Participants	103
Table 2: Location of Participants	104
Table 3: Recruitment Strategies Reported by Participants	105
Table 4: Duration of Time Used to Complete Survey	106
Table 5: Treatment Preferences of Participants	108
Table 6: Examples of Other Helpful Supports Reported by Participants	109
Table 7: Therapist Preferences of Participants	110
Table 8: Activity Preferences of Participants	113
Table 9: Number of Conditions Reported by Participants	118
Table 10: Conditions Reported by Participants	119
Table 11: Chronic Conditions Most Frequently Reported by Participants	120
Table 12: Conditions Reported to Affect Life the Most	121
Table 13: Diagnostic Status, Time, and Coping with Conditions that Affect Life the Most.....	123
Table 14: Self-Rated Illness Identity	124
Table 15: Illness Identity Questionnaire (IIQ) Scores of Participants	125
Table 16: Crosstabulation Between IIQ Scores and Self-Rated Illness Identity	127
Table 17: Relationship Between Chronic Conditions and Illness Identity	130
Table 18: Somers' D Values for Treatment Preferences	134
Table 19: Somers' D Values for Therapist Preferences.....	137
Table 20: Somers' D Values for Activity Preferences.....	141

CHAPTER 1: Chronic Illness Identity and Group Therapy

Chronic health conditions are highly prevalent and pervasive. Many factors contribute to one's ability to cope with chronic illness, and these factors have significant implications for psychological well-being. Often, the psychological consequences of chronic illness may become overshadowed by complex treatments for physical symptoms. I have noted the need for increased mental health support for this population. Considering the existing research, I regard group therapy as valuable support for many people with chronic conditions. Providing adequate support for this population requires an increased understanding of the experiences and perceptions of individuals with chronic illness. However, I argue that the research insufficiently represents the voices of these individuals. More work is needed for the mental health community to recognize and accommodate the needs and preferences of this population.

In this chapter, I will provide an overview of the focus of this study. After outlining my thesis topic, I will present my research question and the intended contribution of my thesis. I will provide some context around my interest in studying chronic illness. Lastly, I will conclude this chapter with an outline of the remainder of this thesis. Throughout the upcoming chapters, I will build my argument for this thesis and its potential impact. With this study, I aimed to contribute a unique perspective to the existing knowledge regarding group therapy for chronic illness.

Chronic Illness and Illness Identity

Chronic illness can be conceptualized as the individual experience of living with a chronic medical condition (Martin, 2007; White et al., 2018). Living with chronic illness is a complex and continuous experience. As such, chronic illness is frequently associated with mental health difficulties and decreased quality of life (Cella & Nowinski, 2002; Coventry et al., 2015; Roberge et al., 2016; White et al., 2018; Zheng et al., 2020). Often, individuals must partake in

self-management of their chronic conditions outside of the care of medical professionals (Ausili et al., 2014). In addition to self-management of physical symptoms, individuals must also navigate the processes of coping with the psychological impacts of chronic illness, which involves integrating their illness into their lives to find new ways of living (Ambrosio et al., 2015). The burden of the self-management of the physical and emotional aspects of chronic illness is often taxing. The extent to which individuals can cope and adjust to chronic illness influences their subjective experiences, perceptions of their circumstances, and psychological well-being (Ambrosio et al., 2015).

Recently, researchers have identified a link between effective coping and *illness identity*: one's ability to integrate their illness into their sense of self (Oris et al., 2018). A person's ability to establish an adaptive illness identity allows them to live a fulfilling life beyond their illness and potentially achieve personal growth (Oris et al., 2018). It has been suggested that a person's state of illness identity depends on their perception of their illness, rather than the condition itself (Oris et al., 2018). Based on the literature, I consider illness identity a helpful construct for mental health professionals to understand their clients' perceptions and experiences associated with their illness. However, before this study, illness identity had not yet been explored in the context of psychotherapy. Through this study, I hope to support the use of illness identity within the counselling community.

Psychological Support for Chronic Illness

There are many ways to reinforce psychological well-being in the face of chronic illness. Notably, social support is essential in the self-management of chronic conditions and is associated with positive outcomes for mental health (Lehardy & Fowers, 2020; Riegel et al., 2012). In addition to social connections with family and friends, some individuals may seek

support in the form of peer support groups, where they can connect with others also living with chronic illness (Lehardy & Fowers, 2020). Recently, online platforms, such as Facebook, have been used by people with chronic conditions to give and receive social support and participate in the self-management of their conditions (Allen et al., 2016; Bartlett & Coulson, 2011; Conrad et al., 2016; Lehardy & Fowers, 2020). Participation in online peer support groups is said to contribute to individual and collective identity development (Kingod et al., 2017; Lehardy & Fowers, 2020).

However, peer support alone may not be adequate for some individuals struggling with the psychological impacts of chronic illness (Chung, 2013; Coventry et al., 2015; Dibb & Yardley, 2006). For these individuals, professional intervention may be necessary. Because life with chronic illness is complex, multidimensional treatment methods are required. Based on the existing literature, the most effective approaches for treating chronic conditions involve collaboration between physical and mental health services (Coventry et al., 2015). Unfortunately, collaborative approaches appear to be frequently underutilized or unavailable in current treatment systems (Coventry et al., 2015). Often, there may be emphasis on treating the physical aspects of chronic conditions at the expense of overlooking the psychological impact of chronic illness (Roberge et al., 2016). Thus, I believe there should be opportunity for mental health professionals to advocate for and support this population wherever possible.

Group Therapy for Chronic Illness

Both social support and professional support are valuable contributors to coping with chronic illness. Group therapy combines peer and professional support and is often effective for clients with medical conditions (Leszcz, 2020). For this reason, I argue that group therapy is an ideal type of support for many people in this population. While support groups may assist

individuals in coping with the things they *cannot* change, group therapy helps individuals create change *despite* the things they cannot control (Brabender et al., 2004; Pollak, 2016).

Consequently, group therapy may play a unique role in adapting to chronic illness beyond peer support alone. While illness identity has not been explored in the context of group therapy, I suspect that the therapeutic factors associated with change in these groups may provide opportunities for adaptive illness identity development.

Recently, some professionals have provided literature for adapting group therapy to individuals experiencing medical illness (Leszcz, 2020; Yalom & Leszcz, 2020). These researchers noted that individuals may require varied forms of group intervention at different points in their illness (Leszcz, 2020). Some researchers identified that individuals with particular diagnoses and at distinct stages of illness may have differing preferences for groups (Gumuchian et al., 2019; Sherman et al., 2007). To adapt group therapy to chronic illness, therapists must understand the population's unique needs (Leszcz, 2020; Yalom & Leszcz, 2020). However, few studies have been conducted to investigate the preferences of this population directly when it comes to the mechanics of group therapy. The lack of client voices in many intervention programs is apparent in the literature. Therefore, I advocate that more research is needed to understand what people with chronic illness want from group therapy.

Researchers who have focused on illness identity have suggested that an individual's ability to cope with chronic illness may depend on their relationship with illness and not the condition itself (Oris et al., 2018). Therefore, I believe illness perceptions may be related to what individuals need from group interventions. The research in this area is limited, but some researchers have pointed to illness self-concepts playing a role in what individuals find helpful from group interventions (Stuber et al., 1988). Thus, illness identity may be a meaningful

construct for understanding what individuals need from group therapy. Whether illness identity relates to preferences for group therapy had yet to be explored.

Research Question

The purpose of this study was to explore the firsthand perceptions of individuals living with chronic illness to expand the knowledge of mental health professionals. This study reinforced the value of incorporating client perspectives in designing therapeutic interventions. In addition, this study suggested a novel approach to understanding clients by conceptualizing illness identity in counselling contexts. Therefore, I aimed to answer the following question as part of my thesis:

How does illness identity relate to preferences for group therapy in a transdiagnostic population?

I utilized an online survey to:

- (a) *invite the perspectives of individuals with chronic illness on group therapy,*
- (b) *characterize illness identity in a transdiagnostic sample, and*
- (c) *explore whether illness identity relates to preferences for group therapy.*

Contribution of this Thesis

With this study, I hoped to contribute to the existing body of knowledge in several ways. Firstly, I hoped to highlight the need for increased opportunities for the psychological care of individuals with chronic health conditions. Given the present systemic barriers to collaborative care, I believe mental health professionals are uniquely able to bridge the gaps in support for this population. Second, I hoped to hold space for the voices of individuals with chronic illness within the research community. I consider their unique perspectives essential for professionals to understand how to improve the care they provide. Therefore, my third aim for this thesis was to

contribute to the ability of group therapists to better adapt their groups according to the needs of this population. Lastly, I hoped to expand the current literature on illness identity by exploring this construct in a novel context with a transdiagnostic population.

For professionals working with chronic illness, theoretical models, empirical research, and clinical practice all lead to the significance of focusing on the psychological wellbeing of these individuals (Folkman & Greer, 2000). Mental wellbeing despite chronic illness is possible, but for many people, achieving it without professional support may be challenging. With this thesis, I have contributed to the empirical research that can, in turn, inform clinical practice. Expressly, this thesis will provide the underpinnings of my counselling practice as I move forward into my professional career. Before continuing with my literature review, I will touch on my motivations for pursuing this topic.

My Personal Interest in this Topic

I wish to be transparent regarding the personal reasons for my interest in studying chronic illness. I have experienced symptoms of chronic illness and chronic pain for many years. Notably, in 2015, I was diagnosed with celiac disease. Before this diagnosis, I did not realize how ill I had been. I spent the first 20 years of my life suffering from symptoms that I considered “normal” because I did not know any other way of living. When I finally got this chronic autoimmune disease under control, the improvements to my wellbeing were indescribable. Celiac disease is a unique condition in that the only known treatment is a lifelong gluten-free diet. However, to suggest that dietary changes alone are sufficient for healing someone with celiac disease is an oversimplification of the many areas of life impacted by this disease.

For me, coping with the psychosocial impacts of celiac disease has been the most difficult. Unfortunately, I was left unprepared for the social and psychological consequences of

my diagnosis. I was also left unsupported in navigating the commonly comorbid physical and mental health concerns associated with celiac disease. While I am grateful that this condition is now more easily managed, coping has involved significant work around my sense of self. I believe this is one of the reasons that the concept of illness identity resonates with me as much as it does. My experience has shown me that physical, psychological, and social well-being are complexly intertwined. Reviewing the existing literature on this topic has affirmed this belief.

My Illness Identity. In this thesis, I describe the four states of illness identity introduced by Oris and colleagues (2016): *rejection*, *engulfment*, *acceptance*, and *enrichment*. Throughout the process of engaging with the literature, I have reflected on my own journey of integrating my chronic health conditions into my sense of self. Through this reflection, I have become familiar with the differential impacts that certain conditions can have on one's life, and how these impacts can shift from one moment to the next. I will briefly describe my experience within the four states of illness identity.

Rejection. In retrospect, I have identified chapters of my life where I was in the state of rejection. However, these chapters took place before I received formal diagnoses. For me, rejection of my symptoms was not intentional. Rather, it took the form of inadvertent denial that my symptoms required medical attention. I was diagnosed with anemia in 2010, but I did not receive any follow-up testing after being prescribed iron supplements. I was told that anemia was "normal" for girls my age. At only 15, I did not understand the importance of advocating for myself when the medication did not work. I also believed that my anemia did not require intervention. Eventually, I stopped taking the iron supplements because of their unpleasant side effects. My celiac disease diagnosis occurred because of routine bloodwork revealing significant nutrient deficiencies. I recall the physician being unsure how I was still getting out of bed and

going to university every day with how severely nutrient deficient I was. Because my grandmother had been diagnosed with celiac disease, I understood that it was a chronic condition that required significant lifestyle changes to heal. After my diagnosis was confirmed, my relationship with my physical health shifted toward engulfment.

Engulfment. When I was first diagnosed with celiac disease, I experienced engulfment for quite some time. As I began to process the necessary adjustments for treating my chronic condition, I encountered a lot of grief for the things I would no longer be able to experience. This grief was accompanied by significant anxiety and hypervigilance around my health. When I received this diagnosis, I was not made aware of the psychological and social impacts of adapting to and coping with a chronic condition. The state of engulfment was challenging to navigate on my own; however, eventually I was able to work through it. Looking back, I was not fully immersed in this state of illness identity for long. I have realized that although this is no longer the predominant theme in my relationship with this condition, there are still moments that I experience engulfment. Even now that this condition is well-managed, certain contexts can contribute to feelings of overwhelm and grief. However, I now know that engulfment does not have to be permanent, as I have developed the tools for shifting to acceptance.

Acceptance. Since my condition is well-managed, I spend most of my time in the state of acceptance. I accept that celiac disease is a part of me, but it does not define me. I have incorporated this condition into my sense of self, but it is only a small facet of my identity. Because I have experienced acceptance with this condition, I have begun to work on my relationship with the other chronic mental and physical health conditions I experience. By working on this thesis, I have taken many opportunities for self-reflection on the differential impacts of certain conditions on my life. I have also reflected on the differences in my

relationships with these conditions. These relationships are complex and shaped by many factors. This type of reflection has allowed me to conceptualize the experience of chronic illness as unique to each person. As I will explore in my literature review, there is little agreement about a specific definition for chronic illness. I believe this is due to the multidimensional nature of the impact of chronic health conditions, as no two people experience chronic illness the same. Thus, I consider the firsthand perceptions of individuals with chronic conditions an invaluable resource for practitioners working with this population. By exploring this topic for my thesis, I believe I have shifted into the state of enrichment.

Enrichment. With this thesis, I hoped to advocate for other individuals with chronic health conditions. It is difficult to say whether I would be pursuing this topic directly if I did not have lived experience in this area. For this reason, I believe that my chronic conditions have made me a better person. They have provided me with a passion for supporting other individuals with similar experiences. They have also given me the empathy to understand that an individual's experience of health and wellness cannot be determined by external appearances. My journey through the states of illness identity required immense amounts of psychological growth to build the tools to adapt. Because I developed these tools independently, I cannot help but wonder how much easier it would have been to do so with the proper professional supports. By channeling my passion for this topic into my research and my future career, I believe I can make a difference for this population. I will continue to advocate for professional mental health support for individuals with chronic conditions.

Through my experience, I have witnessed the fluidity of illness identity. I do not believe these illness identity states are static or permanent, or that being in a "maladaptive" state is necessarily a negative thing. I would argue that the maladaptive states of identity are, to some

extent, inevitable parts of chronic illness. However, I also contend that experiencing wellbeing with a chronic health condition involves developing the ability to shift between different illness perceptions without getting stuck in the maladaptive states. I consider mental health practitioners to be in a unique position to support individuals in developing this flexibility. I will expand on these arguments in my Discussion chapter.

My Experience with Healthcare Professionals. Unfortunately, I have had several negative experiences in the healthcare system. I have had dismissive and invalidating interactions with multiple healthcare professionals for both physical and mental health concerns. My experience has shown me the disconnect between professional supports for physical and mental health. In many cases, current healthcare practices do not align with the gold standard of collaborative care for chronic condition management. I consider this to be the fault of systemic barriers and limitations rather than the fault of healthcare professionals. Because every profession has inevitable limitations to their scope of practice, I believe collaborative care is vital. Therefore, with this thesis (and with my future counselling practice), I hope to do my part to bridge the gap in mental health support for this population.

My Experience with Mental Health Supports. I am comfortable noting that I have had lived experience with many of the approaches to mental wellness mentioned in this thesis. Over time, I have engaged with several types of formal and informal supports for my wellbeing. Many of my positive experiences led me to teaching yoga and pursuing a counselling career. Therefore, I appreciate the value of taking a variety of approaches to enhance mental, emotional, and physical wellbeing. I believe that everyone can benefit from some form of support for their psychological health, and that many types of support complement each other well. Thus, I advocate for collaboration between practitioners to provide individuals with holistic support.

My Experience with Group Therapy. I have had positive experiences with group therapy in both personal and professional contexts. When I began working on this thesis topic in January 2021, I started exploring the literature on group counselling. In the summer of 2021, I completed a Group Counselling and Process Skills course at the University of Lethbridge for my professional development. This course allowed the material I had been learning for this thesis to come to life. In my practicum placement, I was fortunate enough to be involved with facilitating multiple groups. Thus, I advocate for “the essential power of group work” for creating therapeutic change (Drumm, 2006, p.17). I believe that groups are powerful tools for cultivating connection and growth. However, I also recognize that group therapy, as with anything, may sometimes not be the right fit for everyone. Therefore, I support opportunities for practitioners to meet individuals where they are and discover their unique needs.

As I conducted this thesis, my lived experiences informed my interpretation of the literature and my study. However, I mitigated my biases as much as possible by utilizing the expertise of my committee members. My thesis survey was collaboratively designed with the assistance of my thesis committee and other students in my cohort. Further, many of my survey items were adapted with permission from the work of other researchers. I maintained this transparent and collaborative approach when interpreting the results of this study to reduce any personal biases.

Thesis Overview

In this chapter, I have outlined the focus of this thesis and the importance of this work. Chapter 2 provides a foundational overview of the current literature regarding chronic illness and illness identity. Throughout Chapter 2, I will highlight the gaps in research on this topic and the need for psychological support for this population. Chapter 3 will expand on this foundation by

describing the existing research on group therapy for chronic illness. In doing so, I will integrate the research on group therapy and support groups to emphasize the value of combining peer and professional support. Although illness identity had not yet been explored in this context prior to this study, throughout Chapters 2 and 3, I will contribute my ideas for how this construct may fit within counselling practice.

In Chapter 4, I will review the literature regarding the value of client perspectives for preparing counselling interventions. Based on my review of the literature, in Chapter 5, I will provide a synthesis of my research question. In Chapter 6, I will describe the methodology I used for this study, and in Chapter 7, I will outline the results of my data analyses. Finally, in Chapter 8, I will provide a discussion of my study, including its implications, limitations, and areas for future study. With this thesis, I hope to communicate the need for this research such that my passion for this topic is apparent. Now that I have offered an overview of my thesis, I will present my literature review.

CHAPTER 2: Chronic Illness

This chapter is a review of the literature as it relates to chronic illness and illness identity. The literature review includes: (a) an overview of chronic illness, its psychological impacts, and how individuals cope; (b) the value of professional mental health support for individuals with chronic illness; (c) an explanation of illness identity and the four illness identity states; and (d) the impact of social support for people with chronic conditions. This chapter will provide a foundation for understanding the importance of group supports for this population, which will be discussed in Chapter 3.

Defining Chronic Illness

For this study, I conceptualized *chronic illness* as the psychological experience of living with a chronic health condition. The terms *chronic disease* and *chronic illness* are often used interchangeably in the literature. There is a discrepancy in the use of these terms both within and between professional communities (Bernell & Howard, 2016). However, in the context of psychotherapy and health psychology, many researchers separate *chronic disease* and *chronic illness* as differing constructs (Martin, 2007; Sperry, 2009; White et al., 2018). I believe this distinction is important because *disease* and *illness* carry different connotations and meanings within healthcare contexts (Martin, 2007). Thus, for my research, I distinguished between *chronic disease* and *chronic illness* based on the social science literature.

Chronic disease is the biological manifestation of a condition that persists over time and might be objectively measurable (Martin, 2007; Sperry, 2009; White et al., 2018). By this definition, chronic diseases include non-communicable (e.g., arthritis, heart disease, diabetes) and communicable (e.g., hepatitis, HIV/AIDS) diseases. Chronic diseases can typically be treated but not cured. Some chronic diseases are present from birth, while others develop over

time. Some may be preventable through behavioural factors, but others are not preventable due to biological factors (Bernell & Howard, 2016; Martin, 2007; White et al., 2018). Although there are many distinct types of chronic disease, the scientific literature appears limited to only certain conditions. Broad categories of chronic diseases include but are not limited to cardiovascular diseases, joint and bone disorders, autoimmune diseases, respiratory conditions, and gastrointestinal diseases (Bernell & Howard, 2016). Chronic conditions may be visible or invisible to others (Carroll et al., 2020; Pederson et al., 2017).

With this definition of chronic disease, *chronic illness* refers to the personal psychological experience of individuals living with a persistent disease or condition (Martin, 2007; Sperry, 2009; White et al., 2018). In other words, *chronic illness* is the emotional and cognitive experience of living with the physical complications of a chronic disease or condition. I chose to adopt this definition of chronic illness because it focuses on the subjective, affective aspects of chronic health conditions that may be easily overlooked. I believe these aspects are meaningful for counsellors and psychologists to understand. While individuals may have adequate medical support for their *chronic disease*, they may still lack support for their experience of *chronic illness*.

The difficulties of living with chronic illness are complex and recurrent, with many factors influencing the individual's subjective experience (Ambrosio et al., 2015; Moss-Morris, 2013; Spornova et al., 2019). Because of advances in medical science, detection rates for many chronic diseases have become more efficient, and some diseases that were previously fatal are now instead manageable. As such, individuals with chronic diseases tend to live longer with these conditions, making adjustment and coping with chronic illness increasingly important (Moss-Morris, 2013; White et al., 2018).

Numerous influences, both internal and external to the individual, shape life with chronic illness. Factors including beliefs and attitudes, personal support networks, and illness-related education contribute to chronic illness management (Ambrosio et al., 2015; Moss-Morris, 2013; Sporinova et al., 2019). The challenges of adjusting to long-term health conditions are dependent on many personal, condition-specific, and social factors (Moss-Morris, 2013). For example, factors such as age, gender, and culture contribute to the complexity of life with chronic illness (Atobrah, 2012; Dispenza et al., 2017; Malmusi et al., 2011; Samulowitz et al., 2018). Because living with chronic illness is a multidimensional and complicated process, the extent to which chronic illness impacts one's life is associated with barriers to feelings of normality, quality of life, and wellbeing. Thus, in addition to the physical impacts of chronic diseases, living with chronic illness has significant consequences for psychological health (Ambrosio et al., 2015).

To summarize, chronic illness can be conceptualized as the psychological impact of living with a chronic health condition. While shaped by the biological aspects of the disease, the experience of chronic illness is determined by more than just the physical symptoms associated with the health condition. An individual's experience of chronic illness is shaped by many factors which impact both physical and psychological wellbeing. In the following section, I will provide an overview of the literature regarding the psychological impacts of chronic illness to highlight the importance of mental health support for this population.

Psychological Wellbeing and Quality of Life

I believe that counsellors and psychologists can play a significant role in supporting individuals living with chronic illness. To better support this population, it is essential to gain a better understanding of their subjective experiences. Through this study, I hope to expand the knowledge of mental health professionals so they may provide support tailored to the needs of

their clients. This section will summarize the research regarding the influence of chronic illness on individuals' psychological wellbeing and quality of life.

Symptoms of anxiety and depressive disorders are considered the most common mental health concerns in the general population. These common mental health concerns appear to have a reciprocal correlation with chronic diseases (Palmer et al., 2013; Roberge et al., 2016; Sporinova et al., 2019). The bi-directional association between mood disorders and chronic diseases has long-term impacts on the self-management of illness and overall quality of life (Lebel et al., 2020; Voinov et al., 2013; Zheng et al., 2020). Chronic conditions are often associated with difficulty regulating emotions, contributing significantly to developing anxiety and depression (Wierenga et al., 2017). Moreover, chronic health conditions, especially those involving chronic pain, have been associated with an increased likelihood of experiencing suicidal ideation (Ferro et al., 2017; Pederson et al., 2017).

Mental health concerns, such as anxiety, depression, and suicidal ideation, impact subjective feelings of value and satisfaction with life. In turn, perceived quality of life decreases (Cella & Nowinski, 2002; Zheng et al., 2020). Factors directly and indirectly related to health contribute to quality of life. The World Health Organization defines *health* as “a state of complete physical, mental, and social well-being” (Cella & Nowinski, 2002, p.S10). Thus, *health-related quality of life* is “the extent to which one’s usual or expected physical, emotional, and social well-being are affected by a medical condition or its treatment” (Cella, 1995, p.S11). Health-related quality of life is both subjective and multifaceted because it relies on many aspects of an individual’s personal experiences. The individual’s perception of those experiences establishes the felt experience of health-related quality of life (Cella & Nowinski, 2002).

The impact of chronic illness on quality of life has been well-documented. Both positive and negative emotionality can contribute to self-reported quality of life. For example, self-esteem and positive emotions, such as hope and gratitude, may predict health-related quality of life (Griggs & Walker, 2016; Sirois & Wood, 2017; White et al., 2018). Symptoms of depression may be prevented or more easily managed for individuals with higher levels of health-related quality of life (McIntyre et al., 2019; White et al., 2018). In cases where mental health disorders co-occur with chronic health conditions, individuals may be more likely to be hospitalized or require emergency medical services for their health condition (Sporinova et al., 2019).

Lower quality of life in people with chronic illness is associated with treatment burden and difficulties with adhering to treatment (Sav et al., 2013). *Treatment burden* is “the burden associated with the treatment and management of chronic illness” (Sav et al., 2013, p.313). The burden of treatment for chronic diseases presents a barrier to managing both mental and physical health. Many chronic conditions require the patient to attend frequent appointments and partake in extensive treatment regimens. Comorbidity of mental health concerns with chronic physical conditions is associated with increased treatment burden and higher healthcare costs (Sav et al., 2013; Sporinova et al., 2019). Psychological wellbeing significantly impacts treatment adherence, as illustrated by the correlation between health anxiety and treatment adherence. Those who experience higher levels of health-related anxiety tend to be less likely to maintain treatment successfully (Lebel et al., 2020).

For people with chronic diseases, subjective perceptions of stress relate to maintaining both physical and mental wellbeing. Higher levels of perceived stress are associated with increased fatigue, pain, and inflammation for several chronic conditions (Hirsch & Sirois, 2016). In contrast, lower levels of perceived stress relate to lower levels of fatigue, pain, and

inflammation (Hirsch & Sirois, 2016). Positive emotions, such as hope, contribute to the relationship between perceived stress and physical symptoms of chronic diseases (Hirsch & Sirois, 2016). Hope is a central factor for enduring chronic illness in adults and adolescents (Griggs & Walker, 2016). Thus, the individual's perceived stress and emotionality are significant factors in managing physical symptoms and psychological wellbeing (Hirsch & Sirois, 2016).

Based on the existing literature, I believe the impact of chronic illness on psychological wellbeing should be a significant concern for mental health professionals. To provide adequate support for this population, it is necessary to understand how individuals cope with chronic illness. Therefore, before discussing the importance of professional mental health support for chronic illness, I will provide an overview of the research concerning how individuals cope with chronic illness.

Coping with Chronic Illness

Coping is the cognitive and behavioural strategies that one uses to manage stress-provoking circumstances. The methods used for coping depend on individual perceptions of the stressful situation (Kristofferzon et al., 2018; White et al., 2018). Individuals are said to use *emotion-focused coping* for emotional regulation in stressful situations, which typically helps the individual to evade the situation (Kristofferzon et al., 2018). Conversely, individuals are said to use *problem-focused coping* to change the stressful situation or themselves. Individuals tend to use problem-focused solutions when they believe they can handle the situation (Kristofferzon et al., 2018). Generally, in populations with chronic conditions, problem-focused coping is associated with better self-reported quality of life, while emotion-focused coping is associated with decreased quality of life (Kristofferzon et al., 2018).

Unlike acute conditions, coping with a chronic health condition is a continuous and unending process. Upon receiving a chronic disease diagnosis, the person faces the challenge of finding ways to cope with the circumstances. Psychological adjustment to a diagnosis, physical functioning, and social functioning are all impacted by the coping strategies chosen (Homma et al., 2018). The literature suggests coping strategy choices depend on internal cognitive and emotional schemas of chronic illness (Homma et al., 2018). While a person living with chronic illness must learn to cope in a general sense, they must also learn coping strategies that help them adapt to their condition. For instance, the individual must learn new ways to regulate emotions, sustain social bonds, build self-confidence, and brace for uncertainty. However, they must also learn to take part in tasks for symptom management, attain treatment goals, and potentially manage disabilities (Homma et al., 2018).

Every chronic health condition involves different symptoms, treatments, and self-management strategies. However, despite the broad range of distinct chronic conditions, evidence suggests that the experience of *coping* with chronic illness may be comparable across conditions. Scholars have identified that the psychological and social factors associated with chronic illness share significant commonalities across different chronic conditions (White et al., 2018). White and colleagues (2018) reviewed the literature to develop a framework for understanding factors that contribute to coping with chronic illness. One of their goals was to uncover specific coping profiles for different chronic conditions; however, they found “no evidence to suggest individual conditions were associated with a particular subset of coping factors” (White et al., 2018, p.8). Based on their data, they suggested that “much of the overall experience of coping with a chronic illness may well be quite similar across conditions” (White et al., 2018, p.8).

While the commonalities across conditions may be apparent, I would like to acknowledge the limitations of generalizing how individuals cope with chronic illness. Each person possesses unique biological, psychological, and social factors that shape their experience with chronic illness. Therefore, when working with this population, clinicians must assess coping behaviours on an individual basis. However, having a general understanding of coping informed by existing literature may serve as a starting point for individual case conceptualization. For this study, I maintained the assumption that there are individual differences in coping behaviours both within and between diagnostic groups, but that general models of coping can provide foundational knowledge for mental health professionals.

Researchers have outlined models of coping that may assist in case conceptualization. For instance, Paterson (2001) established the ‘*Shifting Perspectives Model of Chronic Illness*,’ which outlines life with chronic illness as a dynamic process that changes over time and includes *illness* and *wellness*. In this model, illness and wellness continually shift positions between the foreground and background in the individual’s perception. Paterson (2001) suggested that the individual’s interpretation of their circumstances, not the reality of the situation, establishes how they will perceive and cope with chronic illness.

The ‘Shifting Perspectives Model’ suggests that when a person first experiences their symptoms or receives a diagnosis, their primary perception may shift from wellness to illness (Paterson, 2001). It is common for people with chronic conditions to experience a sense of loss early on in their illness. They are likely to perceive the loss of their pre-illness sense of self, which may contribute to grief. Feelings of uncertainty and lack of control, as well as a potential loss of independence, can lead to feelings of powerlessness (White et al., 2018). At this stage, the

person will likely utilize emotion-focused coping strategies such as avoidance, sorrow, and self-pity (Paterson, 2001).

Paterson (2001) said that emotion-focused coping is the adaptive coping strategy at this stage because it will allow the person to process their emotions to build toward accepting their diagnosis. After emotions become manageable, the person gains information about their condition, develops new skills, and begins to utilize a supportive environment, thus prioritizing problem-focused coping strategies (Paterson, 2001). Over time, the person's primary perception may shift from illness to wellness as the person's perspective begins to focus on life itself rather than just their chronic condition. Paterson (2001) acknowledged that the shift between illness and wellness may happen continually from moment to moment because coping with chronic illness is an ongoing process. Paterson (2001) proposed that the use of emotion-focused coping in certain situations may give individuals the energy needed to begin the shift toward problem-focused coping and finding acceptance.

In line with the 'Shifting Perspectives Model,' the literature suggests that both problem-focused and emotion-focused coping are essential parts of living with chronic illness. Emotional suppression may negatively impact physical and emotional wellbeing in people with chronic conditions (Karademas et al., 2011). Moreover, negative perceptions of subjective health are related to higher levels of negative emotionality and more emotional suppression (Karademas et al., 2011). Through acceptance and problem-focused coping strategies, individuals can broaden their perception beyond the chronic condition so that the foreground perspective can shift from illness to wellness (Kristofferzon et al., 2018; Paterson, 2001).

I will revisit Paterson's (2001) 'Shifting Perspectives Model' in my Discussion chapter. This model illustrates the capacity of individuals with chronic conditions to cope with illness in

ways that allow them to find wellbeing beyond the presence of the condition itself. It also illustrates the complexity of coping with chronic illness, which may be challenging for some individuals to navigate. Because of this complexity, counselling and other mental health supports can be valuable resources for this population. The literature supports the role of counsellors and psychologists in improving individuals' abilities to cope with chronic illness. In the following section, I will outline the importance of professional mental health support in the lives of people with chronic conditions.

Professional Mental Health Support

The literature suggests that the most effective approach for treating chronic physical conditions is to take a multi-faceted and person-centred approach that involves treating the individual beyond their physical condition (Foley et al., 2020). Comorbid mental health problems, such as depression, can significantly reduce the quality of life of individuals with chronic health conditions (Coventry et al., 2015). Professional mental health supports, such as psychologists, counsellors, and psychiatrists, are intended to improve psychological wellbeing. These supports are related to a higher quality of life, increased knowledge and skills, improved self-care, and more positive moods (White et al., 2018).

Mental health interventions significantly impact individuals with chronic conditions (Radu et al., 2018). Interventions can strengthen an individual's ability to cope with chronic illness and encourage active participation in identifying their resources (Kristofferzon et al., 2018). Psychological treatments predict positive coping outcomes for individuals with chronic conditions. They contribute to developing a more purposeful life, giving individuals the flexibility to cope with stressful situations (White et al., 2018).

Further, psychological supports assist people in gaining the skills for effective emotional regulation, which is related to a higher quality of life (White et al., 2018). When better able to regulate and express their emotions, individuals with chronic illness experience improved health outcomes, lower rates of depression, and more effective self-management (Reynolds et al., 2018; White et al., 2018). Involvement with professional mental health supports helps individuals with chronic illness gain the skills and information needed to increase their life satisfaction and happiness. Patients who participate in psychological interventions tend to have higher reported quality of life (White et al., 2018).

Researchers who conducted a qualitative study with counsellors on a college campus suggested that counsellors in this environment typically have experience supporting individuals living with chronic conditions (Davis & Paro, 2020). Many of the counsellors in this study shared that people with chronic conditions sought counselling for presenting problems other than their physical health (Davis & Paro, 2020). The authors concluded that college students with chronic illness typically seek counselling because they require resources, social support, or strategies for self-management (Davis & Paro, 2020).

Much of the recent research about the benefits of psychological support for this population is limited to literature reviews of qualitative studies. Given the significant impact of chronic illness on emotional wellbeing, more research in this area is essential. To this end, there has been some work surrounding chronic illness treatment that identifies the need for an increase in collaboration between physical and psychological interventions (e.g., Coventry et al., 2015). This approach to the treatment of chronic conditions is known as *collaborative care*.

Collaborative Care

Researchers have advised that mental health supports delivered in a primary care context can significantly improve wellbeing for individuals with chronic illness (Coventry et al., 2015). When treating mental health concerns in patients with chronic conditions, the literature suggests that collaborative care and stepped care approaches should be utilized (Roberge et al., 2016). *Stepped care* models are patient-centred approaches that provide modulated services based on the patient's symptoms, needs, and preferences. These approaches prioritize continuous assessment of patient progress and treatment responses (Roberge et al., 2016). *Collaborative care* approaches involve a case manager and a mental health specialist such as a psychologist or psychiatrist. These models tend to support and improve the wellbeing of people in primary care with anxiety and depression (Coventry et al., 2015; Roberge et al., 2016).

The literature suggests that patients with chronic illness often appreciate the support of professionals in addition to their physicians (Roberge et al., 2016). Taking a collaborative approach to treating chronic conditions involves physical health treatment in conjunction with mental health treatment (Coventry et al., 2015). Physicians' interest in participating in collaborative care is a facilitating factor for effective care of chronic conditions (Roberge et al., 2016). Efficient communication and shared records between professionals assist in amplifying the success of care (Roberge et al., 2016). When pathways between professional supports are simplified, professionals can more effectively support their patients (Roberge et al., 2016). Collaboration between professionals on teams of psychologists, physicians, pharmacists, and social workers facilitates improved patient support (Roberge et al., 2016). Some researchers have also suggested that collaborative care through online health communities may be beneficial (van der Eijk et al., 2013).

Collaborative care may be more effective than typical treatment approaches for anxiety and depression (Coventry et al., 2015). Research for collaborative care in the context of chronic conditions is limited. However, Coventry and colleagues (2015) conducted a cluster randomized controlled trial to explore the effectiveness of collaborative care for individuals with depression that was comorbid with diabetes or cardiovascular disease. They found that incorporating brief psychological interventions into the context of standard care for chronic conditions resulted in a more pronounced reduction of depressive symptoms. The collaborative care patients in their study also reported lower rates of anxiety than regular treatment. In addition, those who received collaborative care experienced greater ease of self-management of their conditions (Coventry et al., 2015). According to Coventry and colleagues (2015), integrating mental health interventions into the routine care of chronic conditions is essential for effective chronic illness treatment.

Upon reviewing the limited research, I recognize that more work is needed in this area. With this study, I hope to bolster the existing support for collaborative care by contributing to the knowledge of chronic illness within the mental health community. By providing the perspectives of individuals with chronic conditions, I intend to fill in some gaps in the existing research. In the process of doing so, I believe it is necessary to acknowledge the current limitations in professional mental health support for individuals with chronic conditions. These limitations highlight the need for an increase in mental health support for chronic illness.

Limitations in Mental Health Support

Based on the existing literature, it is advisable that medical professionals screen individuals with chronic illness for prevalent psychological problems such as depression. Unfortunately, however, these problems are easily overlooked (Davis & Gershtein, 2003). Detection rates for anxiety and depression in this population are low, with some researchers

suggesting that less than half obtain the baseline of sufficient treatment based on clinical practice standards (Roberge et al., 2016). Several factors may contribute to this low detection rate, including the tendency for both clinicians and patients to normalize psychological difficulties as an inevitable part of living with chronic illness (Roberge et al., 2016).

In Western medical practices, physicians typically receive training that follows a biomedical approach which generally does not account for psychological factors (Straub, 2019). As such, the symptoms and management of the physical disease generally receive more emphasis than the patients' psychological wellbeing (Roberge et al., 2016). This underemphasis of psychological wellbeing may be due to a lack of time during physician consultation, an overlap between somatic symptoms of mental and physical disorders, and challenges for physicians in collaborating with mental health professionals (Kessler, 2012; Roberge et al., 2016).

The process of a medical patient receiving a referral to professional mental health supports involves many factors surrounding the physician, the patient, and the clinical practice itself (Anthony et al., 2010). Some of the conditions influencing mental health referrals include the patient's financial resources, the physician's comfort in providing mental health support and prescribing adequate medications, and the physician's familiarity with available resources (Anthony et al., 2010). Physicians who have had personal experience attending professional mental health supports for depression are more likely to make mental health referrals for their patients (Kravitz et al., 2006). The age and experience level of the physician may also play a role in their willingness to carry out mental health interventions and consultations without making a referral (Althubaiti & Ghamri, 2019).

Typically, when an individual in a primary care setting struggles with anxiety or depression, the course of action for treatment is pharmacotherapy (Roberge et al., 2016). For

individuals with chronic conditions, adding additional pharmacological treatment and follow-up to an already complex treatment regimen amplifies their treatment burden (Roberge et al., 2016). The most common factor contributing to treatment burden for patients with chronic illness is having high numbers of medications (Sav et al., 2013). The burden of care for patients with chronic illness may add hesitancy from the clinician and the patient to add additional treatment components such as psychological supports (Roberge et al., 2016).

One of the difficulties with referring patients to mental health supports is the lack of integration between physical and mental health services. Lack of communication and collaboration between physical and mental health supports presents a significant barrier to effective care of patients with chronic conditions (Roberge et al., 2016). When mental health clinics are off-site, patients may be less likely to attend mental health appointments after receiving a referral (Kessler, 2012). However, when mental health support is available on-site for patients at primary care clinics, physicians have an easier time referring their patients to these supports. Further, when psychological supports are on-site, more patients tend to seek mental health support, and rates of attendance for mental health treatments are higher (Kessler, 2012).

The literature suggests that many primary care clinics do not have the availability of psychological supports, and for those clinics that do have psychological supports, availability is limited (Roberge et al., 2016). Researchers have suggested that primary care clinicians may lack knowledge about the existing external resources for supporting the mental health of those with chronic conditions (Roberge et al., 2016; Titzler et al., 2020). Many clinicians may not receive continued education to remain updated on the shifting availability of supports (Roberge et al., 2016; Titzler et al., 2020). Scholars have also suggested that many psychologists require more

training specific to chronic diseases and the experience of living with chronic illness (Roberge et al., 2016).

Because services specialized for those with chronic conditions are limited, there may be extensive delays in accessing these services, if they are accessible at all (Roberge et al., 2016). Studies on physicians' approaches to collaborating with mental health professionals, such as psychiatrists, have shown that physicians typically agree that this collaboration is beneficial but may not be readily available when needed (Althubaiti & Ghamri, 2019). Physicians are more likely to refer patients with chronic conditions to professional mental health supports if they consider mental health consultation to be readily accessible for patients (Kravitz et al., 2006).

Overall, previous researchers have indicated that the process of receiving a referral for mental health support is complex. The common themes within the existing research have clear implications for the future of treating chronic conditions. Because the experience of chronic illness is complex and multidimensional, effective care of chronic conditions requires contributions from a variety of professional supports. However, due to the limited availability of collaborative care within professional practice, there is a need for changes within existing treatment strategies. I consider an increased involvement of mental health professionals to be a necessary improvement. Through this study, I hope to shed light on the importance of mental health support for chronic medical conditions and encourage mental health professionals to find new ways to engage in collaborative care. I believe mental health professionals can help individuals cultivate more adaptive relationships with illness to assist them with effective coping.

In working with this population, I believe it is important for clinicians to understand how individuals perceive their illness. Illness perceptions are related to treatment adherence and treatment results (Sperry, 2009). One way to conceptualize an individual's relationship with their

illness is to consider how they incorporate their illness into their sense of self—a concept known as *illness identity* (Oris et al., 2016; Oris et al., 2018). I believe illness identity may be an effective tool for mental health professionals to capture an individual’s relationship with chronic illness. The research on illness identity is limited; however, there appears to be a recent interest in expanding this body of work. In the following section I will provide an overview of illness identity as it relates to this study.

Illness Identity

The concept of illness identity was first introduced in the sociological literature (Charmaz, 1995). Related constructs have also been introduced in psychological and physical health research (Oris et al., 2018). For instance, illness identity in individuals with severe mental health conditions is linked with self-stigma, self-esteem, hope, and social relationships (Yanos et al., 2020). While the existing literature is limited, current research is actively expanding our understanding of illness self-concept (e.g., Carroll et al., 2020; Meyer & Lamash, 2021; O’Donnell & Habenicht, 2021; Peters & Brown, 2022; Raymaekers et al., 2020; Voorhees, 2022). I believe that understanding how individuals conceptualize chronic illness within their sense of self may help to shape mental health interventions. This thesis will contribute to the growing body of knowledge by giving more data and insight into the various states of illness identity. The following will summarize the literature on illness identity development and the illness identity states.

Identity development is a complex process that has been of significant interest to researchers in multiple disciplines. Of the many identity development theories, three perspectives are the most well-recognized: *identity theories*, *social identity theories*, and *personal identity theories* (Cinoğlu & Arıkan, 2012). *Identity theories* hold that individual identity is a product of

the life roles that the person accepts or is assigned. *Social identity theories* suggest that identity is a product of the groups to which the individual belongs. *Personal identity theories* state that the individual's values play a significant role in shaping their identity (Cinoğlu & Arıkan, 2012). Due to the complexity of identity development, all three perspectives are prominent and accepted within the literature.

Oris and colleagues (2018) suggested that the ability to cope effectively with chronic illness depends on the state of the person's illness identity. *Illness identity* refers to “the degree to which a chronic illness becomes integrated into one’s identity” (Oris et al., 2018, p.429). *Identity* is understood to be a “coherent sense of self” that “translates itself into daily life and guides choices and values” (Oris et al., 2018, p.429). Having a sense of identity is said to contribute to psychological wellbeing (Oris et al., 2018). The experience of chronic illness is likely to disrupt a person's self-concept (Karnilowicz, 2011; Oris et al., 2016; Oris et al., 2018; Voorhees, 2022). The challenges that come with chronic illness often require the individual to take psychological ownership over their experiences (Karnilowicz, 2011). For populations living with chronic illness, establishing an adaptive illness identity is thought to be essential for creating a new sense of self (Oris et al., 2016; Oris et al., 2018).

Oris and colleagues (2018) credit Erikson's (1968) work on lifespan ego-development as inspiration for their research. Erikson's (1968) psychosocial identity theory serves as a prominent foundation for contemporary identity research. According to Erikson (1968), self-awareness and psychosocial wellbeing are dependent on identity development. Erikson's (1968) work emphasizes the transactional nature of identity development, suggesting that identity reflects the bidirectional interactions between self and others (Kerpelman & Pittman, 2018; Rogers, 2018). This transactional approach to conceptualizing identity is said to “broaden the

scope and impact of identity research” (Rogers, 2018, p.286). From a relational perspective, identity is both an individual and social construct that influences relationships and communities at levels internal and external to the individual (Kerpelman & Pittman, 2018; Rogers, 2018). Thus, the literature suggests that identity formation is dependent on factors within the individual and the social context to which they belong. These contexts must be considered in conceptualizing individuals’ adjustment to chronic health conditions (Moss-Morris, 2013).

Oris and colleagues (2016) noted that individuals differ significantly in their ability to manage the challenges of living with chronic health conditions. Through their research, they aimed to “bridge different psychological, sociological, and health perspectives on illness and self-related variables” (Oris et al., 2016, p.758). Oris and colleagues (2016) identified four distinct *illness identity states* in adolescents with type 1 diabetes. Subsequently, Oris and colleagues (2018) confirmed these four states in adults with chronic illness. The following will describe the four states of illness identity and their potential implications for this thesis.

The Four States of Illness Identity

According to the literature on illness identity, the distinct ways individuals relate to their chronic conditions can be categorized as their *illness identity states*. Oris and colleagues (2016) have defined four illness identity states: *rejection*, *engulfment*, *acceptance*, and *enrichment* (see Appendix A). *Rejection* and *engulfment* are considered maladaptive, and *acceptance* and *enrichment* are considered adaptive illness identity states (Oris et al., 2016; Oris et al., 2018). Each illness identity state is uniquely related to the experience of living with chronic illness.

Rejection. The state of *rejection* involves the individual refusing to adopt their chronic illness as part of their identity. Individuals experiencing rejection perceive their illness as a threat or something to be avoided (Oris et al., 2016; Oris et al., 2018). People in this state will typically

exhibit poor adherence to treatment, and they will refrain from thinking about their illness or talking about it with others (Oris et al., 2018). Individuals in rejection view their chronic condition as something unacceptable to the self (Oris et al., 2016). Rejection often involves strong compartmentalization of the chronic health condition to live a “normal” life (Luyckx et al., 2018). By ignoring and minimizing their illness, individuals fight against their condition and the aspects of identity that accompany it (Charmaz, 1995). Rejection is associated with worsening illness symptoms; however, likely due to avoidance of emotions in this state, rejection does not appear to be associated with symptoms of anxiety or depression (Oris et al., 2018).

Engulfment. Conversely, in the state of *engulfment*, the individual allows their illness to govern their identity and their everyday life entirely (Oris et al., 2018). Individuals in engulfment define themselves based solely on their chronic condition and its symptoms, to the detriment of other aspects of their lives (Oris et al., 2016; Oris et al., 2018). Engulfment may involve an apparent loss of personhood due to the over-emphasis of their illness preventing the individual from pursuing their interests (Luyckx et al., 2018). In this state, individuals may experience deterioration of social connections and difficulties with their work (Oris et al., 2018). Engulfment correlates with increased symptoms of depression and anxiety and higher levels of pain and illness symptoms (Oris et al., 2018). Engulfment may also predict the frequency of an individual’s use of healthcare services (Van Bulck et al., 2018). Rejection and engulfment are positively interrelated and result from a lack of adaptive integration of the illness into one’s identity (Oris et al., 2018).

Acceptance. Negatively related to rejection and engulfment is the state of *acceptance*. Acceptance occurs when the individual can reconcile their sense of self with their illness (Charmaz, 1995). Individuals in an acceptance state will incorporate their illness into their

identity without being inundated by the illness (Oris et al., 2018). In the state of acceptance, the person's chronic illness plays a secondary role in their life; the person does not deny having their condition, and it does not get in the way of other aspects of their identity (Oris et al., 2018). People in acceptance "try to accommodate and flow with the experience of illness" (Charmaz, 1995, p.657). They live their lives in a way that is congruent with their values and other aspects of their identity (Luyckx et al., 2018). Acceptance is related to lower levels of depression and anxiety, fewer physical symptoms, and less pain (Oris et al., 2018). These relationships may be bi-directional in the sense that acceptance can lead to better emotional and physical functioning, but better functioning can also lead to acceptance (Oris et al., 2018).

Enrichment. Positively interrelated with acceptance is the final state of *enrichment*. Enrichment is the state in which one's chronic illness improves one's sense of self and facilitates personal growth (Oris et al., 2018). Individuals in this state tend to have a higher appreciation for life. The experience of living with chronic illness has allowed them to shift their priorities in a positive direction. This shift contributes to increased personal strength and stronger interpersonal relationships (Oris et al., 2018). Enrichment involves using cognitive reframing to acknowledge the positive aspects of chronic illness (Luyckx et al., 2018). Unlike acceptance, enrichment is related to more illness symptoms, perhaps because the illness must have a considerable influence on the individual's life to facilitate personal growth (Oris et al., 2018). Potentially for the same reasons, enrichment is also positively related to engulfment (Oris et al., 2018). Consequently, an individual might shift from engulfment to enrichment depending on how their perception changes (Oris et al., 2018). Both acceptance and enrichment come about through adaptively integrating chronic illness into one's identity, thus contributing to improved psychological functioning (Oris et al., 2018).

The Illness Identity Questionnaire (IIQ). Oris and colleagues (2016) introduced the *Illness Identity Questionnaire (IIQ)*: a 25-item survey tool that measures all four dimensions of illness identity. The IIQ has been used to gather information from individuals with a variety of chronic health conditions (e.g., Luyckx et al., 2018; Meyer & Lamash, 2021; Oris et al., 2016; Oris et al., 2018; Rassart et al., 2022; Van Bulck et al., 2018). For this thesis, I used the IIQ to assess the illness identity states of the participants. The IIQ, as well as its limitations, will be described in greater detail in Chapter 6.

For counsellors, I believe that knowing an individual's state of illness identity may be beneficial for case conceptualization with counselling clients. With this thesis, I intended to expand current knowledge for mental health professionals by giving insight into the needs of this population, which I will explore in greater detail in my Discussion chapter. Before discussing the existing research on the factors that shape illness identity, I will provide a brief rationale for using illness identity states in counselling practice.

Illness Identity and Counselling Practice

To the best of my knowledge, there is no prior research on illness identity within the context of psychotherapy or counselling. Thus, it appears the application of illness identity to counselling had yet to be explored before this study. As mentioned, I believe counsellors may benefit from understanding their clients' illness identity states for case conceptualization. Illness identity may help clarify clients' relationship to their illness and help tailor treatment to their needs. Further, it may be the case that those in different illness identity states have distinct needs or preferences for counselling services. For this study, I gave a voice to this population to inform clinical practice. In Chapter 4, I will elaborate on the importance of gaining clients' perspectives. If the concept of illness identity is applied to counselling practice, it is necessary to understand

the factors that shape the illness identity states. The following section will provide an overview of the literature regarding components that influence illness identity.

Factors Shaping Illness Identity

There is limited research on the factors that shape individuals' illness identities. However, it appears this area of research is continually growing. Oris and colleagues (2018) reported conflicting results in the research on illness identity and disease duration, suggesting that time may not necessarily contribute to higher levels of acceptance. The individual's relationship with their illness, and not the amount of time spent living with the illness, appears to determine their state of illness identity (Oris et al., 2018). Oris and colleagues' (2018) research demonstrates that adaptive living with chronic illness is achievable through the perception of the illness as a self-asset to combine with other self-aspects. By integrating illness into their identity, the individual can form a coherent sense of self, including and beyond their illness. This integration of illness into identity, without the need to sacrifice other aspects, such as relationships or work, has been found to have a positive impact on emotional wellbeing (Oris et al., 2018). Further, establishing an adaptive sense of illness identity may also contribute to physical functioning (Oris et al., 2018).

A significant factor in both states of acceptance and enrichment is the individual's efforts to lead a life that is as normal as is possible without suppressing, denying, or avoiding their illness (Oris et al., 2018). When individuals have not yet incorporated their chronic conditions into their identities, they may be more likely to consider external judgments when choosing coping strategies. The literature suggests that some individuals living with a chronic condition will conceal their illness to avoid judgment from others (Cook et al., 2017). For those who choose to hide their illness identity, psychological wellbeing decreases as illness symptoms

increase (Cook et al., 2017). However, one's ability to conceal their illness may be influenced by the type of chronic condition they experience.

In a recent study, O'Donnell and Habenicht (2021) explored the impact of stigma on the development of illness self-concept in individuals with invisible illness. They found that individuals who had internalized stigma and anticipated future stigma from others were more likely to have a "negative, all-consuming illness self-concept" (O'Donnell & Habenicht, 2021, p.15). Internalized and anticipated stigma were also related to "reduced positive meaning in the form of enrichment" (O'Donnell & Habenicht, 2021, p.15). Experiencing stigma firsthand was associated with negative illness self-concept but was not related to enrichment (O'Donnell & Habenicht, 2021).

These findings emphasize the importance of subjective perceptions for the development of adaptive illness identity. However, not all chronic conditions are invisible to others. To my knowledge, there have been no studies comparing the illness identity of those with conditions that are externally visible to those that are invisible. Those with chronic conditions that are visible may not have the option of concealing their illness from others. The visibility of an individual's disease may impact the development of illness identity. Most of the current literature focuses on samples homogenous in their chronic conditions, so it appears these comparisons have not yet been made. Utilizing a transdiagnostic population for this thesis provided an opportunity to begin filling in this gap in the current knowledge.

As the body of research on illness identity continues to develop, longitudinal studies have recently been published. Rassart and colleagues (2021) examined illness identity in adolescents and emerging adults (ages 14-25 years) with type 1 diabetes over three years. Over time, they found small increases in acceptance and engulfment, and small decreases in rejection. In

contrast, Van Bulck and colleagues (2021) assessed adults (ages 22-78 years, median age 34 years) with congenital heart disease over three years and found illness identity to be relatively stable across time. They stated that one-time assessment of illness identity could be more relevant for clinical use than frequent, short-term assessments. There have been conflicting results regarding the influence of age on illness identity (Van Bulck et al., 2021). However, illness identity may be more stable for adults than for adolescents. More research is needed to determine the influence of life stages on illness identity.

Much of the research on illness identity has focused on participants' perceptions of themselves. However, in a recent longitudinal study, Raymaekers and colleagues (2020) examined the relationship between adolescent illness identity and social context. They found that illness identity may impact individuals' perceptions of their relationships and interactions with others. In their study, overprotective parenting was associated with maladaptive illness identity (Raymaekers et al., 2020). Further, participants who had more adaptive illness identities appeared better able to engage in healthy relationships with peers (Raymaekers et al., 2020). These results support the role of social contexts in shaping illness identity. To my knowledge, current research has not yet addressed social contexts and illness identity in adults. Therefore, more work is needed to explore the impact of social context on illness identity states.

To summarize, based on the current research, illness identity may be shaped by many factors that influence the individual's relationship with their condition. Attempts to conceal one's illness, internalized and anticipated stigma, life stages, and social contexts may all play a role in illness identity development. Researchers are beginning to address illness identity in both intrapersonal and interpersonal contexts. The impact of illness identity on emotional and physical wellbeing underlines the importance of providing individuals with opportunities to discover an

integrative sense of self. Thus, more research is needed on the factors that contribute to adaptive illness identity.

As I have noted, identity development is a complex process that involves many interpersonal and intrapersonal elements (Cinoğlu & Arıkan, 2012). Although identity is understood as an individual's sense of self, self-perceptions are influenced by interactions with other people. Further, individuals coping with chronic health conditions experience their illness within the contexts of their life roles as partners, family members, friends, employees, and caregivers. Consequently, I believe it is necessary to address the interpersonal aspects of illness identity formation. Researchers have emphasized the importance of social support for coping with chronic illness. Receiving support from others in coping with chronic illness has significant implications for physical and psychological wellbeing. In the following section, I will outline the research regarding social support for chronic illness.

Social Support

In Chapter 3, I will discuss the value of group therapy for individuals living with chronic health conditions. First, however, I believe it is important to understand the significance of social support for this population. *Social support* encapsulates how interpersonal networks supply emotional and physical resources to help individuals cope with stressful situations. Support from others can act as a buffer for life's stressors and enhance the individual's perception of their ability to manage stress (Lehardy & Fowers, 2020).

There are three types of social support: *informational support*, such as providing knowledge and direction; *instrumental support*, including physical assistance; and *emotional support*, such as empathy and compassion (Lehardy & Fowers, 2020; White et al., 2018). Receiving support from others is an integral part of self-management for chronic illness

populations (Reeves et al., 2014; Riegel et al., 2012). The complexities of managing chronic illness often go beyond the personal capacity of the individual. Therefore, some people living with chronic illness tend to require the help of others to assist with managing their symptoms or daily tasks (Vassilev et al., 2013). Individuals living with chronic conditions may delegate much of the physical work associated with managing their illness to partners, close family, or community care resources (Vassilev et al., 2013; White et al., 2018).

Being diagnosed with a chronic condition often results in social exclusion and an increased risk of marginalization (Lehardy & Fowers, 2020; Wang et al., 2019). An individual's ability to cope with chronic illness is associated with the extent to which others meet their needs for affection, approval, belonging, and security (White et al., 2018). Social support positively impacts coping outcomes in two ways. Firstly, it serves as a protective factor against the negative influences of stress, stigma, and feelings of isolation. Strong social support networks for people with chronic conditions are associated with heightened self-esteem and self-worth and increased feelings of control over the individual's circumstances (White et al., 2018). Secondly, social relations provide the individual with resources for coping. These resources include practical support such as guidance or advice, helpful information, and opportunities to confide in others and engage in self-reflection (Wang et al., 2019; White et al., 2018).

Emotional support, such as empathy and compassion, may also contribute to coping resources (Wang et al., 2019; White et al., 2018). Dependable availability of emotional support may improve emotional regulation and physiological functioning, leading to improved physical and emotional health for those with chronic conditions (Lehardy & Fowers, 2020). Individuals with chronic illness benefit from creating diverse social networks of support (Reeves et al., 2014; Vassilev et al., 2013; Wang et al., 2019; White et al., 2018). Having various networks allows

consistent support that is easily adaptable to changing situations (Reeves et al., 2014; Vassilev et al., 2013). Further, when a substantial network supports the emotional needs of the individual, the burden of care for close friends and family is lowered, which may prevent relationship strain (Vassilev et al., 2013).

Not all social support provides equal benefits for coping with chronic conditions. Without a foundation of approval and understanding, relationships may cause unhealthy dependency and negative consequences for coping. In these instances, self-efficacy and control are depleted (White et al., 2018). The perceived effectiveness of social support is related to levels of self-esteem, physical symptoms, and general adjustment to living with chronic illness (Wang et al., 2019; White et al., 2018). When the individual with the chronic condition perceives their illness as an individual problem, as opposed to a problem to solve together with others, relationships can become strained (Helgeson et al., 2018). Individuals must establish diverse, reliable, and validating social bonds to cope with chronic illness effectively. Some may find this support outside of immediate and previously established social circles (Lehardy & Fowers, 2020).

Considering the current literature on the importance of social support for individuals with chronic illness, I believe that mental health services may benefit from incorporating peer interaction in treating this population. Services that naturally integrate social support, such as group counselling, appear to be valuable resources for the psychological care of those with chronic medical conditions. As modern healthcare services shift toward collaborative care, group therapy has become a useful form of clinical support (Leszcz, 2020). Group support for chronic illness will be the focus of the next chapter, as it is a significant component of this thesis.

Chapter Summary

In summary, *chronic illness* can be conceptualized as the emotional and cognitive experience of living with a chronic health condition. Living with chronic illness is a complex process that impacts mental wellbeing and quality of life. Coping with a chronic disease is a continual and multifaceted process, and an individual's ability to adapt has implications for their physical and psychological wellbeing. Because of the complexities of chronic illness beyond the physical symptoms of the health condition, collaborative care is recommended to provide holistic and individualized treatment. However, there are many limitations to the provision of collaborative care in current healthcare settings. Thus, there is a need for change within the treatment of chronic illness that involves increased involvement of mental health professionals.

Illness identity is the degree to which an individual integrates illness into their self-concept. Recently, research in this area has been expanding. Adaptive illness identity predicts more effective coping in individuals with chronic conditions. Illness identity may be a helpful way for mental health professionals to conceptualize individuals' perceptions of their illness. However, more research is needed to expand the collective understanding of illness identity in intrapersonal and interpersonal contexts. Because identity is developed within social contexts, and social support is an important factor in coping with chronic illness, group support may be a valuable resource for this population. Therefore, this study was intended to expand current research on illness identity and group support for chronic illness to inform the practice of mental health professionals. In this chapter, I have provided a review of the literature on chronic illness and illness identity as it relates to this thesis. Building on this foundation, I will now offer an overview of the current research on group therapy for chronic illness.

CHAPTER 3: Group Therapy for Chronic Illness

The focus of this chapter shall be to review the literature on group support and chronic illness to establish the need for my research to investigate the group therapy preferences of this population. This literature review incorporates: (a) an overview of group counselling, including (b) the advantages of group therapy and (c) the types of groups; (d) the therapeutic factors in group therapy; (e) the mechanics of group therapy; and (f) the group therapy preferences of individuals with chronic conditions, including (g) illness identity and group therapy preferences. This chapter will provide significant support for the purpose and importance of this study, which will be discussed further in subsequent chapters.

I acknowledge that there are many types of group-based supports available for chronic illness, ranging from casual peer support groups to more formalized, professionally facilitated therapy groups. In group counselling, multiple clients receive both peer and professional support led by at least one professional, who has received the appropriate training to facilitate interventions in a group setting (Brabender et al., 2004; Corey et al., 2018; Pollak, 2016; Yalom & Leszcz, 2020). The literature supports using group therapy for chronic illness populations; however, the work in this area is limited, and I believe more research is needed. Through this thesis, I hope to shed light on what individuals with chronic conditions may desire from group therapy. I believe a foundational understanding of group therapy to be important for appreciating the purpose of this study. Therefore, I will provide an overview of group counselling before discussing the various types of groups.

Overview of Group Counselling

Given my research focused on group therapy preferences of adults with chronic illness, it is my intention to outline some of the advantages of group therapy and the different types of

group-based supports available. After providing this review, I will shift my focus of this chapter to establishing how group counselling is well suited for those who present with chronic health conditions. Overall, it is my intention to prove that my research question (*How does illness identity relate to preferences for group therapy in a transdiagnostic population?*) was valid, justified, and suitable for extending the current knowledge about group counselling for chronic illness.

Advantages of Group Therapy

Group therapy can be an impactful and efficient psychological intervention for various concerns, as has been demonstrated by over three decades of quantitative and qualitative research studies (Rosendahl et al., 2021). Based on the literature, group therapy is at least as effective as individual therapy, as evidenced by meta-analyses on therapy outcomes (Burlingame et al., 2015; Burlingame et al., 2016; Rosendahl et al., 2021). For example, Burlingame and colleagues (2016) conducted a meta-analysis comparing the outcomes of group and individual therapies for various mental health concerns. Of the 67 studies they analyzed, 46 studies had equivalent treatment protocols, patients, and dosages, and all the studies demonstrated similar efficacy between group and individual therapies (Burlingame et al., 2016). For some individuals, group therapy may even be more effective than individual therapy because of the helpfulness of social support for combatting the feelings of shame, stigma, or isolation surrounding their concerns (Yalom & Leszcz, 2020). Group therapy can be advantageous for managing chronic pain, improving mood, and decreasing functional impairment (Lamb et al., 2010), and seems to contribute to members improving their self-care, self-efficacy, and quality of life scores (Jackson et al., 2019).

Further, group therapy can be a cost-effective option for individuals seeking treatment, as evidenced by the 6-month randomized controlled trial conducted by Luciano and colleagues (2017). These researchers explored the cost-utility of an Acceptance and Commitment Therapy (ACT) group program as compared to pharmacological treatment for 156 patients with fibromyalgia. By comparing individuals in the ACT group to those on the waitlist and those receiving pharmacological treatment, they found that the ACT group was less expensive and more effective than the recommended pharmacological interventions for this population (Luciano et al., 2017). While many therapeutic groups take place in person, other delivery methods, such as telephone and online platforms have also been introduced, making group therapy more accessible (Heckman et al., 2013; Weinberg & Rolnick, 2019).

To provide a more specific description of what is meant by *group therapy* in this thesis, I will now present an overview of the different types of groups that are described in the literature. In doing so, I will interweave the connection between chronic illness and group therapy wherever possible.

Types of Groups

There are many forms of group therapy, including psychoeducational groups, counselling groups, psychotherapy groups, and brief group therapy (Corey et al., 2018). In the context of chronic illness, these types of group therapy can also be distinguished from more informal supports, such as chronic illness self-management programs and peer support groups. In this section, I will deliver an overview of these types of groups with the intention of providing clarity around the focus of this thesis.

Psychoeducational Groups. *Psychoeducational groups* focus on providing information and developing group members' skills in a specific area of life. These groups typically take place

over a limited time, and the meetings are structured around particular training, rehearsing, and exploring skills (Corey et al., 2018). For example, Fischer and colleagues (2013) described a psychoeducational group for women with breast cancer (n=57). The group facilitators provided information about breast cancer, coping with the diagnosis, coping with anxiety and depression, stress management skills, and the importance of receiving support (Fischer et al., 2013). During the group meetings, members focused on learning new skills, discussing homework assignments, and participating in physical, emotional, and behavioural exercises (Fischer et al., 2013). Pre and post measures revealed significant differences in illness perceptions, coping strategies, and levels of distress. These changes continued to be maintained for at least one year after the end of the program, as indicated by measures at the 12-month follow-up (Fischer et al., 2013).

Counselling Groups. *Counselling groups* aim to help group members resolve short-term problems but usually do not address major psychological or behavioural concerns (Corey et al., 2018). For instance, Shavandi and Veshki (2021) described the effectiveness of group-delivered compassion-focused therapy for women applying for divorce (n=30). The researchers compared the women's self-criticism before and after the eight-session group intervention. Compared to the control group, those who received the compassion-focused group intervention exhibited significant decreases in self-criticism, allowing them to navigate the divorce process with more acceptance and less self-judgment (Shavandi & Veshki, 2021).

Psychotherapy Groups. *Psychotherapy groups* address specific symptoms of acute or chronic mental or emotional concerns. These groups focus on creating significant changes in participants' personalities (Corey et al., 2018). An example of this type of group was offered to university students who struggled with symptoms of severe emotion dysregulation in a study by Uliaszek and colleagues (2016). In their study, 54 students were randomly assigned to one of two

groups, a dialectical behaviour therapy (DBT) group or a positive psychotherapy (PPT) group. Over the course of 11-12 weeks, the participants' skill usage, psychiatric symptom levels, and wellbeing were monitored. Both groups exhibited significant changes from pre- to posttreatment; however, the effect sizes were larger for the DBT group intervention (Uliaszek et al., 2016).

Brief Group Therapy. *Brief group therapy* is time-limited and focused on clear and structured goals (Corey et al., 2018). This type of group was demonstrated in a study by Ilbay and Akin (2014) that analyzed the efficacy of a solution-focused brief group intervention for combatting burnout in university students (n=24). Compared to those in the control group, the students who received this brief group intervention displayed significant improvements in their self-reported burnout levels following the intervention. These improvements remained consistent when follow-up tests were completed two months later (Ilbay & Akin, 2014).

The group types described thus-far are considered *group therapy*, as they are therapeutic interventions delivered by professionals with the appropriate training. In group therapy, the facilitator works with each individual and with the group as an entity to create interpersonal and intrapersonal change (Drumm, 2006). In contrast, more informal group-based supports for chronic conditions are also prevalent in the literature. These include *chronic illness self-management programs* and *support groups*. I shall describe these two types of informal group-based support to distinguish them from group therapy.

Chronic Illness Self-Management Programs. In previous studies, researchers have supported the use of manual-based programs for chronic disease self-management, such as the Chronic Disease Self-Management Program (CDS-MP). These programs, led by trained peer facilitators, focus on behavioural changes, such as increasing medication adherence, improving nutrition, and using community resources (Lee et al., 2019; Lorig et al., 2001). They are typically

developed by healthcare professionals, and do not tend to emphasize profound personal change beyond these behavioural changes (Donald et al., 2018). Thus, they serve a different purpose than group therapy in the lives of those with chronic conditions.

Relative to this thesis, these programs appear to address chronic *disease* rather than chronic *illness*. Thus, based on the conceptualization of chronic illness I adopted for this thesis, programs such as the CDS-MP only address part of what is necessary for many people to cope with chronic health conditions. Group therapy can assist in the self-management of physical *disease* by incorporating psychoeducational components. However, it can also tend to the psychological and social aspects of chronic *illness* by facilitating deeper intrapersonal and interpersonal exploration.

Chronic Illness Support Groups. In a 2010 survey of 3000 adults by the Pew Research Institute, “one in four Internet users living with a chronic condition reported going online to find others with similar health conditions” (Conrad et al., 2016, p.3). For individuals with chronic illness, online support groups may be easily accessible options, as they allow for asynchronous connections at any time of day (Allen et al., 2016; Bartlett & Coulson, 2011). Whether in-person or online, chronic illness support groups are becoming increasingly popular (Lehardy & Fowers, 2020). Rather than clinical professionals, people who have experience living with chronic illness typically administrate the online groups (Lehardy & Fowers, 2020). Presently, almost every medical condition has at least one dedicated website or page on a social media platform such as Facebook, Instagram, or Twitter (Conrad et al., 2016).

Support groups typically serve the purpose of helping individuals cope with problems that they may not be able to change (Brabender et al., 2004; Pollak, 2016). Beyond the benefits of social support in general, peer support groups may contribute to additional well-being for

individuals with chronic illness by providing a level of empathetic support that they may not find with friends and family (Chung, 2013; White et al., 2018). Kingod and colleagues (2017) conducted a systematic review of thirteen qualitative studies regarding online peer communities for chronic illness. They found that the individuals in these groups are often drawn to connect with others with similar conditions for “mutual solidarity and emotional support in relation to the day-to-day management of illness” (Kingod et al., 2017, p.95).

Limitations of Groups. Support group members must be mindful of over identifying with the helplessness element of their illness, as this may promote a state of engulfment (Oris et al., 2018). Considering the isolation that may accompany some chronic conditions, individuals must avoid becoming dependent on online communities that normalize the expression of maladaptive behaviours (Chung, 2013). Moreover, support groups lack the professional guidance that some individuals may need to navigate social comparisons in an adaptive way (Dibb & Yardley, 2006). Thus, online chronic illness communities provide substantial support, but for many people, these groups are likely best seen as complementary supports to use in conjunction with other interventions (Chung, 2013).

Both support groups and therapy groups may have therapeutic effects for group members. However, beyond social support, group therapy interventions also include the professional components that can effectively treat psychological difficulties such as anxiety and depression (Barkowski et al., 2020; Tong et al., 2019). Therefore, group therapy can have a unique role in improving individuals’ lives which may have a differential impact from peer-led support groups. For many individuals, group therapy may provide the support needed for adaptive perception of their chronic health conditions. Thus, I contend that group therapy is an

ideal intervention to explore in this thesis. I will now shift the focus of this literature review to the therapeutic factors that have been suggested to contribute to the efficacy of group therapy.

Therapeutic Factors in Group Therapy

Yalom and Leszcz (2020) described eleven therapeutic factors for group therapy. Relevant to my thesis, Leszcz (2020) identified seven of these therapeutic factors that are significant for group therapy for medical conditions. I will outline each factor, in no specific order, by defining the factor and connecting it to group counselling for chronic illness. I will also outline two additional factors (collective identity and attachment) that I have identified based on recurring themes in the literature on group-based support for chronic illness.

Instillation of Hope. In group therapy, *hope* is the essential belief that change is possible. Group facilitators can instill members' hope by bolstering positive expectations for the efficacy of group therapy (Yalom & Leszcz, 2020). As mentioned in Chapter 2, hope is an important factor for coping with chronic illness, as it contributes to perceived stress and health-related quality of life. For example, Hirsch and Sirois (2016) found that, for individuals with fibromyalgia (n=419), arthritis (n=433), and inflammatory bowel disease (n=428), higher self-reported hopefulness was associated with decreased pain, stress, and fatigue. Researchers who have studied the efficacy of hope-focused group therapies for individuals living with diabetes have suggested that these approaches significantly increase psychological wellbeing (Ghazavi et al., 2015; Pouraboli et al., 2018). In the absence of hope, individuals may find themselves in the state of engulfment (Oris et al., 2018). Based on the literature, I would argue that instillation of hope in group therapy could also contribute to the development of adaptive illness identity by encouraging individuals to view their chronic health conditions more optimistically.

Universality. *Universality* refers to the experiences that allow one to recognize that they are not alone in their feelings (Yalom & Leszcz, 2020). While all individuals within the group arrive from their own unique experiences, the commonalities between members quickly contribute to relief from isolation. Group facilitators can support universality by creating group norms of self-disclosure to uncover shared experiences. For people with chronic health conditions, feelings of loneliness and isolation may be common. Petersen and colleagues (2020) recently examined a combination of quantitative surveys (n=302) and qualitative, semi-structured interviews (n=50) to uncover the motivations of individuals with chronic conditions in using digital media. They found that individuals with chronic illness often seek connections with others to validate their experiences and struggles (Petersen et al., 2020). I believe that the experiences of universality in group therapy may contribute to the development of more adaptive illness identity because they can relieve the isolation and loneliness that may contribute to engulfment (Oris et al., 2018).

Imparting Information. In group therapy, *imparting information* includes didactic instruction from the facilitators and direct advice from others (Yalom & Leszcz, 2020). This can lead to interpersonal connections and further understanding of one's concerns (Yalom & Leszcz, 2020). As mentioned in Chapter 2, informational support is an important form of social support for individuals with medical conditions. The effects of informational support were recently explored in a study by Pourfallahi and colleagues (2020). These researchers used a quasi-experimental design to examine the illness perceptions of cancer patients (n=80) undergoing chemotherapy before and after a 10-week nurse-led informational-emotional support program. Compared to the control group, those who received the informational support exhibited significant positive changes in their illness perceptions, as indicated by their pre- and post-group

ratings of illness timeline, consequences, controllability, and coherence (Pourfallahi et al., 2020). Given the contribution of illness perceptions to illness identity, I would argue that informational support in group therapy could contribute to adaptive illness identity development.

Altruism. In group therapy, *altruism* involves providing support to others, which bolsters feelings of purposefulness, meaning, hope, and self-esteem (Yalom & Leszcz, 2020). In group therapy, altruism can be encouraged by placing emphasis on interactions between group members. Warner and colleagues (2010) studied the impact of giving emotional support on quality of life in a community sample of 1415 adults with multiple co-occurring chronic health conditions. For these participants, giving emotional support more often was significantly associated with increased physical and mental quality of life. The researchers also found providing emotional support to be positively related to self-esteem and control beliefs (Warner et al., 2010). These results suggest that helping others provides significant benefits for individuals with chronic conditions. Further, I believe that altruism may contribute to developing adaptive illness identity, as the ability to help others because of one's experience with chronic illness may encourage enrichment and personal growth (Oris et al., 2018).

Catharsis. *Catharsis* describes strong release of emotions, and it is necessary, but not sufficient, for therapeutic change (Yalom & Leszcz, 2020). Feelings of belonging and safety are usually required for cathartic experiences in group therapy. The authors of a qualitative meta-analysis found that experiencing and exploring emotions during sessions leads to acceptance and higher levels of engagement (Levitt et al., 2016). Thus, group therapists can encourage group members to focus on building awareness and tolerance for their emotions through group interactions. According to Karademas and colleagues (2011), emotional suppression negatively impacts physical functioning and emotional wellbeing for people with chronic conditions. In

their study of 135 adults with chronic coronary artery disease, they found that emotional suppression led to increased negative emotionality and decreased subjective health. They suggested that emotional expression has important impacts for physical and mental wellbeing (Karademas et al., 2011). I contend that learning how to process and accept the emotions associated with chronic illness through catharsis may contribute to the development of more adaptive illness identity, as it may lead to greater acceptance of one's chronic condition.

Existential Factors. As group members learn more about themselves, *existential factors*, such as mortality, responsibility for life's outcomes, and the search for meaning, often arise (Yalom & Leszcz, 2020). Group therapists can encourage this therapeutic factor by inviting contemplation and discussion of topics related to human existence. For example, a cognitive-existential therapy group was delivered to 11 women with chronic kidney failure disease in a study by Bahmani and colleagues (2016). The participants engaged in the 12 group sessions for 90 minutes two days per week prior to receiving hemodialysis treatments. Based on the pre- and post-group measures, the researchers reported that the participants experienced significant increases in hope and significant decreases in helplessness, isolation, and other depressive symptoms (Bahmani et al., 2016). As group members grapple with existential topics in group therapy, I believe there is opportunity for the experience of chronic illness to contribute to greater meaning in life. Thus, this therapeutic factor may contribute to a shift toward enrichment (Oris et al., 2018).

Group Cohesiveness. *Cohesion* refers to the feelings of unity or "we-ness" experienced by the group members that allows them to feel belonging, warmth, and security (Yalom & Leszcz, 2020, p.125). After conducting a meta-analysis of 55 studies on cohesion in group therapy, Burlingame and colleagues (2018) concluded that cohesion reliably predicts the

outcomes of group therapy, especially when group leaders bolster member interactions. Thus, they suggested that group leaders introduce interventions that encourage a positive group environment (Burlingame et al., 2018). Group cohesiveness was an important factor in a support group for women with disabilities that was described by Mejias and colleagues (2014). These researchers conducted qualitative interviews with nine women who had been members of the support group for an average of seven years. The women identified feelings of belonging within the support group as important for building more positive self-concepts (Mejias et al., 2014). I believe that the feelings of connection and belonging experienced in groups may assist in developing more adaptive illness identity by contributing to the ability to accept one's illness as a part of oneself without being inundated by it (Oris et al., 2018).

Collective Identity. Researchers have emphasized the importance of group membership for contributing to one's sense of self, a concept known as *collective identity* (Lehardy & Fowers, 2020). As mentioned in Chapter 2, social identity theories, which are prominent and well-accepted in the literature, suggest that identity is a product of the groups to which the individual belongs (Cinoğlu & Arıkan, 2012). Aviram and Rosenfeld (2002) applied social identity theory to group therapy when working with stigmatized adults with cognitive disabilities. In their clinical examples, they described how group exercises focused on collective identity can increase group members' self-esteem (Aviram & Rosenfeld, 2002). The experience of chronic illness may leave an individual feeling marginalized in many group contexts; however, engaging with others that have similar experiences can help to establish feelings of belonging within one's identity.

Stigma and marginalization can contribute to negative perceptions of group identity for individuals with chronic conditions. Fuster-Ruizdeapodaca and colleagues (2014) explored the

perceived stigma, group identification, and quality of life of 557 individuals with HIV. They found that individuals with higher levels of internalized stigma reported negative perceptions of their diagnostic group, which contributed to decreased quality of life (Fuster-Ruizdeapodaco et al., 2014). These results exemplify the importance of individuals' perceptions in shaping identity. Thus, I contend that group therapy can provide a unique setting to influence the development of adaptive collective and individual identity.

Attachment. *Attachment* involves the formation of interpersonal bonds. It is related to the inherent desire to both give and receive support (Lehardy & Fowers, 2020). Marmarosh (2014) reviewed the literature on attachment in group therapy and reported that group therapy helps support more secure interpersonal attachments within and outside of the group. According to Lehardy and Fowers (2020), the experience of chronic illness may result in changes in previously established relationship bonds with important attachment figures. However, they suggested that seeking support from other individuals with chronic illness may elicit the formation of new, adaptive attachment bonds (Lehardy & Fowers, 2020).

I would argue that attachment could be considered another therapeutic factor in group therapy for chronic illness and that more secure attachment could contribute to greater acceptance of one's condition. For example, Meredith and colleagues (2007) found an association between attachment and depressive symptoms in patients with chronic pain (n=99). In their study, individuals with more relationship anxiety reported more depressive symptoms and higher levels of pain before and after their pain treatments (Meredith et al., 2007). Similarly, Hinnen and colleagues (2012) explored the attachment styles, depressive symptoms, and perceived social support of individuals with HIV (n=233). They found that insecure attachment was related to depressive symptoms and that individuals who received less social support

reported more symptoms of depression (Hinnen et al., 2012). I wonder whether involvement in group therapy would assist these individuals in developing more secure attachments and, in turn, experiencing fewer depressive symptoms.

In summary, I presented a review of nine factors that seem to reflect the value of groups for those with chronic illness. It is my belief that the value of group therapy for this population also underscores the importance of this study. To establish further understanding of the components of group therapy that will be addressed in this study, I will now describe what I refer to as the *mechanics* of group therapy.

Mechanics of Group Therapy

The *mechanics* of group therapy are the organizational and structural components that are chosen by the group facilitators when planning the group. These components are usually chosen based on the type and purpose of the group (Corey et al., 2018; Drumm, 2008; Yalom & Leszcz, 2020). With this study, I explored the group therapy preferences of individuals with chronic health conditions. To assist group therapists in accommodating for this population, I believe it was useful to inquire about their preferences for these organizational components. Thus, in this section, I will describe some of the mechanics of group therapy, including: (a) group leadership; (b) group membership; (c) group size; (d) open and closed groups; (e) structure; and (f) group goals.

Group Leadership. It is recommended group therapy is co-led by two facilitators (Corey et al., 2018). It is considered advantageous for the co-leaders to bring different skill sets to the group so that they may approach facilitation with a broader scope (Miles & Kivlighan, 2010). For instance, Schaefer and colleagues (2012) explored the efficacy of a collaborative group intervention for medical patients with unexplained symptoms co-facilitated by physicians and

psychosomatic psychotherapists. Compared to the physician training alone, the collaborative groups contributed to significant increases in patients' psychological quality of life (Schaefer et al., 2012). Schaefer and colleagues (2012) suggested that "the collaborative approach could bridge the gaps between general practice and mental health care" (p.116).

Group Membership. The composition of the group significantly affects the dynamics within the group (Yalom & Leszcz, 2020). Homogeneity within the group can lead to increased cohesion, and the group content may focus on issues specific to the relevant population (Corey et al., 2018; Yalom & Leszcz, 2020). However, heterogeneity allows members to interact with other diverse individuals, which may benefit members in many contexts. The group facilitators must decide what characteristics the members should have in common, such as age, life experiences, or symptoms (Yalom & Leszcz, 2020).

The experience of chronic illness is often accompanied by marginalization, stigmatization, and social exclusion (Lehardy & Fowers, 2020). Thus, for individuals with chronic conditions, membership within groups of similar individuals can lead to heightened levels of empathy for one another, leading to increased emotional support (Lehardy & Fowers, 2020). One's inherent desire for connection and belonging may serve as motivation to seek others with similar experiences. Group membership allows individuals with chronic conditions to create significant connections with others, experience belonging, and enhance their wellbeing (Lehardy & Fowers, 2020).

Group Size. The size of a group depends on the age of the members and the group's focus, among other factors (Corey et al., 2018). Groups with more interaction between adult members are typically made up of five to nine members, whereas more structured psychoeducational groups may be much larger (Corey et al., 2018; Yalom & Leszcz, 2020). For

example, the psychoeducational group described by Fischer and colleagues (2013) included 57 women, while the brief solution-focused group described by Ilbay and Akin (2014) included 12 students. The group's capacity must have a lower limit that promotes consistent engagement and an upper limit that will still allow enough time to focus on each individual (Yalom & Leszcz, 2020).

The sizes of groups for chronic illness discussed in the literature vary significantly. For instance, Brown and colleagues (2019) designed a self-compassion group for outpatients with chronic illness that included eight group members. They intended to use their study to test the feasibility of this group intervention. In contrast, in a randomized controlled trial, Ruesch and colleagues (2017) ran a cognitive behavioural group intervention for 38 group members with health conditions. These researchers intended to improve symptoms of depression and overall health-related quality of life. Smaller group sizes appear to be underrepresented in the quantitative research as quantitative studies generally aim for a larger sample size.

Open and Closed Groups. Groups may be *open*, whereby members may leave or join the group at their leisure, or *closed*, in which case all members register for the duration of the program and new members do not enter the group after it begins (Corey et al., 2018; Drumm, 2008; Yalom & Leszcz, 2020). Closed groups are typically offered over a pre-determined number of sessions, while open groups may be continuous (Corey et al., 2018). Thus, membership in a therapy group may be short-term or long-term. While open groups give members the prospect of creating an increased number of interpersonal connections, closed groups tend to be more cohesive (Corey et al., 2018).

In the aforementioned study by Ruesch and colleagues (2017), the researchers described the eight-session cognitive behavioural group for medical illness as half-open: new group

members could join the group every second session when a new module began. This approach was distinct from Brown and colleagues' (2019) closed self-compassion group that included the same eight members for all four sessions.

Structure. Groups differ in the degree of structure provided by the facilitators. Groups that are more *structured* include more facilitator engagement with members, while more *unstructured* groups involve less facilitator engagement (Corey et al., 2018). Groups may begin more structured but slowly become less structured over time as the group develops (Corey et al., 2018). The degree to which the facilitators are involved in the group depends on its purpose and goals. For example, psychoeducational groups typically require more facilitator involvement because they focus on information and skill-building (Corey et al., 2018).

A study by Blanchard and colleagues (2007) demonstrates structured psychoeducational groups for medical illness. They evaluated cognitive therapy group treatments for individuals with irritable bowel syndrome (n=210). Both intervention groups in this study utilized a manualized protocol for the group programs to teach group members active strategies that they found contributed to symptom reduction (Blanchard et al., 2007). Thus, these groups would have involved a significant amount of facilitator engagement to provide the psychoeducational components of the program material.

Group Goals. The goals of the group, which are identified by the purpose of the group program, are specific to the nature of the group. For example, the goals of a psychoeducational group may involve gaining knowledge and building skills around a particular topic, while the goals of a psychotherapy group may be focused on alleviating psychological symptoms (Corey et al., 2018). The group's goals tend to shape the group interactions and activities that are facilitated within the group. A psychoeducational group may include activities that allow

members to discuss and integrate the information presented (Corey et al., 2018). This was illustrated by the psychoeducational group for women with breast cancer described by Fischer and colleagues (2013), in which the group activities focused on learning new physical, emotional, and behavioural coping exercises that could be incorporated into the participants' lives outside of the group.

In contrast, psychotherapy groups may include activities that encourage members to interact with one another to explore their psychological struggles on a deeper level (Corey et al., 2018). For example, in the psychotherapy groups for university students with severe emotional dysregulation described by Uliaszek and colleagues (2016), group members engaged in activities that allowed them to improve their distress tolerance and interpersonal effectiveness, practice finding meaning in life, and engage in deeper self-exploration of their values and strengths (Uliaszek et al., 2016).

According to Leszcz (2020), groups for medical illness typically focus on improving coping and wellbeing. Groups that emphasize on *emotion-focused coping* highlight social support and emotional expression (Leszcz, 2020). This was demonstrated in a 10-session mindfulness-based group for individuals with inflammatory rheumatic joint diseases described by Zangi and colleagues (2012) that aimed to increase self-efficacy and emotion-focused coping (n=73). In this program, group members learned to increase their awareness and intentionally attend to their emotions, thoughts, and body sensations. Compared to the control group post-intervention and at the 12-month follow-up, those who received the group intervention reported significant improvements in self-efficacy, psychological distress, and ability to process their emotions and fatigue symptoms (Zangi et al., 2012).

Groups that emphasize *problem-focused coping* tend to concentrate on self-care, information, and education (Leszcz, 2020). A group for individuals with multiple sclerosis in a study by Sadri Damirchi and Agazadehasl (2017) utilized cognitive-behavioural therapy to improve problem-focused coping skills (n=80). The researchers found that their cognitive-behavioural group therapy program significantly increased problem-based coping skills and reduced the group members' avoidant coping behaviours (Sadri Damirchi & Agazadehasl, 2017).

Lastly, groups that emphasize *meaning-focused coping* feature existential topics such as issues of mortality, reframing, and spirituality (Leszcz, 2020). According to Leszcz (2020), meaning-focused coping is essential for clients that may find emotion- and problem-focused coping inadequate. This was illustrated by a 12-week group teletherapy program described by Heckman and colleagues (2013) that was designed to improve depressive symptoms in older adults with HIV (n=361). These researchers explored the efficacy of supportive-expressive group therapy (SEGT) and coping effectiveness training (CET) as compared to a standard of care control group. Each 90-minute weekly group intervention was delivered with six to eight participants at a time (Heckman et al., 2013).

In Heckman and colleagues' (2013) study, the CET group received a manualized intervention using cognitive-behavioural techniques to develop problem- and emotion-focused coping skills, while the SEGT group received a manualized intervention to improve participants' ability to express feelings about and contemplate existential issues (e.g., death, isolation, loss of freedom). Post-intervention, and at the 4- and 8-month follow-ups, participants from the SEGT group reported significantly lower depressive symptoms than the standard of care control group (Heckman et al., 2013). In contrast, those who participated in the CET group reported symptoms

of depression that were equivalent to those in the control group post-intervention and at both follow-ups (Heckman et al., 2013).

To summarize, the *mechanics* of group therapy are the organizational components of the group. Each group is uniquely designed according to its purpose, leader and member characteristics, size, structure, and goals. The mechanics of a group are decided on by the facilitator(s) before the group begins. In this thesis, I utilized my study to invite the perspectives of adults with chronic illness on the mechanics of group therapy. In my Discussion chapter, the input provided by the participants will be used to provide recommendations for group therapists to design their groups to better suit the needs of this population.

In this literature review so far, I have provided an overview of the advantages, types, and mechanics of groups, as well as the therapeutic factors that have been suggested to contribute to change in group therapy. This material has set the stage for me to now reinforce the connection between the current literature and my thesis study. Thereafter, I will conclude this chapter by outlining the potential connection between illness identity and preferences for group therapy.

Group Therapy Preferences of Individuals with Chronic Conditions

The American Group Psychotherapy Association (n.d.) encourages evidence-based practice among group therapists. In doing so, they recommend that group therapists use empirical research and client values and preferences to guide their work. The literature outlined in this chapter describes the options for the types and mechanics of groups, as well as the therapeutic factors that can be incorporated into group programs. In the literature, researchers have advised that best practice for chronic illness self-management includes long-term, individualized programs (Pinchera et al., 2018). However, researchers have also suggested that patients are usually not involved in developing self-management programs (Donald et al., 2018).

The next chapter will outline the importance of incorporating client perspectives when planning therapeutic interventions. First, however, I believe it is necessary to acknowledge that the research that illustrates the group therapy preferences of individuals with chronic illness is limited.

To my knowledge, there are very few studies addressing the group therapy preferences of individuals with medical conditions. One study by Sherman and colleagues (2007) examined the perspectives of 425 outpatient participants regarding cancer psychotherapy groups. They constructed an original survey to assess patient interest and preferences for group therapy (Sherman et al., 2007). While only some of the respondents in this study had previously participated in a group, many were interested in attending (Sherman et al., 2007). Interest in attending did not vary based on demographic information; type of cancer; the amount of time since diagnosis; recommendations from family, friends, or physicians; or amount of social support (Sherman et al., 2007).

Sherman and colleagues (2007) assessed motivations for attending group therapy in those that were interested. Receiving medical information and learning about health and wellness were common motivations, while emotional support and learning coping skills were less common (Sherman et al., 2007). The reasons for attending a therapy group appeared to vary based on the type of cancer diagnosis (Sherman et al., 2007). When asked about their preferences for group mechanics, a drop-in format appeared preferable over a closed group, but there were gender differences in these preferences (Sherman et al., 2007). While many participants were open to attending a group that would be heterogeneous for disease type, preferences for homogeneity appeared more common for those with certain types of cancer (Sherman et al., 2007).

I believe these results are significant for group therapists to understand the perceptions of individuals with cancer. However, because there are many types of cancer and they are not always long-term conditions, these results may not be generalizable to individuals with chronic health conditions. Therefore, to expand the current research, I explored preferences for group therapy in a transdiagnostic population. Because the topics addressed by Sherman and colleagues (2007) aligned well with my study, I am grateful that they granted me access to the survey they used in their research. In Chapter 6, I will describe how their work contributed to the construction of my survey.

In addition to exploring the preferences of individuals with chronic conditions for group therapy, I expanded the current research by determining whether illness identity relates to these preferences. While the relationship between illness identity and preferences for group therapy had not yet been addressed in the literature, I believe some previous findings alluded to the possibility that the two are related. Before concluding this chapter, I will briefly touch on the potential connection between illness identity and preferences for group therapy in previous research.

Illness Identity and Preferences for Group Therapy

Leszcz (2020) suggested that psychoeducational groups are the most beneficial for individuals early after diagnosis, while people later in their illness trajectory may benefit from groups that focus on meaning-based themes. Similarly, in Sherman and colleagues' (2007) study, most participants gravitated toward group therapy soon after being diagnosed with cancer or during active treatment rather than later in their illness trajectory or recovery. However, considering the research on illness identity, it may be more than the time the individual has lived with their chronic condition that contributes to their preferences for group therapy.

Stuber and colleagues (1988) described a therapy group for chronic medical illness that ran for just over three years. Their transdiagnostic group consisted of 14 members who participated in therapeutic work around the psychological experience of chronic illness (Stuber et al., 1988). The researchers described an unexpected distinction within the group: those who identified themselves as *chronically ill* compared to those who identified themselves as *disabled* (Stuber et al., 1988). Stuber and colleagues (1988) noted that these two types of group members differed in their self-concepts. They described these differences in self-concept as related to the visibility of the health condition and the individual's attitudes toward their disease.

According to Stuber and colleagues (1988), those who identified as *disabled* rather than *ill* were more independent and more commonly led active lives outside of the group. These members were also less likely to remain members of the group long-term, despite showing significant interest when first joining (Stuber et al., 1988). Stuber and colleagues (1988) described their therapy group as a long-term, closed group that met in a medical centre for 1.5 hours weekly. Those who identified as *disabled* rather than *chronically ill* did not appear to benefit as much from this format and may have preferred a short-term group in which the members were less dependent on one another (Stuber et al., 1988). It appears that those who identified themselves as *disabled* were better able to adaptively integrate their illness into their identity and consequently needed different types of support, which also impacted their interactions and perceptions within the group.

Based on the existing research reviewed in this thesis, I believe that an individual's illness identity state may contribute to what they would find helpful in a therapy group. If this is the case, therapists could use the concept of illness identity to get a clearer picture of what their

clients may need from group therapy. With this thesis, I added the voices of this population to the existing research by exploring how illness identity can inform group therapy.

Chapter Summary

My work in this chapter has established the value of asking: *How does illness identity relate to preferences for group therapy in a transdiagnostic population?* I believe my research question is valid because of the value of group therapy for this population and the importance of illness identity in coping with chronic illness. The significance of my research is to highlight how the factors of group are also critical in groups for those with chronic illness. I believe this thesis research expands and strengthens the current research on chronic illness, illness identity, and group therapy. I also believe this thesis fills some of the gaps I have identified in this chapter, namely, the exploration of the firsthand perspectives of this population on group therapy programs and how illness identity relates to those preferences. I have argued that it is important to incorporate the preferences of this population in adapting group interventions, which I will further elaborate on in the following chapter.

CHAPTER 4: Client Preferences

Chapters 2 and 3 have offered an overview of the literature supporting the value of group counselling for chronic illness. To adequately adapt group therapy in this manner, practitioners must have a strong understanding of this population. I have discussed how I believe the concept of illness identity may be helpful for group therapists to improve their comprehension of their clients. Moreover, I have identified the scarcity of this population's firsthand perspectives on group therapy in the literature. I consider these firsthand perspectives invaluable for designing group interventions. In this chapter, I will elaborate on the purpose of this study. This chapter will address: (a) the importance of incorporating clients' perspectives in therapy, and (b) strategies for exploring client preferences.

Importance of Client Perspectives

Previous researchers have explored several different domains that contribute to client perspectives. For example, some scholars have focused on clients' *expectations*: beliefs about their treatment outcomes or what will occur during their time in therapy (McLeod, 2012; Strauss et al., 2015; Swift et al., 2018). In contrast, clients' *preferences* are what they desire from the therapy experience (Cooper et al., 2021; McLeod, 2012; Swift et al., 2018). Preferences and expectations are interrelated; however, preferences are also shaped by other factors, such as personality, motivation for change, and previous treatment experiences (Anestis et al., 2021; Cooper et al., 2021; Strauss et al., 2015; Swift et al., 2018). This study focused on client preferences to determine what clients *want* from group therapy.

McLeod (2012) suggested three practice principles regarding client preferences. First, he stated that "effective therapy requires a capacity to respond to client preferences" (McLeod, 2012, p.22). Some researchers suggest that accommodating client preferences in therapeutic

interventions impacts dropout rates and treatment outcomes (Swift et al., 2018). Swift and colleagues (2018) conducted a meta-analysis of data from 53 studies including over 16,000 psychotherapy clients. They found that psychotherapy clients who were not given treatment options or did not have their preferences accommodated were more likely to drop out of therapy than those who had their preferences matched. They also found improved outcomes for clients whose preferences were accommodated (Swift et al., 2018). This may be because clients are more committed to therapeutic change when their preferences are accommodated (Cooper et al., 2021; McLeod, 2012).

As the second practice principle, McLeod (2012) noted that “client preferences are complex and multidimensional” (p.23). Every individual is different, so it is necessary to engage in open dialogue with clients to determine their preferences (Cooper et al., 2021). Thus, although this study aimed to explore the relationship between illness identity and preferences for group therapy, active involvement with each unique client’s preferences will be necessary regardless of the outcomes of this study. For example, some individuals may prefer alternatives to therapeutic interventions such as medications, physicians, or non-professional support (McLeod, 2012; Swift et al., 2018). Therapists must acknowledge that some therapeutic interventions (e.g., group therapy, individual therapy, or therapy in general) may not be the best fit for certain individuals. By inquiring about client preferences, therapists can collaborate with clients to meet their needs. With the complexity of individual preferences in mind, I believe this study provides a helpful foundation for practitioners working with this population.

Lastly, McLeod (2012) suggested that “attention to client preferences supports core therapeutic processes: meaning-making and the development of a therapeutic alliance” (McLeod, 2012, p.25). Assessing and incorporating client preferences in therapeutic practice allows

collaboration with the client, increasing opportunities for meaningful reflection (McLeod, 2012). Further, exploring and integrating these preferences into therapy fosters a stronger therapeutic relationship, contributing to better treatment outcomes (Cooper et al., 2021; McLeod, 2012). Accommodating treatment preferences gives clients autonomy and choice in the therapeutic relationship. McLeod (2012) recommended that therapists assume their clients have a good idea of their preferences and what will be effective for them. Some clients may require more guidance than others in discovering their preferences, but therapists may facilitate this discovery.

Thus, in this thesis, I invited individuals with chronic health conditions to share their group therapy preferences in hopes of expanding the current knowledge in this area and informing group counselling programs. In my Discussion chapter, I will elaborate on how the results of this study may be used by group therapists to accommodate for the needs of this population. I will now outline the types of client preferences that have been emphasized in the literature and how they will be explored in this thesis.

Exploring Client Preferences

When addressing client preferences, several preference categories may be of importance. Swift and colleagues (2018) recommended that practitioners assess clients' *activity, therapist, and treatment preferences* (Swift et al., 2018). *Activity preferences* describe the types of activities clients would like to have included in therapy, such as worksheets or homework assignments (Swift et al., 2018). These preferences relate to the structure of therapy groups discussed in Chapter 3. Swift and colleagues (2018) also included preferences for different treatment formats (e.g., individual, group) in this category. Some individuals may gravitate toward individual therapy rather than group therapy, as it may be perceived as less anxiety-inducing (Strauss et al., 2015). These preferences are essential to explore when determining

clients' treatment plans. As such, I asked participants in this study about their preferences for treatment formats and group structure.

In their recent study, Cooper and colleagues (2021) found that clients' activity preferences may indicate readiness for change. Their study included 470 psychotherapy clients who completed several formal outcome measures meant to capture broad-scale psychological distress throughout their treatment. Clients who showed preferences for therapists who would challenge them to grow rather than focusing only on warm support had better treatment outcomes, as indicated by greater improvement in scores on four of the six outcome measures (Cooper et al., 2021). They suggested that clients who communicate a significant preference for support over challenge (i.e., more client-directiveness and less active therapist involvement) may be less motivated or not yet contemplating change (Cooper et al., 2021).

Treatment preferences refer to the desire for intervention types (Swift et al., 2018). For example, some individuals may prefer alternative approaches, such as peer support groups, over therapeutic interventions (Swift et al., 2018). Treatment preferences may also include preferences for therapies based on certain theoretical orientations, such as cognitive-behavioural or psychodynamic approaches (Swift et al., 2018). This category could also hold client preferences for the different groups mentioned in Chapter 3 (e.g., psychoeducational, brief). Client treatment preferences are necessary to consider when determining the appropriate interventions. Therapists must not assume that particular treatment options are suitable for every client (McLeod, 2012). Thus, in this study, I asked participants about their preferences regarding intervention and group types.

Therapist preferences relate to the practitioner's characteristics, such as educational background or personality traits (Swift et al., 2018). From the beginning of therapy, clients

consider whether the therapist can understand their lived experiences (McLeod, 2012). Clients often prefer to connect with therapists with personality traits like their own (Anestis et al., 2021). Some clients may also favour a therapist with similar life experiences. For example, a study by Johnson and colleagues (2018) found that members of the military may prefer to work with therapists who are veterans. These shared experiences were significant for the participants and resulted in more favourable views of the therapists (Johnson et al., 2018).

For group therapy, these preferences may translate to decisions about the people that facilitate the group. In recent study, Muralidharan and colleagues (2021) explored the efficacy of a health and wellness group for medical illness self-management in individuals with serious mental health concerns. This group intervention was co-facilitated by a peer and a non-peer professional. The peer facilitator had lived experiences with the same concerns as the group members (Muralidharan et al., 2021). They found that this co-facilitation model allowed for diverse perspectives and a positive group environment (Muralidharan et al., 2021). The presence of both peer and non-peer facilitators was well-received by the group members (Muralidharan et al., 2021). Given the effectiveness of peer and professional support for chronic illness, this type of co-facilitation model appears promising. Muralidharan and colleagues (2021) emphasized that the titles of peer and non-peer facilitators are often not black-and-white, as some facilitators may fit into both categories. Therefore, I used this study to inquire about the therapist preferences of individuals with chronic health conditions.

Based on the recommendations of Swift and colleagues (2018), this study explored the *activity, treatment, and therapist preferences* of individuals with chronic health conditions. As the research exploring the group therapy preferences of this population is limited, this study aimed to fill a significant gap within the literature. Moreover, this study compared these

preferences to participants' illness perceptions to answer the question: *How does illness identity relate to preferences for group therapy in a transdiagnostic population?* This study was intended to give voice to individuals living with chronic illness and advocate for group therapy programs that effectively support this population.

Chapter Summary

This chapter has outlined the existing research on the importance of understanding client preferences and implementing them in counselling practice. The literature suggests that integrating client perspectives into therapeutic interventions is beneficial for treatment adherence, treatment outcomes, and the therapeutic alliance. Clients' *activity, treatment, and therapist preferences* are all important considerations for counsellors to explore. Therefore, this study explored these three types of group therapy preferences in a transdiagnostic population. This thesis brings light to the firsthand preferences and experiences of individuals with chronic illness. The upcoming chapter outlines the synthesis of my research question for this thesis.

CHAPTER 5: Synthesis of Research Question

Before describing the methods used for this study, I will provide an overview of the synthesis of my research question. This transition chapter will link together the information from the previous four chapters to inform my research question: *How does illness identity relate to preferences for group therapy in a transdiagnostic population?* To answer this question, I aimed to (a) invite the perspectives of individuals with chronic illness on group therapy, (b) characterize illness identity in a transdiagnostic sample, and (c) explore whether illness identity relates to preferences for group therapy. I will conclude this chapter by outlining the intended contribution of this study.

Invite the Perspectives of Individuals with Chronic Illness on Group Therapy

In Chapter 3, I described the current research on group therapy for chronic conditions, and in Chapter 4, I addressed the literature on the importance of understanding client perspectives. Based on the existing research, understanding client preferences is an important part of planning therapeutic interventions, as it has significant implications for treatment outcomes and the therapeutic relationship. However, research that includes the firsthand perspectives of individuals with chronic illness is scarce. This study aimed to fill this gap in knowledge and give voice to this population by inquiring into what people with chronic illness want from group therapy. Often, the preferences of therapists and the preferences of clients differ significantly (Cooper et al., 2019). Thus, practitioners must avoid making assumptions about clients' needs or projecting their desires onto clients (Cooper et al., 2019). I intended to explore the *activity, treatment, and therapist preferences* of individuals with chronic illness.

In exploring client preferences for therapy, a combination of qualitative and quantitative methods has been recommended for gaining a more holistic understanding (McLeod, 2012).

Following these recommendations, this study included quantitative items and opportunities for participants to provide qualitative comments. In Chapter 6, I will describe the survey questions that invited individuals with chronic conditions to indicate their preferences for group therapy. Through this study, I hoped to uncover what adults with chronic health conditions would want out of group therapy.

Characterize Illness Identity in a Transdiagnostic Sample

In Chapter 2, I provided an overview of the existing literature on chronic illness and illness identity. *Chronic illness* is the psychological experience of living with a chronic health condition. The experience of chronic illness is complex and multifaceted, with many factors contributing to wellbeing. *Illness identity* describes the extent to which a person incorporates their chronic illness into their sense of self (Oris et al., 2018). An individual's illness identity state (*rejection, engulfment, acceptance, or enrichment*) is related to wellbeing and coping abilities (Oris et al., 2018). Illness identity can be a useful construct for understanding how individuals relate to their chronic conditions. In the existing studies on illness identity, researchers have addressed diagnostically homogenous populations. In contrast, this study explored illness identity in a transdiagnostic population, including individuals with a variety of chronic health conditions.

This study included quantitative questions addressing chronic illness and illness identity, as well as opportunities for participants to provide qualitative comments. I will describe the survey questions that addressed chronic illness and illness identity in Chapter 6. With this study, I aimed to expand the existing knowledge of illness identity in adults with chronic conditions. Characterizing illness identity in this transdiagnostic population allowed for comparisons between illness identity and group therapy preferences.

Explore Whether Illness Identity Relates to Preferences for Group Therapy

In Chapter 2, I outlined the research on the benefits of peer and professional support for individuals with chronic health conditions. As mentioned in Chapter 3, group therapy provides a combination of peer and professional support, making it an ideal intervention option for this population. To adapt group therapy for specialized populations, it is important for group therapists to understand the unique needs of that population (Leszcz, 2020). It has been suggested that individuals may have different therapy preferences at different stages in their illness progression (Leszcz, 2020). However, based on the research on illness identity, it may be the individual's perception of their condition and not the time with their condition that determines their ability to cope (Oris et al., 2018; Van Bulck et al., 2021).

I believe that illness identity may be a helpful concept for mental health practitioners to conceptualize how their clients relate to their chronic conditions. To my knowledge, illness identity had yet to be explored in the context of psychotherapy prior to this study. However, as mentioned in Chapter 3, results from some previous studies pointed to a potential relationship between therapy preferences and factors such as the type of condition and how an individual relates to their condition (Sherman et al., 2007; Stuber et al., 1988). It was interesting to determine whether preferences for group therapy are related to individuals' illness identity states.

This study examined the relationship between illness identity and therapy preferences to determine whether individuals in different illness identity states express differential preferences for group therapy. I will outline the methodology used to examine this relationship in Chapter 6. I believe gaining insight into this relationship is helpful for adapting group therapy to best suit the needs of this population. I will now expand on the intended contributions of this study.

Contribution of Thesis Study

This study has potential implications for both research and professional practice. The results of this study expand the existing research on illness identity in adults with chronic illness, allowing researchers to increase their understanding of this construct in adults with a variety of health conditions. Further, the results of this study give voice to the unique perspectives of individuals with chronic illness on group therapy, which are difficult to find in the current body of knowledge. In addition to enhancing the existing research on illness identity and group therapy, this thesis can aid group therapists in understanding their clients' unique needs and how to adapt their groups to support this population. Illness identity may be a useful tool for understanding clients' perceptions of their chronic conditions. This thesis contributes a novel approach to conceptualizing chronic illness in the counselling context. Lastly, this research highlights a need for enhanced mental health support for this population. Through this thesis, I am advocating for collaborative care in the treatment of chronic conditions. Considering the present systemic barriers to collaborative care, I consider mental health professionals to be in a unique position for bridging the gaps in support for this population.

Evidence from theory, research, and clinical practice points to the need for professionals to focus on the psychological wellbeing of people with chronic conditions (Folkman & Greer, 2000). Psychological wellbeing despite chronic illness is possible, but for many individuals, it may be challenging to achieve without professional support. With this thesis, I have contributed to the empirical research that can, in turn, inform clinical practice. This thesis will provide the foundations of my counselling practice as I move forward into my professional career. The upcoming chapter will outline the methods used in this study and how I answered my research question.

CHAPTER 6: Methods

To answer the research question I outlined in the previous chapters, I created an online survey directed to adults living with chronic illness and this was used to understand how illness identity relates to preferences for group therapy. I intend to use the results of this study to inform group therapists of the needs of this population and how to adapt group interventions accordingly when working with those with chronic conditions. In this chapter, I will outline the methods used for executing this study. I will describe the (a) participants, (b) measures, (c) procedure, and (d) data analysis strategy for this study.

Participants

The inclusion criteria were two-fold. Participants attested that they: (a) were 18 years of age or older, and (b) identified as living with chronic physical illness. In line with the conceptualization of *illness* previously described, participants did not need a formal diagnosis to participate. As participation was entirely anonymous, the survey relied on participants' self-reports of having chronic conditions. Although there were limitations that accompanied being unable to confirm the validity of participants' reports of chronic illness, the experience of chronic illness is highly subjective. Because I was interested in learning about individuals' subjective experiences and self-concepts, I considered these self-reports valuable.

Beyond the noted requirements, there were no specific exclusion criteria for this study. Based on previous research, a larger sample size is preferable for quantitative surveys (Gall et al., 2007). I hoped to recruit around 100 participants for this study, but I did not place an upper limit on the number of participants. This ideal number was selected because researchers, such as Gall and colleagues (2007), have suggested that quantitative surveys should have a minimum of 100 participants in each major subgroup. Considering the number of individuals that could have

been reached through my recruitment strategies, I believed 100 participants was a reasonable objective.

Measures

This study included an anonymous online survey created by combining a previously validated measure with items I created. The survey was intended to take participants approximately 10 minutes to complete. The 16 questions of this survey consisted of 75 items organized into five main categories: (a) chronic illness (six items), (b) illness identity (25 items), (c) group therapy preferences (35 items), (d) demographic information (four items), and (e) open response (five items distributed throughout the other categories). I will describe each of these categories in further detail.

Chronic Illness Survey Items

Description. This category included five survey questions (Q1, Q2, Q3, Q4, and Q8) that addressed participants' chronic conditions (see Appendix E). These questions included six items and two optional open text responses. The first four items were grouped into one survey question (Q1). The first item requested that participants list the chronic condition(s) they experience by typing the condition(s) into text boxes. If the participant did not have a diagnosis or label for their condition(s), they could list their symptom(s) instead. Second, participants were asked to indicate whether the condition was *diagnosed* (by a healthcare professional) or *undiagnosed* (no diagnosis, seeking a diagnosis, or unknown cause). The third item asked participants to indicate the number of years they had lived with the condition from a drop-down box. The fourth item prompted participants to rate how well they believed they were coping with the condition on a drop-down scale from 1-5 (with 1 being very poor and 5 being very good).

The second chronic illness survey question (Q2) was a multiple-choice question in which participants were asked to self-rate their illness identity by choosing the image that best described them over the past month (see Appendix E). The question included four images, each containing pictures and words to represent the states of illness identity (rejection, acceptance, engulfment, and enrichment). I constructed these images using Canva for Education.

The third question that addressed chronic illness (Q3) asked participants to indicate the condition that they believe affects their life the most. They did so by selecting one of their conditions from a drop-down box that carried over their responses from the list of conditions they reported previously (in Q1). This question was followed by an optional open text response (Q4) inviting the participants to explain their choice. Participants were presented with these questions and the illness identity self-rating before completing the Illness Identity Questionnaire. Lastly, the survey included one optional open text response item (Q8) following the Illness Identity Questionnaire. This item invited respondents to include any other comments they may have had about their relationship with their illness. This optional qualitative component was intended to add some depth and context to the survey responses.

Scoring. The chronic illness survey items (Q1 and Q2) were treated as categorical variables. Because the first survey item (Q1) was open-text response, the possible responses for this item were unknown. Therefore, the conditions listed by participants were arranged into an ordinal scale after data collection was completed. To create an ordinal scale for the first survey item, I arranged the responses into the numbered categories outlined in the World Health Organization's (2019) *International Statistical Classification of Diseases and Related Health Problems* [(11th ed.; *ICD-11*) see Appendix G]. I also used ordinal scales to score the remaining categorical variables: diagnosed vs. undiagnosed (Q1), and illness identity self-rating (Q2). The

ordinal scale for illness identity self-rating was ranked based on Oris and colleagues' (2018) conceptualization of the most maladaptive state to the most adaptive state (i.e., rejection, engulfment, acceptance, enrichment). Responses to the third survey item (Q1) were rank scored according to the number of years with each condition. Lastly, the fourth item (Q1) was rank scored with a value from 1 to 5 according to the Likert scale response.

Rationale. Oris and colleagues (2018) found differences in predominant illness identity states between two diagnostic populations. Their study included 276 adults with congenital heart disease and 241 adults with connective tissue disorders. Measures of rejection and engulfment were higher, and acceptance was lower for patients with connective tissue disorders than those with congenital heart disease (Oris et al., 2018). Within their congenital heart disease group, patients with more complex conditions showed higher rates of engulfment and enrichment than those with less complex conditions (Oris et al., 2018). Thus, in this survey, participants' diagnoses were used to characterize the sample and examine between-group differences in illness identity across different conditions. This will be further elaborated on in my Results chapter.

As discussed in Chapter 3, it has been suggested that individuals require different types of group therapy at differing points in their illness trajectory (Leszcz, 2020). These responses helped determine whether time with chronic illness symptoms may relate to preferences for group therapy. This relationship was then compared to the relationship between illness identity and group preferences. These relationships will be further described in my Results chapter. Because this survey was completed by a transdiagnostic population, I believe it was important to gather information about the impact of certain conditions compared to others, as this may play a role in illness identity development. While a full evaluation of the differential impacts of certain

conditions on illness identity was beyond the scope of this study, these survey items opened opportunities for future research.

With this thesis, I intended to shed light on the firsthand perceptions of individuals with chronic health conditions. To my knowledge, most existing studies have measured illness identity through surveys, such as the Illness Identity Questionnaire, rather than self-rating illness identity states. I was keen to explore how the participants' self-rated illness identity states related to their scores on the Illness Identity Questionnaire, which will be described in my Results chapter. Utilizing this novel way of assessing illness identity states appears to have potential implications for group counselling. These implications will be examined further in my Discussion chapter.

Limitations. Because these were original survey items, they had not been used in previous research. Although I conducted informal pilot testing while constructing the survey (see below), due to the time limitations of my program, it was not realistic to run a formal pilot trial of these survey questions. Therefore, the reliability and validity of these questions are currently unknown. Moreover, because this survey relied on anonymous, online self-reported data, there was no way to verify the chronic conditions experienced by the study participants. I will explore these limitations further in my Discussion chapter and how this research will set the stage for future investigations.

Illness Identity Questionnaire (IIQ)

Description. The Illness Identity Questionnaire (IIQ), a 25-item survey developed by Oris and colleagues (2016), can be used for assessing an individual's state of illness identity. This questionnaire has been previously validated for use with adults with chronic illness (Oris et al., 2018). Oris and colleagues (2018) performed exploratory and confirmatory factor analyses to

validate the items of this questionnaire in their samples of adults with congenital heart disease (n=276) and connective tissue disorders (n=241). They used a four-factor solution (which explained 60.81% of the variance) to create four subscales measuring participants' feelings of rejection, engulfment, acceptance, and enrichment (Oris et al., 2018). The IIQ lists multiple statements that correspond with each illness identity state: five rejection items, five acceptance items, eight engulfment items, and seven enrichment items (Oris et al., 2018). This questionnaire has now been cited in the research numerous times (e.g., Luyckx et al., 2018; Meyer & Lamash, 2021; Oris et al., 2016; Rassart et al., 2021; Rassart et al., 2022; Raymaekers et al., 2020; Van Bulck et al., 2018, Van Bulck et al., 2021).

In this survey, the 25 items of the IIQ were presented sequentially in one question (Q7). Participants were asked to indicate the extent to which they agreed with each statement on a 5-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). Participants' responses on this part of the survey were used to assess their predominant illness identity state. Oris and colleagues (2018) stated that the IIQ subscales differentiate between the four distinct, yet interrelated illness identity states, as they found the factor correlations between the four subscales to be below .80. They also found the scores from the four subscales to be reliable for both diagnostic groups, as they reported Cronbach's alphas of .75/.75 for rejection, .92/.91 for engulfment, .83/.85 for acceptance, and .95/.90 for enrichment for congenital heart disease and connective tissue disorders, respectively (Oris et al., 2018).

Scoring. Mean or sum scores can be calculated based on the Likert scale responses for each of the four illness identity dimensions: rejection, acceptance, engulfment, and enrichment (Oris et al., 2018). After considering the methodology used in previous studies (e.g., Luyckx et al., 2018; Meyer & Lamash, 2021; Oris et al., 2016; Rassart et al., 2021; Raymaekers et al.,

2020; Van Bulck et al., 2018, Van Bulck et al., 2021), I created sum scores for each of the four subscales of the IIQ. Of the items in Q7 of this survey, the *rejection subscale* included items 1 to 5 (possible scores ranging from 1 to 25), the *acceptance subscale* included items 6 to 10 (possible scores ranging from 1 to 25), the *engulfment subscale* included items 11 to 18 (possible scores ranging from 1 to 40), and the enrichment subscale included items 19 to 25 (possible scores ranging from 1 to 35). For this study, the Likert scale of the original IIQ was reversed to match the scales on the other survey items. As a result, a lower score indicates higher agreement with the items of each subscale.

Rationale. I chose to integrate the IIQ into my survey, as creating a new measure of illness identity would not have been possible during the duration of my program. For this thesis, I would not have adequate time to engage in a formal pilot study to test the validity and reliability of an original measure. Therefore, I chose to integrate the IIQ into my survey because of its previous success in identifying individuals' states of illness identity. I believe that the illness identity states help conceptualize individuals' relationships with their chronic conditions. Because the experience of chronic illness is subjective and multifaceted, it is often difficult to understand from the outside looking in. Capturing illness identity states may help increase others' understanding of life with chronic illness. Further, if illness identity is related to preferences for group therapy, discovering a person's state of illness identity may provide an opportunity to determine their needs and desires regarding mental health support.

Limitations. I have identified some limitations for using the IIQ in this study. First, to my knowledge, this questionnaire had only been used in studies that focused on diagnostically homogenous populations. Because this was the first study to use this questionnaire in a transdiagnostic population in which many individuals had multiple conditions, I decided that

clarification for the IIQ items may be necessary. For this study, I chose to adopt a definition of *chronic illness* that focused on the psychological experience of living with one or more chronic health conditions. However, in a general population, the terms *chronic illness* and *chronic disease* are often considered synonymous. Therefore, I added a description before the participants were introduced to the IIQ that requested that individuals with multiple conditions keep in mind the condition that affects them the most (as indicated in Q3) when answering the IIQ items (see survey in Appendix E). Further, I adapted the items of the IIQ to read “chronic condition” rather than “illness” to better fit the framework of this thesis and the rest of the survey. To maintain the integrity of the survey items, no further changes were made.

As a result of a two-year three-wave observational cohort study of 276 adults with congenital heart disease, Van Bulck and colleagues (2021) found IIQ scores to be relatively stable over time. However, there may be variations in an individual’s experience of chronic illness from one day to the next. As described in Chapter 2, according to Paterson’s (2001) Shifting Perspectives Model of chronic illness, illness perceptions may shift from illness to wellness depending on many factors. Paterson (2001) suggested that some people may experience these shifts in perceptions multiple times per day. Therefore, I believe one limitation to using the IIQ in this survey was that it captured the individual’s illness perceptions at the moment. The contextual factors the individual was experiencing while they completed the questionnaire may have influenced their responses, potentially limiting the generalizability of their illness identity to their overall disposition. Therefore, I believe it is important to keep in mind that the results of the IIQ indicate the individual’s illness identity at a particular moment in time, and many contextual factors could have impacted the results. This limitation will be further explored in the Discussion chapter.

Lastly, there are limitations related to the diversity of conditions I received within my sample. Oris and colleagues (2018) validated the IIQ for use with adults with chronic illness. However, previous studies with this questionnaire are limited to particular diagnoses. For this study, the participants had a broad range of health conditions. Although some of my participants had the conditions that the IIQ has been used with previously (e.g., diabetes, congenital heart disease, epilepsy, celiac disease, inflammatory bowel disease), some experienced other conditions that have not yet been studied with this questionnaire. While it is exciting to explore new areas of this research, I believe this is important to consider when considering the results of this study. I will explore the implications in more detail in my Discussion chapter. Finally, I recognize that researchers will need to validate the IIQ for certain conditions that have not yet been studied.

Group Therapy Preferences Survey Items

Description. The survey for this study included four questions (Q5, Q6, Q9, and Q10) that addressed participants' preferences for group therapy (see Appendix E). These questions consisted of 35 items and one open text response. The items utilized a variety of question styles, including multiple-choice and Likert scale responses. These questions were inspired by the questionnaire used by Sherman and colleagues (2007) to explore the group psychotherapy preferences of individuals with cancer. The questions requested that participants report their preferences for group therapy, topics addressed in groups, characteristics of group facilitators, and aspects of group mechanics. Thus, these questions aimed to address participants' *activity preferences, therapist preferences, and treatment preferences* (Swift et al., 2018). These items were intended to capture participants' desires for group therapy to explore the relationship between these preferences and illness identity. The optional open text response invited

participants to add any additional comments about their preferences for group therapy. As with the open response for chronic illness, this open-response item was intended to assist with understanding the survey answers in greater detail.

Scoring. Participants' responses to these survey items provided categorical scores, as they had no quantitative meaning (Gall et al., 2007). Therefore, each category of the Likert scale was assigned an arbitrary score to create ordinal scales (Gall et al., 2007). The analysis of these responses will be described further in my Results chapter.

Rationale. Rather than using the exact items from previous studies, I chose to modify the survey questions to align with my thesis work. There were certain limitations to using original survey items, as they have not been previously validated. However, as I reviewed the literature on group therapy for chronic illness, I came across many clinical recommendations for adapting groups to this population. While many of these recommendations may have come from practitioners' experience working with this population directly, the voices of people with chronic conditions appeared to be missing. Therefore, I chose to use items to inform how well these recommendations fit certain illness identity states. To my knowledge, there were no existing questionnaires that addressed the relationship between illness identity and group preferences. Therefore, modifications were necessary. I chose Sherman and colleagues' (2007) questionnaire to inform my own because, of the studies I came across in the literature, their questions seemed to align the closest with my intention to measure preferences for group therapy.

Limitations. Because I wanted to keep the questionnaire relatively short to respect the time and energy of the participants, the questions in this survey addressed only some aspects of group therapy that may be relevant for adults with chronic health conditions. Thus, further research will be needed to explore clients' perspectives on the aspects of group therapy not

addressed in this study. Further, although these survey items were informed by a questionnaire used by other researchers, I significantly adapted the questions. Due to time limitations, it was not possible to run a formal pilot study using the survey questions in their current form. This may have placed some limitations on the survey's efficacy. I will further address these limitations in my Discussion chapter.

Demographic Information

Description. The last six survey questions (Q11, Q12, Q13, Q14, Q15, and Q16) collected demographic information to characterize the sample and offer opportunity for further qualitative responses (see Appendix E). Three of these items used multiple choice responses to gather participants' age (Q11), gender identity (Q12), and country (Q14). The demographic questions also included open text responses that prompted participants to identify any other identities that were important to them (Q13) and provide any additional comments or points of clarification (Q16). Lastly, one item (Q15) requested that participants report how they found the survey, which indicated the success of each of the four recruitment strategies described below.

Scoring. The survey item that collected participants' age (Q11) was rank scored based on the numeric value of the responses. Because the remaining items represented categorical variables with no quantitative meaning, they were assigned arbitrary numbers and then measured by nominal scales (Gall et al., 2007).

Rationale. As identity development depends on many self-aspects, I needed to collect other participant characteristics to gain a more holistic understanding. While it was not realistic to analyze every aspect of the participants' identities in this survey, these questions were intended to characterize the sample and give direction to future research. In their study of 276 adults with congenital heart disease and 241 adults with connective tissue disorders, Oris and

colleagues (2018) found no gender differences in illness identity. However, they did find age differences that varied between different conditions (Oris et al., 2018). As described in previous chapters, gender, age, and other cultural factors may impact identity development, chronic illness self-management, and healthcare access. Further, many countries differ in the structure of their healthcare systems, which may influence individuals' relationships with their conditions. Therefore, I believe it was necessary to understand these descriptors of the sample. Further, because fatigue may be an issue for individuals with chronic conditions, I inserted these questions near the end of the survey as I believed they would require less energy to complete.

Limitations. The number of demographic questions I have included in this survey was limited due to the length of the survey. Therefore, there may be other demographic factors that would have been relevant for this population that were not be addressed in this study. For example, the open text response asking participants to identify the other identities that are important to them (Q13) only began to scratch the surface of the complexities of identity in this population. Thus, I believe more research is still needed to expand on what is revealed in this survey. These limitations will be further explored in my Discussion chapter.

Procedure

Following approval of my proposal by my thesis committee (December 13, 2021), I submitted my Application for Ethical Review of Human Participant Research to the University of Lethbridge Human Subject Research Committee (HSRC). Due to unique circumstances at the time of submission, my application was processed by the University of Alberta Health Research Ethics Board (HREB). The certificate of approval for my ethics application can be found in Appendix F. In conducting this study, I ensured to adhere to the Canadian Psychological Association's (2017) *Canadian Code of Ethics for Psychologists*. I have ensured an ethical

approach toward my research participants and their private information has been continuously maintained. In addition, my research abided by the *Tri-Council Policy Statement* endorsed by the University of Lethbridge Human Subject Research Committee (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council, 2018).

Upon receiving ethics approval (January 7, 2022), I launched the survey that I produced using Qualtrics survey creation software (www.qualtrics.com). The survey was open for data collection over approximately seven weeks (from January 8, 2022, until February 25, 2022). Invitations for the anonymous survey were distributed in several ways. This section explains (a) my informal pilot test, (b) recruitment methods, (c) ethical considerations, (d) informed consent procedures, and (e) the structure of the online survey for this study.

Informal Miniature Pilot Testing

To ensure that the survey was understandable, appeared efficient, and took a reasonable amount of time to complete, I invited five Master of Education (Counselling Psychology) students to participate in informal pilot testing of the survey at various stages of its development. This group included individuals with and without chronic conditions; however, each student was instructed to provide artificial responses incorporating two chronic conditions. This was to protect the privacy of those piloting the survey. Each of the students completed a test version of the survey on Qualtrics. We engaged in a group discussion about each survey question to confirm that their understanding matched the intent of the questions. The only information collected was their verbal comments about the survey and the time it took them to complete it. I incorporated their feedback into my survey revisions.

Recruitment Strategies

Following ethics approval from the University of Lethbridge HSRC (via the University of Alberta HREB), I began circulating my survey. I activated the survey as soon as possible after receiving ethics approval and kept it open for approximately seven weeks. To recruit participants for this study, the survey was distributed in four ways: (a) chronic illness support groups on Facebook, (b) survey distribution groups, (c) my personal social media pages, and (d) snowball sampling. I will describe each of these recruitment methods in more detail.

Chronic Illness Support Groups. I requested and received permission to post the invitation to my survey in the following Facebook groups: *Chronic Illness Support*, *Coping with Chronic Illness and Chronic Pain*, and *Science-Based Chronic Illness Support*. These permissions are noted in Appendix B. I posted the invitation message one time to each of the groups' main pages or in the places they have designated for survey distribution (see Appendix C). Because the Facebook groups are 'closed' groups, only group members saw the posts. I chose to recruit participants through these groups because of the value of support groups illustrated by the literature. Further, these groups all included individuals with many different diagnoses, so my invitation could attract a diverse population. Moreover, because participation in these groups requires that individuals be able to navigate the technological interface of Facebook, completion of this survey may have been less challenging for this population. Thus, I believed this sample would include a wide array of people that would find this survey accessible.

Survey Distribution Groups. In exploring online platforms to distribute my survey, I came across a website called SurveyCircle (www.surveycircle.com/en/). This website and its affiliated pages on several social media platforms are designed for the purpose of distributing and participating in research surveys. I joined some of their social media groups to distribute my

survey through these platforms. I joined two Facebook groups (*Survey Exchange / Survey Group / Survey Participants – Dissertation, Thesis*; and *Research Participation – Dissertation, Thesis, PhD, Survey Sharing*) and one LinkedIn group [*Survey Exchange – Find participants for research studies (for dissertation, thesis, market research)*]. To join these groups, I requested membership and answered a couple of short questions about my motivations for joining the group. I disclosed that I would be sharing a survey for my master's thesis, and my group membership was approved. As these groups are designed for distributing surveys, special permission to use these groups to recruit participants was not necessary (see Appendix B). I shared the invitation to my survey one time in each group at the beginning of my data collection period. By sharing my survey in these groups, I hoped to attract a more diverse population.

Personal Social Media Pages. I also posted, with permission from the University of Lethbridge HSRC (via the University of Alberta HREB), the invitation to participate in my survey on my personal social media pages (i.e., Facebook, Instagram, and LinkedIn). I posted the survey link and invitation on my pages by creating posts on Facebook, Instagram, and LinkedIn. I attached the link to my bio and stories on Instagram and communicated about my survey through word of mouth (see Appendix C). Therefore, I extended my recruitment invitation to my followers and friends. I ensured that all participants knew that the survey was entirely voluntary and that they had the right to withdraw without penalty at any time. Because the survey was completely anonymous, I had no way of knowing which of my friends or followers participated in my study unless they volunteered that information unprompted. I shared my survey to each of my personal social media pages once at the beginning of the data collection period, and then again periodically until data collection was complete. In total, over the seven weeks, I shared the invitation to my LinkedIn page once, Facebook page twice, Instagram feed once, and Instagram

story three times. In between these postings, I utilized my personal networks to share my survey through word of mouth.

Snowball Sampling. My fourth and final recruitment strategy, as outlined in my ethics application, involved providing exiting survey participants with the opportunity to recruit additional participants. Before they left the survey, participants were provided with the survey link and invited to share the link with friends and family (see Appendix E). By utilizing this recruitment strategy, I hoped to increase the reach of my survey and attract a diverse sample. The survey question requesting that participants report how they heard about the survey (Q15) provided information regarding which recruitment strategy was the most successful (see Appendix E). The results of this analysis will be described in my Results chapter.

Online Survey

Participants received an invitation to participate in the survey through one of my posts (see Appendix C) or were invited to the survey by another participant. After reading the invitation to participate, individuals who were interested in taking the survey could click the link included in the invitation. I will now describe the survey process.

Informed Consent. After participants clicked the invitation link, additional details about the study and their rights as a participant were provided (see Appendix D). The informed consent document for this study was presented in relational language to be as participant-friendly as possible. Individuals were given the option to download a copy of the informed consent document. The informed consent document outlined the purpose of the study, the risks and benefits of participating, how confidentiality and privacy would be protected, how the survey data would be used and stored, who was eligible to participate, and how to withdraw from the

study. The informed consent document also included a link to access global mental health resources.

Participants were informed that the end of the survey included an option to enter a raffle type draw to win an incentive prize. The raffle details included in the consent form were decided after consultation with one of the Ethics Officers from the Office of Research Ethics at the University of Lethbridge (S. Entz, personal communication, September 29, 2021). In conducting this raffle, I was required to abide by Canadian lottery laws, which mandate the disclosure of the number and value of prizes and the odds of winning (S. Entz, personal communication, September 29, 2021). Because it was not possible to determine the exact number of people that would participate, I chose a high estimate of 200 participants. Therefore, the consent form indicated that the odds of winning a gift card were approximately 1 in 100. If the raffle draw received more than 200 participants, more winners would be chosen and more gift cards would be added to align with the odds disclosed to participants (S. Entz, personal communication, 2021). Further details about the draw are discussed below. To continue to the survey questions, participants had to attest that they understood the informed consent details, were 18 years of age or older, and had a chronic health condition.

Survey Format. The anonymous survey included 75 items and was intended to take approximately 10 minutes to complete (see Appendix E). The survey was intentionally designed to be brief to minimize the fatigue it may cause, as many participants may already feel fatigued before beginning the survey. Analyses of the exact time participants took to complete the survey, and the potential implications of those findings, will be described in the Results chapter. While the items were primarily quantitative, there were opportunities for participants to input text

comments if they desired. These text entries were intended to add some context to participants' responses during data analysis.

The survey began by asking participants to describe the chronic conditions they experienced and their self-reported illness identity. These questions were intentionally included first to give participants an opportunity to share their experiences with chronic illness before proceeding to questions about their therapy preferences. Then, after answering two questions about group therapy preferences, the participants were presented with the IIQ. The remaining questions on group therapy preferences followed the IIQ. Lastly, the survey requested demographic information. Participants were prompted to answer all questions; however, they could skip questions if they desired. The participants were notified in the informed consent process that none of the questions were mandatory. The option to skip questions was chosen after seeking consultation regarding strategies to mitigate any psychological distress that may come from answering questions about potentially sensitive topics such as chronic illness (S. Entz, personal communication, September 29, 2021).

Optional Raffle Entry. The final question of the survey gave participants the option to enter a raffle type draw to win one of two fifty-dollar gift cards to The Unchargeables Shop (www.theunchargeablesshop.com). The Unchargeables Shop is an independently owned company that raises awareness for chronic illness through apparel, homeware, and other items. They also have online communities for chronic illness support on Facebook and Discord. All participants who reached the final question of the survey were invited to enter the draw, regardless of the number of questions completed. If participants were not interested in entering the draw, they were directed to the final survey page after submitting their results. If survey participants were interested in entering the draw to win the raffle prize, they were prompted to

submit their email addresses. The email addresses submitted were not associated with participants' survey responses to protect their anonymity. I will describe the handling of participant email addresses in further detail below. After entering their email addresses for the draw, participants were directed to the final survey page.

Final Survey Page. The final page of the survey thanked participants for their responses and invited them to share the survey link with friends and family. This page provided links to resources for global mental health supports and finding local therapy groups. Participants were also be reminded of how they could ask questions about the survey or receive a copy of the survey results (see Appendix E). The online survey remained active and accessible to collect data until the study was terminated. However, because no identifying information was attached to participants' submissions, it was not possible to remove participant data following the submission of the survey, as outlined in the informed consent document (see Appendix D).

Controlling and Collecting Internet Data. Participants were notified in the informed consent document of how their responses would be handled and protected (see Appendix D). As with any online survey, confidentiality and anonymity could not be completely guaranteed due to the risk of unauthorized third-party access. However, research participants had no direct contact with any of the researchers, supervisors, committee members, or consultants involved in the study. Further, no identifying information associated with survey responses was collected, including IP addresses. Information gathered using the survey may be used in an aggregate format in report summaries and future publications. However, no individual will be identified in any reports or publications. Therefore, the risk of participating in the survey was minimal.

Draw Data. Participants were given the option to provide their email addresses for the draw at the end of the survey, regardless of the number of questions they completed. The

opportunity to provide an email address was designed as a separate survey within Qualtrics to protect anonymity (see Appendix E). As such, data were separated into two distinct groups: (a) survey response data, and (b) draw data. After I have successfully defended my thesis (around September 2022), the draw data will be sent to a University of Lethbridge staff member, who will assign each email address a number. Then, a random number generator will be used to select the winning numbers. The University of Lethbridge staff member will contact the winners to arrange delivery of the draw prizes. Because the draw prizes are electronic gift cards, the only information needed from the participants was their email addresses.

Storing Survey Data. Participants were also informed of how the survey data would be stored (see Appendix D). Once the survey period elapsed, the data collected through Qualtrics was downloaded to the encrypted external hard drive where the data are stored. Only the researcher, thesis supervisor, committee members, and statistical consultant involved with this study have access to the raw data and the encrypted external hard drive. The raw data contain no identifying information about the participants. The data will be destroyed from Qualtrics one month after I have successfully defended my thesis. When not in use, the encrypted external hard drive will be kept in a locked filing cabinet within a private office. The encrypted hard drive will be kept for a period of at least 7 years, after which it will be cleared of any study data. During the 7-year period the data may be used in future comparison studies. The results of the study will be shared with the researchers who have granted their permission to adapt their survey questions for this study (see Appendix B).

Data Analysis Strategy

After the period for the survey elapsed, the collected data were analyzed to attempt to answer my research question. Following the termination of the study, I exported the data from

Qualtrics to SPSS Statistics Software for analysis. Due to the predominantly quantitative and nonparametric nature of the current study, data analysis primarily involved descriptive statistics and correlational analyses. In my plan for data analysis, I reserved the right to conduct post hoc analyses of the data as needed. Thus, while the data analysis strategies used for this thesis were kept as simple as possible, I plan to conduct further analyses for publication purposes.

Data Preparation

After importing the data into SPSS, I removed incomplete surveys from the response pool. Responses were classified as incomplete if they did not reach 95% completion for the entire survey. Further, I removed all responses that did not meet the inclusion criteria (i.e., the participants who indicated that they did not have a chronic condition and participants who did not list at least one chronic condition in their response to Q1). Of the 387 recorded responses, 160 (41.3%) incomplete responses and 14 responses (3.6%) that did not meet the inclusion criteria were removed from the response pool. Following this stage, 213 responses were retained for data analysis.

All participants completed all the chronic illness and illness identity survey items described in the Measures section of this chapter. Some of the participants chose not to respond to a couple of the survey items addressing activity preferences and demographic information (see Results chapter). Because the missing data points were minimal, these survey items were analyzed using the same procedures as the other items. Items with more than 30% of responses incomplete were excluded from analysis. All survey items were scored according to the scoring procedures described above (see Measures section).

Normality Diagnostics

Using SPSS, I ran diagnostic tests for normality (i.e., summary statistics, skewness, kurtosis, Kolmogorov-Smirnov tests, and Shapiro-Wilk tests) to analyze the distribution of the data and guide my approach for data analysis (Grech & Calleja, 2018). When the data were not found to be normally distributed, and hence did not meet the requirements for parametric tests to be run, nonparametric analyses were utilized (Grech & Calleja, 2018). This approach was applied when reviewing each part of my research question.

Somers' D

Because the data for this study included ordinal variables, I chose to use *Somers' Delta* (*Somers' D*), a nonparametric measure that assesses the strength and direction of dependent and independent variables, to explore these relationships (Statistics Laerd, n.d.). The range for *Somers' D* is -1 (all pairs agree) to 1 (all pairs disagree), with larger values (tending toward -1 or 1) suggesting good predictive ability and smaller values (tending toward zero) suggesting poor predictive ability (Statistics Laerd, n.d.). To use *Somers' D* computations, two assumptions must be met: (a) the data are ordinal dependent and independent variables and (b) there is a monotonic relationship between the variables (Statistics Laerd, n.d.). Based on consultation with my thesis committee, the data were considered to meet these assumptions.

With this thesis, I aimed to answer the question: *How does illness identity relate to preferences for group therapy in a transdiagnostic population?* To answer this question, an online survey was used to: (a) invite the perspectives of individuals with chronic illness on group therapy, (b) characterize illness identity in a transdiagnostic population, and (c) explore whether illness identity relates to preferences for group therapy. After describing how I addressed each of

these three sub-parts to my research question, I will touch on how I analyzed: (d) the demographic data and (e) the open text responses.

Invite the Perspectives of Individuals with Chronic Illness on Group Therapy

Group Therapy Preferences. To describe the group therapy preferences of this population, I analyzed the data according to participants' *treatment preferences* (Q5), *therapist preferences* (Q9), and *activity preferences* (Q6 and Q9). This involved using descriptive statistics to analyze the number of records, frequency counts, and percentages for the survey responses. These results were used in further data analyses, as described below. The results of these initial analyses were used to describe the general group therapy preferences of this sample and inform treatment recommendations, as described in my Results and Discussion chapters.

Characterize Illness Identity in a Transdiagnostic Population

To characterize illness identity in this transdiagnostic population, I: (a) described the chronic conditions experienced by this sample, (b) described the illness identity states of the participants, and (c) analyzed the relationship between illness identity and participants' chronic conditions.

Chronic Conditions. I illustrated the chronic conditions experienced by this sample (Q1) by using descriptive statistics. I examined the number of conditions reported by each participant as a scale variable for use in further analyses. Based on the number of respondents I received, I chose to group the conditions into clinical categories to increase the ease of further examination of the data. This involved using the World Health Organization's (2019) *International Statistical Classification of Diseases and Related Health Problems* (11th ed.; *ICD-11*) to categorize the chronic conditions reported (see Appendix G).

Illness Identity. I analyzed the participants' self-rated illness identity (Q2) and IIQ scores (Q7) to describe the illness identity states within this transdiagnostic population. For my initial analyses, I treated the IIQ scores as scale variables. Thus, I reported the ranges, medians, and standard deviations of the IIQ subscale scores. In addition, I reported the number of responses and the missing cases from the data. I utilized a crosstabulation table to describe the relationship between IIQ score and self-rated illness identity (Q2). Self-rated illness identity was prioritized over IIQ scores for most of the analyses, as this is the measure of illness identity that is more likely to be used in a practice setting, as I will describe in my Discussion chapter.

Illness Identity and Chronic Conditions. I then investigated the connection between self-rated illness identity and the types (*ICD-11* categories) and numbers of chronic health conditions reported by participants using *Somers' D* computations, as described above (Statistics Laerd, n.d.).

Explore Whether Illness Identity Relates to Preferences for Group Therapy

To explore the relationship between illness identity and group therapy preferences, I investigated how the participants' *treatment preferences*, *therapist preferences*, and *activity preferences* related to their: (a) chronic conditions and (b) illness identity states.

Chronic Conditions and Group Therapy Preferences. I explored the association between participants' *treatment*, *therapist*, and *activity preferences* and the types of chronic conditions they experience (based on their *ICD-11* categories). Further, I also compared these preferences with the number of years they have lived with chronic illness. To analyze the relationships between these variables, I used *Somers' D* computations (Statistics Laerd, n.d.).

Illness Identity and Group Therapy Preferences. To uncover the relationships between illness identity and group therapy preferences, I compared participants' self-rated illness identity

with their *treatment, therapist, and activity preferences*. I used *Somers' D* computations to investigate these relationships (Statistics Laerd, n.d.).

Demographic Data

Descriptive statistics were used to analyze participants' demographic information (Q11, Q12, Q14, Q15) to determine the personal characteristics of the participants. Frequencies and percentages were calculated to characterize the population surveyed in the study.

Qualitative Responses

As mentioned, the participants were provided with the option of providing additional comments or details about their quantitative responses (Q4, Q8, Q10, Q13, Q16). Due to time limitations and unforeseen circumstances during my program, the participants' open text responses were not analyzed in this study. However, these responses may be analyzed in the future to target a deeper understanding of the relationship between illness identity and preferences for group therapy.

Permissions

I requested and received permission to use and adapt the Illness Identity Questionnaire (IIQ) created by Oris and colleagues (2016) as part of my survey (see Appendix B). Further, I requested and received permission to adapt the questionnaire used by Sherman and colleagues (2007) to address participant's preferences for group therapy (see Appendix B). I would like to acknowledge the kindness of these researchers in their allowing me to extend their work. I am very grateful for their indirect yet meaningful contributions to this thesis. To express my gratitude, I have offered to share with them the results of this thesis study.

Chapter Summary

In this chapter, I provided an outline of the methodology I used for this study. I described the participants and how they were recruited, details about the online survey, and a rationale for the measures chosen. I stated how ethical conduct was maintained throughout the study, including how participants' anonymity and confidentiality was protected. Lastly, I described my approaches to analyzing the data following its collection, and how this survey answered my research question. In the following chapter, I will provide an outline of the results of the analyses described above.

CHAPTER 7: Results

In this chapter, I will present the results of my data analysis by: (a) outlining the demographic information by using descriptive statistics to characterize the sample; and (b) answering my research question by using a combination of descriptive statistics and correlational analyses. The results described in this chapter, along with the potential limitations to the generalizability of my findings, will be elaborated on in my Discussion chapter. I have included tables to enhance the interpretation of the results.

Demographic Information

The demographic information provided by the participants included their age, gender identity, and location. This section of the survey also included the recruitment strategies that brought them to the survey. These responses were analyzed using descriptive statistics to characterize the survey sample and determine the success of each recruitment strategy. In the following section, I will share the results of these analyses. Further exploration of the potential limitations of the frequency distributions of the data will be presented in my Discussion chapter.

Age and Gender Identity. Of the 213 eligible participants, nine chose not to provide their age. The ages of the 204 participants who answered this question ranged from 18 to 72 years old. The mean of the age distribution was 31.61 years, the median was 29.00, and the standard deviation was 10.44. When asked to report their gender identity, all 213 participants responded. Of the participants, 84.0% ($n = 179$) were female, 5.2% ($n = 11$) were nonbinary, 4.7% ($n = 10$) were male, 1.9% ($n = 4$) were transgender, 1.9% ($n = 4$) preferred not to disclose, 1.4% ($n = 3$) indicated that they were unsure, and 0.9% ($n = 2$) reported a gender that was not listed (one participant was trans masculine, and the other was femme/woman). Table 1 presents the frequency distribution of the participants' age and gender identities.

Table 1*Age and Gender Identity of Participants*

Variable	Mean	Median	SD	Range
Age	31.61	29.00	10.44	18-72
	<i>n</i>	%		
Gender Identity				
Male	10	4.7		
Female	179	84.0		
Non-binary	11	5.2		
Transgender	4	1.9		
Other	2	0.9		
Unsure	3	1.4		
Prefer Not to Disclose	4	1.9		

Note. $N = 213$. Nine participants chose not to disclose their age.

Location. The majority of the eligible participants indicated that they lived in Canada ($n = 95$; 44.6%) or the United States ($n = 94$; 44.1%). Of the participants from Canada, 71 (33.3% of the total sample) were from Alberta, eight (3.8% of the total sample) were from British Columbia, eight (3.8% of the total sample) were from Ontario, four (1.9% of the total sample) were from Manitoba, two (0.9% of the total sample) were from Saskatchewan, one (0.5% of the total sample) was from New Brunswick, and one (0.5% of the total sample) was from Quebec. Other countries reported included the United Kingdom ($n = 9$; 4.2%), Germany ($n = 3$; 1.4%), Ireland ($n = 3$; 1.4%), New Zealand ($n = 3$; 1.4%), Andorra ($n = 1$; 0.5%), Australia ($n = 1$; 0.5%), Cabo Verde ($n = 1$; 0.5%), Indonesia ($n = 1$; 0.5%), South Africa ($n = 1$; 0.5%), and Sweden ($n = 1$; 0.5%). The frequency distribution of for the participants' locations is presented in Table 2.

Table 2*Location of Participants*

Country	<i>n</i>	%
Andorra	1	0.5
Australia	1	0.5
Cabo Verde	1	0.5
Canada	95	44.6
Alberta	71	33.3
British Columbia	8	3.8
Manitoba	4	1.9
New Brunswick	1	0.5
Ontario	8	3.8
Quebec	1	0.5
Saskatchewan	2	0.9
Germany	3	1.4
Indonesia	1	0.5
Ireland	3	1.4
New Zealand	3	1.4
South Africa	1	0.5
Sweden	1	0.5
United Kingdom	9	4.2
United States of America	94	44.1

Note. *N* = 213.

Recruitment Strategies. When asked to report how they had heard about this survey, 95 participants (44.6%) reported that they found the invitation in a chronic illness support group on Facebook; 85 participants (39.9%) reported finding the survey through a social media page, such as my personal social media pages; 37 participants (17.4%) reported that they had heard about the survey through word of mouth; 11 participants (5.2%) found the invitation in a survey

sharing group; and 15 participants (7.0%) reported hearing about the survey through an option that was not listed. Some of the ‘other’ ways participants reported hearing about the survey included Tumblr; Reddit; the University of Saskatchewan Student Wellness Centre; private Facebook pages; and other social media support groups, such as groups coordinated by *Plenty and Well with Nat* on Instagram and Facebook. Except for the one individual who listed my name as the ‘other’ way they heard about the survey, these methods of distribution appear to reflect snowball sampling, as I did not share the survey on these pages myself. Table 3 outlines the distribution of the data regarding the recruitment strategies used for this study.

Table 3

Recruitment Strategies Reported by Participants

Recruitment Strategy	<i>n</i>	%
Facebook via Chronic Illness Support Group	95	44.6
A person told me about this survey and/or sent me the link	37	17.4
Social media page, including researcher’s social media page(s)	85	39.9
Survey-sharing group/website	11	5.2
Other	15	7.0

Note. *N* = 213.

Time to Complete Survey. I used descriptive statistics to determine whether the time I estimated for survey completion (~ 10 minutes) was accurate. The frequency counts for survey completion times are reported in Table 4. To complete the survey, 20.7% (*n* = 44) took under 10 minutes, 38.0% (*n* = 81) took 10 to 15 minutes, 17.8% (*n* = 38) took 15 to 20 minutes, 9.9% (*n* = 21) took 20 to 25 minutes, 2.3% (*n* = 5) took 25 to 30 minutes, and 11.3% (*n* = 24) took more than 30 minutes.

Table 4*Duration of Time Used to Complete Survey*

Amount of Time	<i>n</i>	%
Under 10 minutes	44	20.7
10 – 15 minutes	81	38.0
15 – 20 minutes	38	17.8
20 – 25 minutes	21	9.9
25 – 30 minutes	5	2.3
More than 30 minutes	24	11.3

Note. *N* = 213.

Research Question

In this study, I utilized a combination of descriptive statistics and correlational analyses to answer the question: *How does illness identity relate to preferences for group therapy in a transdiagnostic population?* I will outline the steps I took to answer this question and then share the results: (a) invite the perspectives of individuals with chronic illness on group therapy, (b) characterize illness identity in a transdiagnostic sample, and (c) explore whether illness identity relates to preferences for group therapy.

Invite the Perspectives of Individuals with Chronic Illness on Group Therapy

This survey gathered the participants' *treatment preferences, therapist preferences, and activity preferences* with the hope that this research will inform practitioners what adults with chronic illness would want from group therapy. Thus, the first step of answering this thesis question involved analyzing each of these three types of client preferences.

Treatment Preferences. The treatment preferences reported by the participants in Q5 and two of the items in Q9 are presented in Table 5. Less than 1% of respondents (*n* = 2) indicated that they would not seek support to enhance their mental or emotional wellbeing. Of

the treatment options to improve mental or emotional wellbeing (as listed in Q5), in-person individual therapy was the most frequently chosen (selected by 68.5% of participants). Around 57% of participants indicated that a physician would be a helpful support. Online individual therapy was deemed helpful by around 53% of participants. Both peer support groups and alternative holistic approaches were chosen by approximately 55% of respondents.

Almost 50% of the participants reported that they believed medication would be helpful to enhance their emotional or mental wellbeing. In-person group therapy was chosen by around 43% of participants, while around 40% of participants selected creative expressive arts therapy. Approximately 35% of respondents selected online group therapy as a helpful treatment option. Lastly, just under 20% of the survey participants added open text comments to indicate other supports they believed would be helpful for improving emotional or mental wellbeing. Table 6 includes examples of some of these open text responses (spelling errors have been corrected).

In addition to the items from Q5, two items from Q9 touched on participants' treatment preferences. More specifically, these items inquired about participants' preferences for the location of a group if they were to attend group therapy. The vast majority of participants shared that they would prefer to meet in a community setting (67.1%, with 30% strongly preferring this option). Further, most participants indicated that they would not want to meet in a healthcare facility (53.9%, with 30% expressing a strong preference against it). In fact, only around 20% of participants expressed a preference for this setting (18.8%, with 7.5% strongly preferring this option).

Table 5*Treatment Preferences of Participants*

Treatment Preferences											
Q5. Please select the supports you believe would be helpful for improving your mental/emotional wellbeing.											
		<i>n</i>				%					
Individual therapy in person		146				68.5					
Individual therapy online		112				52.6					
Group therapy in person		91				42.7					
Group therapy online		74				34.7					
Peer support group		116				54.5					
Physician		122				57.3					
Medication to treat mental/emotional wellbeing		106				49.8					
Alternative holistic approaches		117				54.9					
Creative expressive arts therapy		86				40.4					
Other		42				19.7					
I would not seek support to enhance my mental/emotional wellbeing		2				0.9					
Q9. Assume you are interested in attending group therapy for chronic illness. Please rate your preferences for these options:											
		Strongly prefer		Somewhat prefer		Somewhat disprefer		Strongly disprefer		No preference	
		<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
A group that meets in a healthcare facility.		16	7.5	24	11.3	51	23.9	64	30.0	58	27.2
A group that meets in a community setting.		64	30.0	79	37.1	15	7.0	12	5.6	43	20.2

Note. $N = 213$. Please see survey in Appendix E for full questions.

Table 6*Examples of Other Helpful Supports Reported by Participants*

Treatment Preferences	Example Quotes
Therapies or support involving animals	<p>“Equine therapy”</p> <p>“A pet for snuggles and companionship”</p> <p>“Psychiatrist service dog”</p>
Physical therapies	<p>“Massage therapy”</p> <p>“Physiotherapy”</p> <p>“Chiropractor”</p>
Support in the workplace	<p>“Understanding boss, flexible work”</p> <p>“Mental health days off in addition to sick and vacation days”</p> <p>“Medical assistance for employers”</p> <p>“Education in the workplace”</p>
Other professional supports	<p>“Trauma-informed healthcare”</p> <p>“Doctors and therapists who take my pain seriously”</p> <p>“Doctors that listen, support, and believe we know our bodies”</p> <p>“Biofeedback”</p> <p>“Occupational therapy”</p> <p>“Neurologist”</p> <p>“Surgical procedures”</p> <p>“A health advocate that could help communicate and connect my different health specialists and help me advocate and organize”</p> <p>“Advice and guidance on how to address and remove barriers [in the physical environment]”</p> <p>“Access to quality healthcare in a timely manner where pain is properly acknowledged and addressed”</p>
Other medications and substances	<p>“Opioids, narcotics”</p> <p>“Medical marijuana”</p>
Other community activities and supports	<p>“Programs or free cooking classes for those with chronic stomach issues and dietary aides”</p> <p>“General better understanding of these conditions in the community”</p> <p>“Guidance on nutrition and exercise”</p> <p>“Meditation training”</p> <p>“CBT education programs”</p> <p>“Cleaning services in the home, errand services, on-call support”</p>

Note. Spelling errors have been corrected. This table includes only some of the examples for ‘other’ supports for mental/emotional wellbeing listed by participants when answering Q5 of the survey.

Therapist Preferences. The results of the therapist preferences reported through Q9 of the survey can be found in Table 7. The most relevant finding to present is that many participants indicated that they wanted a leader in their group. Specifically, around half of the participants expressed a preference to be in a group led by one or two professionals, and around 85% of respondents preferred to have at least one leader with personal experience dealing with a chronic health condition [see Table 7; for 53.1% of the sample ($n = 113$), this was a strong preference]. In fact, around 72% of participants shared that they would not want to attend a group led by professionals without chronic health conditions. Many of the participants of this study also preferred a group collaboratively led by mental health professionals and medical professionals (63.4%, with 31% strongly preferring this option). Lastly, the majority of participants expressed a preference for the option of having a peer specialist (i.e., someone with lived experience with chronic illness) leading the group along with a professional (75.6%, with 37.1% strongly preferring this option).

Table 7

Therapist Preferences of Participants

Therapist Preferences										
Q9. Assume you are interested in attending group therapy for chronic illness. Please rate your preferences for these options:	Strongly prefer		Somewhat prefer		Somewhat disprefer		Strongly disprefer		No preference	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
	A group led by one professional.	39	18.3	68	31.9	31	14.6	12	5.6	63
A group led by two professionals.	36	16.9	71	33.3	23	10.8	15	7.0	68	31.9
A group led by at least one professional with a chronic health condition(s).	113	53.1	67	31.5	11	5.2	4	1.9	18	8.5

Therapist Preferences										
Q9. Assume you are interested in attending group therapy for chronic illness. Please rate your preferences for these options:	Strongly prefer		Somewhat prefer		Somewhat disprefer		Strongly disprefer		No preference	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
	A group led by professionals without chronic health conditions.	9	4.2	14	6.6	76	35.7	77	36.2	37
A group led by one professional and one peer specialist (someone with lived experience with chronic illness).	79	37.1	82	38.5	18	8.5	7	3.3	27	12.7
A group led by two mental health professionals.	35	16.4	78	36.6	43	20.2	14	6.6	43	20.2
A group led by one mental health professional and one medical professional.	66	31.0	69	32.4	28	13.1	16	7.5	34	16.0

Note. *N* = 213. Please see survey in Appendix E for full questions.

Activity Preferences. The detailed results of the activity preferences reported in Q6 and Q9 of the survey are presented in Table 8. All the activity options listed in Q6 were considered at least somewhat helpful by more than three quarters of the participants. In fact, many of the options were considered helpful by over 90% of the sample. The topic that the participants deemed to be the most helpful was discussing coping skills for dealing with chronic illness, as over 98% of respondents indicated that this topic would be helpful to address in group. This option was followed closely by receiving emotional support for chronic illness (chosen by 97.7% of participants).

A vast majority of the participants (around 94%) reported that it would be helpful to receive medical education about their illness or treatment. Receiving information to support

wellness (e.g., nutrition, stress management, exercise) was considered helpful by around 91% of participants. Just over 90% of participants shared that it would be helpful to learn how to understand their emotions in group therapy. Further, around 88% of participants reported that it would be helpful to discuss topics that do not directly relate to chronic illness. Discussing existential topics was found to be the least popular option of those listed in Q6, but it was still deemed helpful by just over 75% of the sample.

The participants' preferences for the different group options listed in Q9 are presented in Table 8. Most of the respondents (around 85%) expressed a preference for a group that includes members with the same health conditions. Exactly 78% of the participants shared that they would prefer a smaller group with fewer members, while just under 22% preferred a larger group with more members. Around 72% of the participants shared a preference for a group that emphasizes hope and change, and 69% preferred a group that spends ample time exploring the suffering associated with chronic illness. Around 70% of the participants expressed a preference for a long-term group, while only around 33% preferred a short-term group.

A majority of the participants (around 64%) expressed a preference for a group that meets weekday evenings, while far fewer (38%) preferred a group that meets during weekday mornings or afternoons. A more unstructured group with fewer activities was preferred by around 63% of respondents, while a more structured group with many planned activities was preferred by around 43% of participants. Just over 62% of the sample expressed a preference for a closed group that includes the same members each time, while around 49% of the sample preferred an open drop-in group.

The respondents expressed similar preferences for in-person group therapy as compared to online group therapy, as both options were preferred by 61.5% of the sample. Lastly, when

asked about the frequency of group meetings, just over 58% of respondents preferred a group that meets less often (e.g., once per month/once every two months), while around 45% preferred a group that meets more often (e.g., once per week/once every two weeks).

Table 8

Activity Preferences of Participants

Activity Preferences												
Q6. Assume you are interested in attending group therapy for chronic illness. To what degree do you believe these topics would be helpful if you chose to attend group therapy?	Very helpful		Somewhat helpful		Slightly helpful		Not at all helpful		I'm not sure		No response	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Receiving medical education about my illness/treatment.	103	48.4	62	29.1	35	16.4	6	2.8	5	2.3	2	0.9
Receiving emotional support for chronic illness.	154	72.3	43	20.2	11	5.2	2	0.9	1	0.5	2	0.9
Discussing topics that do not directly relate to chronic illness (e.g., how to improve self-esteem).	68	31.9	61	28.6	58	27.2	16	7.5	8	3.8	2	0.9
Discussing coping skills for dealing with chronic illness.	152	71.4	42	19.7	16	7.5	0	0.0	1	0.5	2	0.9

Activity Preferences

	Very helpful		Somewhat helpful		Slightly helpful		Not at all helpful		I'm not sure		No response	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Being given information to support my wellness (e.g., nutrition, stress management, exercise).	99	46.5	62	29.1	33	15.5	12	5.6	5	2.3	2	0.9
Learning how to understand my emotions.	91	42.7	65	30.5	36	16.9	16	7.5	4	1.9	1	0.5
Discussing existential topics (e.g., life's purpose/meaning, death/mortality, spirituality).	54	25.4	62	29.1	44	20.7	42	19.7	10	4.7	1	0.5

Q9. Assume you are interested in attending group therapy for chronic illness. Please rate your preferences for these options:

	Strongly prefer		Somewhat prefer		Somewhat disprefer		Strongly disprefer		No preference		No response	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
A group that meets face-to-face in person.	71	33.3	60	28.2	35	16.4	33	15.5	14	6.6	0	0.0
A group that meets face-to-face online.	55	25.8	76	35.7	51	23.9	20	9.4	11	5.2	0	0.0

Activity Preferences												
Q9. Assume you are interested in attending group therapy for chronic illness. Please rate your preferences for these options:	Strongly prefer		Somewhat prefer		Somewhat disprefer		Strongly disprefer		No preference		No response	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
	A group where members have the same health condition(s) as me.	97	45.5	83	39.0	11	5.2	3	1.4	19	8.9	0
A group where members have different types of health conditions.	16	7.5	65	30.5	72	33.8	26	12.2	34	16.0	0	0.0
A drop-in group where members can come and go as they please.	40	18.8	64	30.0	43	20.2	34	16.0	32	15.0	0	0.0
A group that includes the same members each time.	58	27.2	75	35.2	30	14.1	10	4.7	40	18.8	0	0.0
A short-term group (e.g., 4 sessions).	25	11.7	45	21.1	79	37.1	42	19.7	22	10.3	0	0.0
A long-term group (e.g., 10 sessions).	75	35.2	74	34.7	27	12.7	13	6.1	24	11.3	0	0.0
A group that meets less often (e.g., once per month/once every two months).	52	24.4	72	33.8	49	23.0	21	9.9	19	8.9	0	0.0

Activity Preferences

	Strongly prefer		Somewhat prefer		Somewhat disprefer		Strongly disprefer		No preference		No response	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
A group that meets more often (e.g., once per week/once every two weeks).	39	18.3	56	26.3	68	31.9	27	12.7	23	10.8	0	0.0
A group with fewer members (e.g., 8 or less).	93	43.7	73	34.3	13	6.1	9	4.2	25	11.7	0	0.0
A group with more members (e.g., 10 or more).	12	5.6	34	16.0	94	44.1	44	20.7	29	13.6	0	0.0
A group that meets during the weekday (i.e., morning/afternoon).	40	18.8	41	19.2	50	23.5	54	25.4	27	12.7	1	0.5
A group that meets in the weekday evening.	78	36.6	58	27.2	24	11.3	24	11.3	29	13.6	0	0.0
A more structured group with many planned activities.	36	16.9	55	25.8	59	27.7	40	18.8	23	10.8	0	0.0
A more unstructured group with fewer activities.	60	28.2	74	34.7	40	18.8	15	7.0	24	11.3	0	0.0
A group that emphasizes hope and change.	82	38.5	72	33.8	25	11.7	13	6.1	21	9.9	0	0.0

Activity Preferences												
	Strongly prefer		Somewhat prefer		Somewhat disprefer		Strongly disprefer		No preference		No response	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
A group that spends ample time exploring the suffering associated with chronic illness.	71	33.3	76	35.7	33	15.5	16	7.5	17	8.0	0	0.0

Note. *N* = 213. Participants were permitted to skip questions they did not want to answer. Please see survey in Appendix E for full questions.

Characterize Illness Identity in a Transdiagnostic Sample

The second step toward answering my research question involved characterizing illness identity in a transdiagnostic sample. First, I will describe the chronic conditions reported by the participants of this study. Then, I will report the illness identities within this population by describing their self-reported illness identity and their scores on the subscales of the Illness Identity Questionnaire.

Chronic Conditions. Following the procedure outlined in Chapter 6, I categorized the chronic health conditions reported by participants using the World Health Organization’s (2019) *International Statistical Classification of Diseases and Health Related Problems* (11th ed.; *ICD-11*). After categorizing the chronic conditions, I used descriptive statistics to characterize the sample. Table 9 describes the number of chronic conditions reported by participants. The number of chronic conditions reported ranged from one condition to ten conditions, which was also the minimum and maximum number available to report in Q1. The mean was 3.5 conditions, and the standard deviation was 2.3. Of the 213 participants, 20.2% (*n* = 43) reported one condition, 20.2% (*n* = 43) reported two conditions, 19.7% (*n* = 42) reported three conditions, 13.6% (*n* =

29) reported four conditions, 8.9% ($n = 19$) reported five conditions, 6.6% ($n = 14$) reported six conditions, 4.2% ($n = 9$) reported seven conditions, 2.3% ($n = 5$) reported eight conditions, 0.5% ($n = 1$) reported nine conditions, and 3.8% ($n = 8$) reported ten conditions.

Table 9

Number of Conditions Reported by Participants

Number of Chronic Conditions Reported	Range	<i>M</i>	<i>SD</i>
	1 – 10	3.5	2.3
	<i>n</i>		%
One Condition	43		20.2
Two Conditions	43		20.2
Three Conditions	42		19.7
Four Conditions	29		13.6
Five Conditions	19		8.9
Six Conditions	14		6.6
Seven Conditions	9		4.2
Eight Conditions	5		2.3
Nine Conditions	1		0.5
Ten Conditions	8		3.8

Note. $N = 213$. A total of 745 conditions were reported, with 642 being diagnosed, and 103 undiagnosed. See Appendix G for a full list of conditions reported.

Table 10 describes the frequency distributions for the chronic conditions reported by the participants, and Table 11 outlines the top five most frequently reported chronic conditions. In total, 745 conditions were reported, with 642 (86.2%) being diagnosed, and 103 (13.8%) being undiagnosed. A full list of the 201 different chronic conditions reported by participants can be found in Appendix G. The chronic conditions reported fit into 20 of the categories listed in the *ICD-11*: certain infectious or parasitic diseases ($n = 2$; 0.9%); neoplasms ($n = 20$; 9.4%); diseases of the blood or blood-forming organs ($n = 2$; 0.9%); diseases of the immune system ($n = 22$; 10.3%); endocrine, nutritional, or metabolic diseases ($n = 78$; 36.6%); mental, behavioural, or

neurodevelopmental disorders ($n = 65$; 30.5%); sleep-wake disorders ($n = 9$; 4.2%); diseases of the nervous system ($n = 136$; 63.8%); diseases of the visual system ($n = 4$; 1.9%); diseases of the ear or mastoid process ($n = 3$; 1.4%); diseases of the circulatory system ($n = 14$; 6.6%); diseases of the respiratory system ($n = 27$; 12.6%); diseases of the digestive system ($n = 85$; 39.9%); diseases of the skin ($n = 12$; 5.6%); diseases of the musculoskeletal system or connective tissue ($n = 50$; 23.5%); diseases of the genitourinary system ($n = 49$; 23.0%); developmental anomalies ($n = 35$; 16.4%); symptoms, signs, or clinical findings not elsewhere classified ($n = 126$; 59.2%); injury, poisoning, or certain other consequences of external causes ($n = 3$; 1.4%); and codes for special purposes ($n = 3$; 1.4%).

Table 10

Conditions Reported by Participants

Types of Conditions Reported	<i>n</i>	%
Certain infectious or parasitic diseases	2	0.9
Neoplasms	20	9.4
Diseases of the blood or blood-forming organs	2	0.9
Diseases of the immune system	22	10.3
Endocrine, nutritional, or metabolic diseases	78	36.6
Mental, behavioural, or neurodevelopmental disorders	65	30.5
Sleep-wake disorders	9	4.2
Diseases of the nervous system	136	63.8
Diseases of the visual system	4	1.9
Diseases of the ear or mastoid process	3	1.4
Diseases of the circulatory system	14	6.6
Diseases of the respiratory system	27	12.6

Types of Conditions Reported	<i>n</i>	%
	Diseases of the digestive system	85
Diseases of the skin	12	5.6
Diseases of the musculoskeletal system or connective tissue	50	23.5
Diseases of the genitourinary system	49	23.0
Developmental anomalies	35	16.4
Symptoms, signs, or clinical findings, not elsewhere classified	126	59.2
Injury, poisoning, or certain other consequences of external causes	3	1.4
Codes for special purposes*	3	1.4

Note. *N* = 213. Chronic conditions grouped according to categories from the ICD-11 (see Appendix G for full list of conditions reported). *All of those who were categorized into Codes for Special Purposes reported a Post COVID-19 Condition.

Table 11

Chronic Conditions Most Frequently Reported by Participants

Chronic Condition	<i>n</i>		
	Total	Diagnosed	Undiagnosed or Not Specified
Migraine	66	60	6
Endometriosis	38	36	2
Fibromyalgia	37	31	6
Irritable Bowel Syndrome (IBS)	35	27	8
Ehlers-Danlos Syndrome (EDS)	31	29	2

Note. *N* = 213. This table outlines the five chronic health conditions reported most by the participants of this study. A comprehensive list of all the conditions reported by participants can be found in Appendix G.

In Q3, participants were asked to report the chronic condition that affects their life the most. The frequency distributions of these responses are reported in Table 12. Around 66% of participants chose the first condition they listed in Q1. The *ICD-11* category that was most frequently reported to affect life the most was symptoms, signs, or clinical findings not

elsewhere classified (around 21% of participants). Diseases of the nervous system were also frequently chosen (around 20% of participants). Around 12% of participants chose diseases of the digestive system, while just under 11% reported endocrine, nutritional, or metabolic diseases. Approximately 9% of participants chose diseases of the genitourinary system. Developmental anomalies were reported to affect life the most by 8.5% of participants, while diseases of the musculoskeletal system or connective tissue were reported by 7% of the sample. The other conditions reported (by less than 3% of the sample) can be found in Table 12.

Table 12

Conditions Reported to Affect Life the Most

Condition that Affects Life the Most	<i>n</i>	%
First condition listed	140	65.7
Second condition listed	39	18.3
Third condition listed	17	8.0
Fourth condition listed	7	3.3
Fifth condition listed	2	0.9
Sixth condition listed	4	1.9
Seventh condition listed	2	0.9
Eighth condition listed	1	0.5
Ninth condition listed	1	0.5
Tenth condition listed	0	0.0
Certain infectious or parasitic diseases	0	0.0
Neoplasms	5	2.3
Diseases of the blood or blood-forming organs	1	0.5
Diseases of the immune system	5	2.3
Endocrine, nutritional, or metabolic diseases	23	10.8

Condition that Affects Life the Most	<i>n</i>	%
Mental, behavioural, or neurodevelopmental disorders	6	2.8
Sleep-wake disorders	2	0.9
Diseases of the nervous system	42	19.7
Diseases of the visual system	1	0.5
Diseases of the ear or mastoid process	1	0.5
Diseases of the circulatory system	1	0.5
Diseases of the respiratory system	1	0.5
Diseases of the digestive system	26	12.2
Diseases of the skin	0	0.0
Diseases of the musculoskeletal system or connective tissue	15	7.0
Diseases of the genitourinary system	19	8.9
Developmental anomalies	18	8.5
Symptoms, signs, or clinical findings, not elsewhere classified	44	20.7
Injury, poisoning, or certain other consequences of external causes	1	0.5
Codes for special purposes*	1	0.5
No response	1	0.5

Note. *N* = 213. Chronic conditions grouped according to categories from the ICD-11 (see Appendix G for full list of conditions reported). *All of those who were categorized into Codes for Special Purposes reported a Post COVID-19 Condition.

Based on the answers to Q3, I used participants' responses to Q1 to determine whether the condition that affected their life the most was diagnosed or undiagnosed, how long they had been living with the condition, and how well they believed they were coping with the condition. These results are noted in Table 13. For the diagnostic status of the condition that affects their life the most, around 88% reported that the condition was diagnosed, and around 12% reported that it was undiagnosed. When asked how long they had been living with symptoms of the condition, around 40% of the sample reported five years or less, around 31% reported five to 15

years, and around 25% reported 15 years or more. In terms of how well the participants were coping with the condition that affected their life the most, around half the sample was coping well (i.e., around 57% reported acceptable or better). Of relevance, around 11% shared that they were coping very poorly with this condition.

Table 13

Diagnostic Status, Time, and Coping with Conditions that Affect Life the Most

Condition that Affects Life the Most		
Diagnostic Status	<i>n</i>	%
Diagnosed	187	87.8
Undiagnosed	25	11.7
No response	1	0.5
Time with Condition		
6 months – 1 year	11	5.2
1 – 2 years	20	9.4
2 – 5 years	53	24.9
5 – 10 years	41	19.2
10 – 15 years	25	11.7
15 – 20 years	19	8.9
20 – 25 years	10	4.7
25 – 30 years	5	2.3
30 – 35 years	7	3.3
35 – 40 years	7	3.3
45 – 50 years	1	0.5
50 + years	5	2.3
No response	9	4.2
Coping with Condition		
Extremely well	2	0.9
Quite well	31	14.6
Acceptable	88	41.3
Poorly	56	26.3
Very poorly	24	11.3
No response	12	5.6

Note. *N* = 213.

Self-Rated Illness Identity. In this survey, Q2 asked participants to self-rate their illness identity over the past month using a visual scale based on images I created (see Appendix E). For analysis, the four images were regarded as categorical variables to describe the self-rated illness identity of the participants. The responses to this question are displayed in Table 14. Around 50% of the participants self-rated as being in the state of *engulfment*, while 39% self-rated as being in the state of *acceptance*. Only around 6% of participants reported being in the state of *enrichment*, and just under 5% reported being in the state of *rejection*.

Table 14

Self-Rated Illness Identity

Illness Identity Self-Rating	<i>n</i>	%
Rejection	10	4.7
Acceptance	83	39.0
Engulfment	107	50.2
Enrichment	13	6.1

Note. *N* = 213. Illness identity was self-rated by participants using images I created to reflect each of the four illness identity states (see Appendix A).

Illness Identity Questionnaire (IIQ) Scores. The Illness Identity Questionnaire (IIQ) scores of the participants are displayed in Table 15. As described in the previous chapter, for each of the four IIQ subscales, a lower score indicates that the participant agreed more strongly with the statements related to that illness identity state. The participants of this study showed the strongest agreement with the items of the rejection subscale. These responses were quite closely followed by the scores for the acceptance subscale. While the enrichment subscale received lower agreement than rejection and acceptance, the engulfment subscale received the lowest agreement of all the subscales.

Table 15*Illness Identity Questionnaire (IIQ) Scores of Participants*

Illness Identity Subscale Scores	Range	M	SD
Rejection	6 – 23	14.1	3.4
Acceptance	8 – 25	18.1	3.9
Engulfment	12 – 40	28.9	6.4
Enrichment	7 – 35	24.4	7.0

Note. $N = 213$. Subscale scores were calculated by determining the sum score of the items corresponding to each category, with rejection including items 1 to 5 (maximum 25 points), acceptance including items 6 to 10 (maximum 25 points), engulfment including items 11 to 18 (maximum 40 points), and enrichment including items 19 to 25 (maximum 35 points).

Self-Rated Illness Identity and IIQ Scores. Table 16 contains the crosstabs to compare participants' self-rated illness identity over the past month (Q2) to their scores on the Illness Identity Questionnaire (IIQ) subscales (Q7). This was done to further strengthen the value of using the images from Q2 to determine self-rated illness identity. Specific findings will be presented next, with the details available in Table 16.

Rejection. Of the 10 individuals who identified as being in the state of *rejection*, most received a score between 16 to 20 on the IIQ rejection subscale ($n = 5$). These individuals appeared to show higher agreement with the IIQ acceptance subscale, as most of these individuals scored from 11 to 15 ($n = 5$). For the IIQ enrichment subscale, most of the individuals scored from 16 to 20 ($n = 4$) or higher, indicating a lower amount of agreement with these survey items than the acceptance items. The lowest agreement for these participants was reported on the IIQ engulfment subscale, was most scored from 26 to 30 ($n = 5$) or higher.

Engulfment. Of the 83 individuals who self-rated as being in the state of *engulfment*, most scored 31 or higher on the IIQ engulfment subscale ($n = 62$), indicating a low level of agreement with these survey items. These participants appeared to show the highest amount of

agreement with the IIQ rejection subscale, as most scored from 11 to 15 ($n = 45$). In contrast, most of these participants indicated low levels of agreement with the IIQ acceptance subscale, as many scored between 16 to 20 ($n = 40$) or higher. The responses for the IIQ enrichment subscale were widely dispersed within this subgroup of participants.

Acceptance. Of the 107 individuals who self-rated as being in the state of *acceptance*, most scored from 16 to 20 ($n = 52$) or higher on the IIQ acceptance subscale, indicating a lower level of agreement with these survey items. Interestingly, these individuals appeared to show the highest level of agreement with the IIQ rejection subscale, as most individuals scored between 11 to 15 ($n = 61$). In contrast, these individuals tended to have lower levels of agreement with the IIQ engulfment subscale, as most scored from 26 to 30 ($n = 52$). While the scores on the IIQ enrichment subscale were more widely dispersed, the most common score was from 26 to 30 ($n = 37$).

Enrichment. Of the 13 individuals who self-rated as being in the state of *enrichment*, most scored from 31 to 35 on the IIQ enrichment subscale ($n = 8$). In fact, none of these individuals scored below 16 on this subscale. These individuals appeared to show the highest level of agreement with the IIQ rejection subscale, as most individuals scored from 11 to 15 ($n = 6$). Slightly over half of the individuals scored from 21 to 25 on the IIQ acceptance subscale ($n = 7$), but the remaining 6 individuals received lower scores. For these participants, the most common scores on the IIQ engulfment subscale were from 21 to 25 ($n = 6$) or higher.

Table 16

Crosstabulation Between IIQ Scores and Self-Rated Illness Identity

Self-Rated Illness Identity	IIQ Subscale Scores															
	Rejection															
	0 – 5		6 – 10		11 – 15		16 – 20		21 – 25							
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%						
Rejection					2	20.0	5	50.0	3	30.0						
Engulfment			16	19.3	45	54.1	20	24.0	2	2.4						
Acceptance			15	14.0	61	56.9	28	26.2	3	2.8						
Enrichment			1	7.7	6	46.2	3	23.1	3	23.1						
	Acceptance															
	0 – 5		6 – 10		11 – 15		16 – 20		21 – 25							
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%						
Rejection			1	10.0	5	50.0	2	20.0	2	20.0						
Engulfment			5	4.8	24	28.8	40	48.0	15	18.0						
Acceptance			1	0.9	17	15.9	52	48.6	37	34.6						
Enrichment							6	46.2	7	53.8						
	Engulfment															
	0 – 5		6 – 10		11 – 15		16 – 20		21 – 25		26-30		31-35		36-40	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Rejection							1	10			5	50.0	3	30.0	1	10.0
Engulfment							3	3.6	3	3.6	15	18.1	33	39.8	29	34.9
Acceptance					2	1.9	17	15.9	20	18.7	52	48.6	14	13.1	2	1.9
Enrichment							2	15.4	6	46.2	1	7.7	4	30.8		

Self-Rated Illness Identity	IIQ Subscale Scores													
	Enrichment													
	0 – 5		6 – 10		11 – 15		16 – 20		21 – 25		26-30		31-35	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Rejection					1	10.0	4	40.0	2	20.0	2	20.0	1	10.0
Engulfment					16	19.3	21	25.3	18	21.2	16	19.3	12	14.5
Acceptance			3	2.8	8	7.5	15	14.0	21	19.6	37	34.6	23	21.5
Enrichment							2	15.4			3	23.1	8	61.5

Note. $N = 213$. Illness identity was self-rated by participants in Q2 as Rejection ($n = 10$), Engulfment ($n = 83$), Acceptance ($n = 107$), or Enrichment ($n = 13$). IIQ Subscale scores were calculated by determining the sum score of the items corresponding to each category, with rejection including items 1 to 5 (maximum 25 points), acceptance including items 6 to 10 (maximum 25 points), engulfment including items 11 to 18 (maximum 40 points), and enrichment including items 19 to 25 (maximum 35 points). Lower scores indicate higher agreement.

Somers' D. The Methods chapter contains the rationale for conducting *Somers' Delta* (*Somers' D*) analyses. These overall results are presented in Tables 17 – 20. For the relationships between chronic conditions and illness identity, the dependent variable of self-rated illness identity was analyzed with several independent chronic condition variables (see Table 17). Significant associations demonstrate that the independent chronic condition variables indicate a level of prediction regarding the dependent illness identity variable. For the relationships between illness identity and therapy preferences, the dependent preference variables (i.e., treatment preferences, therapist preferences, and activity preferences) were analyzed with the independent variables related to illness identity and chronic conditions (see Table 18, Table 19, and Table 20). Significant associations demonstrate that the independent illness identity and chronic condition variables indicate a level of prediction regarding the dependent preference variables. I will now describe the results of these analyses.

Chronic Conditions and Illness Identity. Detailed results for the *Somers' D* analyses of the relationships between the participants' chronic conditions and their illness identity are presented in Table 17. In this section, I will outline the statistically significant findings related to the (a) number of conditions reported and (b) self-rated coping scores.

Number of Conditions Reported. In analyzing the data, I was interested in exploring the relationship between the number of conditions the participants reported and their subsequent illness identity. *Somers' D* computations indicated a significant negative relationship between the number of conditions and self-rated illness identity (*Somers' D* = -.139; *p* = .002).

Self-Rated Coping Scores. In Q1, individuals were asked to indicate how well they believed they were coping with their chronic conditions (see Appendix E). While the relationship between self-rated coping scores and self-rated illness identity was not significant for the

condition reported to affect the participant's life the most (Q3), self-rated illness identity was significantly related to self-rated coping for their first identified condition (*Somers' D* = -.465; $p = <.001$), second condition (*Somers' D* = -.276; $p = <.001$), and third condition (*Somers' D* = -.186; $p = .006$) reported in Q1.

Table 17

Relationship Between Chronic Conditions and Illness Identity

Chronic Condition Variables	<i>Somers' D</i> Values
	Self-Rated Illness Identity
Number of Conditions Reported	-.139**
Condition that Affects Life the Most	
<i>ICD-11</i> Category of Condition	.007
Diagnostic/Undiagnosed	-.041
Time with Condition	-.006
Self-Rated Coping	.011
First Condition Reported	
<i>ICD-11</i> Category of Condition	.029
Diagnosed/Undiagnosed	.001
Time with Condition	-.015
Self-Rated Coping	-.465***
Second Condition Reported	
<i>ICD-11</i> Category of Condition	-.033
Diagnosed/Undiagnosed	-.129
Time with Condition	.034
Self-Rated Coping	-.276***
Third Condition Reported	
<i>ICD-11</i> Category of Condition	.004
Diagnosed/Undiagnosed	-.077
Time with Condition	.074
Self-Rated Coping	-.186**

Note.

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

Explore Whether Illness Identity Relates to Preferences for Group Therapy

The third and final step for answering my research question involved exploring the relationships between illness identity and preferences for group therapy. The *Somers' D* correlations assessed the strength and direction of the relationships between illness identity and (a) treatment preferences, (b) therapist preferences, and (c) activity preferences. The full results of the analyses can be found in Tables 18 – 20, respectively, with treatment preferences designated as the dependent variable. The following shall highlight the significant results.

Treatment Preferences. *Somers' D* values for the relationships between illness identity and treatment preferences can be found in Table 18. There are multiple significant relationships between illness identity and participants' treatment preferences in the results of this study.

Individual Therapy. Whether a participant selected in-person individual therapy as a helpful support for improving their mental or emotional wellbeing was significantly related to their self-rated coping with the first condition they listed (*Somers' D* = $-.127$; $p = .021$), their self-rated illness identity (*Somers' D* = $.117$; $p = .040$), and the total number of conditions they reported (*Somers' D* = $-.083$; $p = .049$). In other words, individuals were more likely to select in-person individual therapy as a helpful support if they reported higher levels of coping with the first chronic condition they reported, their self-rated illness identity was more adaptive (i.e., acceptance or enrichment), or if they reported experiencing fewer chronic conditions.

Choosing online individual therapy as a helpful support for mental or emotional wellbeing was significantly related the diagnostic status of the condition that affected them the most (*Somers' D* = $-.276$; $p = .010$) and the number of years they had experienced that condition (*Somers' D* = $.112$; $p = .015$). Thus, individuals were more likely to choose online individual

therapy as a helpful support if the condition that affected their life the most was diagnosed than if it was undiagnosed or if they had experienced the condition for a shorter duration of time.

Peer Support Groups. Choosing peer support groups as a helpful support for improving emotional or mental wellbeing was related to participants' self-reported coping with the first condition reported (*Somers' D* = .140; *p* = .012) and the total number of conditions reported (*Somers' D* = .096; *p* = .036). Therefore, individuals were more likely to consider peer support groups to be a helpful support if they reported higher levels of coping with the first condition they listed and if they reported experiencing fewer chronic conditions.

Physician. The total number of conditions reported (*Somers' D* = .099; *p* = .027) and self-rated illness identity (*Somers' D* = -.130; *p* = 0.29) were significantly related to participants' likelihood of considering a physician to be a helpful support for improving mental or emotional wellbeing. In other words, those who experienced fewer chronic conditions and those who reported more maladaptive illness identity (i.e., rejection or engulfment) were more likely to consider physicians to be helpful supports.

Medication for Mental or Emotional Wellbeing. The most significant predictor of choosing medication as a helpful support for improving emotional wellbeing was the total number of conditions reported by participants (*Somers' D* = .160; *p* = <.001). That is, individuals who reported experiencing fewer chronic conditions were significantly more likely to consider medications to be a helpful support.

Alternative Holistic Approaches. Self-reported coping scores for the first condition reported were significantly related to the likelihood of choosing alternative holistic approaches as helpful for improving mental wellbeing (*Somers' D* = -.111; *p* = .049). Thus, those who reported

higher levels of coping with the first condition they indicated were more likely to consider alternative holistic approaches to be a helpful support.

Creative Expressive Arts Therapy. There was a significant relationship between the total number of conditions reported and the likelihood of choosing creative expressive arts therapy as a helpful support for emotional or mental wellbeing (*Somers' D* = .148; *p* = <.001). Therefore, participants who reported experiencing a higher number of chronic conditions were more likely to choose creative expressive arts therapy as a helpful support.

Meeting in a Community Setting. Whether the condition the condition reported to affect the individual's life the most was diagnosed or undiagnosed was found to be significantly related to preferences for a group that meets in a community setting (*Somers' D* = .246; *p* = .044). In other words, participants who reported that the condition that affected their life the most was diagnosed (rather than undiagnosed) were significantly more likely to prefer a group that meets in a community setting.

Table 18*Somers' D Values for Treatment Preferences*

Treatment Preferences	<i>Somers' D Values</i>						
	Self-Rated Illness Identity	Number of Conditions Reported	First Condition Reported	Condition that Affects Life the Most			
			Coping	ICD-11 Category	Diagnosed/ Undiagnosed	Time with Condition	Coping
Individual therapy in person	.117*	-.083*	-.127*	.044	-.095	.006	-.078
Individual therapy online	-.016	.032	.065	.010	-.276*	.112*	.035
Group therapy in person	.018	.026	-.043	.063	-.073	.027	.041
Group therapy online	-.015	.052	.025	.006	-.164	-.014	.089
Peer support group	-.023	.096*	.140*	.048	-.161	-.015	-.001
Physician	-.130*	.099*	.032	.062	-.154	-.005	-.040
Medication for mental/emotional wellbeing	-.020	.160***	-.011	.062	.028	.039	-.043
Alternative holistic approaches	.062	.048	-.111*	.051	-.036	-.072	-.032
Creative expressive arts therapy	.013	.148***	-.059	-.022	.084	.008	.040
I would not seek support	-.009	-.009	-.011	-.013	.035	.012	.014
Meeting in a healthcare facility	-.106	.057	.057	.042	.164	.038	-.049
Meeting in a community setting	-.111	.028	.086	-.026	.246*	.005	.059

Note. Items regarding treatment preferences were included in Q5 and Q9 of the survey (see Appendix E).

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

Therapist Preferences. *Somers' D* values for the relationships between illness identity and therapist preferences can be found in Table 19. Based on the results of this study, there are several significant relationships to be described.

Number of Group Leaders. The number of years the participant had lived with the condition that affected them the most was significantly related to their preferences for a group led by one professional (*Somers' D* = .118; *p* = .020). Thus, those that had lived with the condition that affected their life the most for a shorter duration of time were significantly more likely to prefer a group led by one professional.

Health Status of Group Leaders. Preferences for at least one group leader with a chronic condition were significantly predicted by self-rated coping with the first condition reported (*Somers' D* = -.166; *p* = .004), self-rated illness identity (*Somers' D* = .130; *p* = .045), and the total number of conditions reported (*Somers' D* = -.094; *p* = .048). In other words, individuals were more likely to prefer a group leader with lived experience with a chronic condition if they reported lower levels of coping with the first condition they listed, their illness identity was more maladaptive, or they reported experiencing fewer chronic health conditions.

Preferences for a group led by professionals without chronic conditions were significantly predicted by self-rated illness identity (*Somers' D* = -.202; *p* = .003), the total number of conditions reported (*Somers' D* = .139; *p* = .008), and the number of years with the condition that affected their life the most (*Somers' D* = .106; *p* = .039). That is, individuals were more likely to prefer this option if they reported more adaptive illness identity, experienced a fewer number of chronic conditions, or if they had experienced the condition that affected their life the most for a longer duration of time.

Mental Health Professionals. There were significant relationships between participants' preferences for a group led by two mental health professionals and the type of condition that affected life the most (*Somers' D* = .103; *p* = .033), meaning that this option was preferred significantly more often by participants who reported certain conditions to affect their lives the most (i.e., diseases of the nervous system, digestive system, or immune system). These preferences were also significantly related to the total number of conditions reported (*Somers' D* = .113; *p* = .035). Thus, those who experienced fewer chronic conditions were more likely to express a preference for a group led by two mental health professionals.

Activity Preferences. *Somers' D* values for the relationships between illness identity and activity preferences can be found in Table 20. Accordingly, I will highlight the statistically significant relationships based on my analyses.

Discussing Topics Not Directly Related to Chronic Illness. Self-rated coping with the first condition listed by participants (*Somers' D* = .215; *p* = <.001) and self-rated illness identity (*Somers' D* = -.188; *p* = .004) were significantly related to preferences for discussing topics that are not directly related to chronic illness. In other words, individuals who reported a higher level of coping with the first condition they listed and those who reported a more adaptive illness identity also more commonly indicated that this activity option would be helpful.

Information to Support Wellness. Self-rated illness identity (*Somers' D* = -.163; *p* = .009) and self-rated coping with the first condition listed (*Somers' D* = .215; *p* = .023) were also significantly related to preferences for receiving information to support wellness. That is, individuals who reported more adaptive illness identity and those who reported higher levels of self-rated coping with the first condition they listed were also more likely to consider receiving information to support wellness to be a helpful activity for group therapy.

Table 19*Somers' D Values for Therapist Preferences*

Therapist Preferences	<i>Somers' D Values</i>						
	Self-Rated Illness Identity	Number of Conditions Reported	First Condition Reported	Condition that Affects Life the Most			
			Coping	ICD-11 Category	Diagnosed/ Undiagnosed	Time with Condition	Coping
Group led by one professional	-.005	-.002	.019	.046	.168	.118*	-.061
Group led by two professionals	-.056	.047	.002	.092	.080	.064	-.044
Professional with a chronic condition	.130*	-.094*	-.166**	-.014	-.001	.028	.032
Professional without a chronic condition	-.202**	.139**	.092	.009	.020	.106*	.011
One professional, one peer specialist	-.015	.002	-.063	.015	.061	-.001	.074
Two mental health professionals	-.087	.113*	.043	.103*	.174	.066	.109
One mental health professional, one medical professional	.021	.071	-.059	.003	-.009	.028	-.006

Note. Items regarding therapist preferences were included in Q9 of the survey (see Appendix E).

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

Learning How to Understand Emotions. In addition to self-rated illness identity (*Somers' D* = -.145; *p* = .027) and self-rated coping with the first condition listed (*Somers' D* = .215; *p* = <.001), preferences for learning how to understand emotions were also related to the number of years with the condition reported to affect life the most (*Somers' D* = .124; *p* = .011). Thus, individuals were more likely to believe this activity option to be helpful if they reported more adaptive illness identity, they reported higher levels of coping with the first condition listed, or if they had lived with the condition that affected them the most for a shorter duration of time.

Group Members with the Same Conditions. Preferences for a group with members that have the same chronic conditions were significantly predicted by self-rated coping with the first condition reported (*Somers' D* = -.137; *p* = .025), meaning that those who reported poorer coping with the first condition they listed were more likely to prefer a group where other members had the same conditions as them.

Drop-In Group. Self-rated coping with the first condition reported also significantly predicted preferences for an open drop-in group (*Somers' D* = .149; *p* = .019), as those who reported higher levels of coping with the first condition they listed were more likely to prefer a drop-in group where they may be different members every week and members can come and go as they please.

Group Program Duration. Regarding preferences for the duration of a group program, self-rated coping with the first condition reported (*Somers' D* = .173; *p* = .003), self-rated illness identity (*Somers' D* = -.146; *p* = .025), and the total number of conditions reported (*Somers' D* = .121; *p* = .025) were all significantly related to responses for short-term groups. That is, short-term groups were preferred significantly more often by participants who expressed higher levels

of coping with the first condition they listed, reported more adaptive illness identity, or experienced fewer chronic conditions. The total number of conditions reported was also significantly predictive of preferences surrounding long-term groups (*Somers' D* = -.109; *p* = .024), meaning that long-term groups were preferred more often by those who reported a higher number of chronic conditions.

Frequency of Group Meetings. While it did not quite reach significance, the total number of conditions reported appeared to be related to preferences surrounding groups that meet less often (*Somers' D* = .097; *p* = .050). Thus, the data appeared to trend toward individuals with fewer conditions being more likely to prefer a group that meets less frequently.

Group Size. Preferences regarding a smaller group size were significantly related to the type of chronic condition reported to affect life the most (*Somers' D* = .115; *p* = .015) and the number of conditions reported by participants (*Somers' D* = -.115; *p* = .022). In other words, those who reported experiencing a higher number of chronic conditions and those who reported certain types of conditions to affect their life the most were more likely to prefer a smaller group with fewer members (the conditions included diseases of the nervous system, digestive system, or genitourinary system; developmental anomalies; or symptoms not elsewhere classified).

Preferences regarding a larger group size were significantly related to self-rated coping with the first condition reported (*Somers' D* = .138; *p* = .022) and the duration of time with the condition reported to affect life the most (*Somers' D* = .101; *p* = .048). Thus, a larger group with more members was more commonly preferred by individuals who reported higher coping with the first condition they listed and those who reported a shorter duration of time with the condition that affected their life the most.

Group Structure. The amount of time participants had lived with the condition that affected them the most was significantly related to their preferences surrounding a more unstructured group (*Somers' D* = .127; *p* = .011). That is, individuals who reported a shorter duration of time with the condition that affected their life the most were more likely to prefer a more unstructured group with fewer activities.

Exploring Suffering Related to Chronic Illness. Lastly, the relationship between self-rated illness identity and preferencing surrounding a group that spends ample time exploring the suffering related to chronic illness was statistically significant (*Somers' D* = .168; *p* = .009). In other words, individuals who reported more maladaptive illness identity were more likely to prefer a group that spends ample time exploring the suffering associated with chronic illness.

Table 20*Somers' D Values for Activity Preferences*

Activity Preferences	<i>Somers' D Values</i>						
	Self-Rated Illness Identity	Number of Conditions Reported	First Condition Reported	Condition that Affects Life the Most			
				Coping	ICD-11 Category	Diagnosed/ Undiagnosed	Time with Condition
Receiving medical education	-.082	.038	.063	-.018	.006	.015	.037
Receiving emotional support	.030	-.047	.026	.008	.154	.036	.015
Discussing topics not directly related to chronic illness	-.188**	.115*	.215***	-.001	.027	.092	.053
Discussing coping skills	.045	-.051	-.007	-.026	.099	-.002	.001
Information to support wellness	-.163**	.065	.138*	-.040	-.009	.034	.034
Learning how to understand emotions	-.145*	.063	.215***	-.035	-.069	.124*	-.002
Discussing existential topics	-.068	.070	.026	.029	.162	.071	.048
Group face-to-face in-person	-.054	.103	.029	-.019	-.042	.081	-.023
Group face-to-face online	.003	.005	-.004	.084	.035	.029	-.088
Group members with same condition(s)	.097	.036	-.137*	.009	-.036	.086	.105
Group members with different conditions	-.049	-.046	-.010	-.031	-.095	.096	.051
Open (drop-in) group	-.123	-.046	.149	.090	-.181	.003	-.039

Activity Preferences	<i>Somers' D Values</i>						
	Self-Rated Illness Identity	Number of Conditions Reported	First Condition Reported	Condition that Affects Life the Most			
				Coping	ICD-11 Category	Diagnosed/ Undiagnosed	Time with Condition
Closed group	.029	-.009	-.076	.054	.135	-.002	-.003
Short-term group	-.146*	.121*	.173**	-.044	-.002	.015	-.042
Long-term group	-.021	-.109*	-.038	-.021	.098	.081	.034
Meeting less often	-.108	.097	.087	-.011	-.088	.027	.028
Meeting more often	-.035	-.044	-.031	.045	.152	.016	-.044
Smaller group size	.002	-.115*	-.097	.115*	.121	.008	-.083
Larger group size	-.116	.045	.138*	.018	-.083	.101*	.025
Meeting weekday mornings/afternoons	-.094	-.089	.018	.012	.060	-.030	.016
Meeting weekday evenings	-.117	.057	.057	-.002	.093	.024	.005
More structured	-.080	-.009	.051	.066	.109	.079	.031
More unstructured	.046	-.047	-.100	.070	.062	.127*	.042
Emphasizing hope and change	-.056	.055	.039	.059	.003	.048	-.088
Exploring suffering	.168**	-0.66	-.048	-.007	.236	.059	.036

Note. Items regarding activity preferences were included in Q6 and Q9 of the survey (see Appendix E).

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

Chapter Summary

In this chapter I described the 213 individuals who participated in this study and systematically analyzed the data collected to answer my research question: *How does illness identity relate to preferences for group therapy in a transdiagnostic population?* Overall, it appears that several factors surrounding chronic illness and illness identity are related to group therapy preferences, including Illness Identity Questionnaire (IIQ) scores, self-rated illness identity, the number of chronic conditions reported, self-reported coping, and aspects of the condition reported to affect life the most. In the upcoming Discussion chapter, I will outline the final synthesis and implications of this data, provide practice recommendations for mental health professionals working with this population, and discuss the limitations to my thesis.

CHAPTER 8: Discussion

This thesis was centered around an important question: *How does illness identity relate to preferences for group therapy in a transdiagnostic population?* To answer this question, a profile of the 213 participants who fully completed the online survey will be presented followed by a clear answer to the three parts of my research question. Thereafter, I will describe the strengths and limitations of this study. It is important to me that the data I collected for my thesis has meaning to professionals and clients. Therefore, the last portion of this chapter will be dedicated to exploring future research directions and potential treatment implications.

Discussion of Results

Demographic Information

Most of the people who completed the online survey found the survey via social media and were female, came from North America, and were around 32 years of age, with the youngest participant being 18 and the oldest being 72. For more details, please refer to Tables 1 – 3. The representativeness of this sample will be discussed in the Limitations section below; however, young, primarily female samples have also been included in other recent studies on illness identity (e.g., Na et al., 2021; Peters & Brown, 2022; Rassart et al., 2022).

What Do Adults with Chronic Illness Want from Group Therapy?

Overall, participants shared that what they want from group therapy is a group leader who has personal experience with chronic illness and can offer hope, provide education, and engage in collaborative care. Their strong desires for a leader with similar lived experiences were consistent with the previous literature (e.g., Anestis et al., 2021; Johnson et al., 2018). The participants in this study expressed a desire for a group that emphasizes coping skills, emotional support, and improving wellness. They wanted a more unstructured, long-term group that

includes members with similar conditions and would hold space to explore the suffering associated with chronic illness while also providing opportunities to bolster hope and change. The participants' preferences support the use of many of the therapeutic factors suggested by Yalom & Leszcz (2020), including belonging, universality, hope, cohesion, and catharsis. Receiving options to meet either in-person or online or to meet more or less frequently seemed to be important to these individuals. More details regarding the group therapy preferences shared in this study can be found in Tables 5 – 8.

How was Illness Identity Characterized in this Transdiagnostic Sample?

A vast majority of the participants in this study experienced more than one chronic condition, and a wide variety of conditions were reported, as presented in Appendix G. Overall, the participants' responses to the Illness Identity Questionnaire (IIQ) suggested that they identified the most with the state of rejection, followed by acceptance, then enrichment, and the least with engulfment. However, around half of the sample self-rated their illness identity as being in the state of engulfment. The remaining half mostly rated as being in acceptance, but some did select enrichment or rejection.

Although self-rated illness identity did not appear to align with the scores from the IIQ, this finding is not necessarily surprising, as the IIQ captures illness identity at one moment in time, while the self-ratings addressed illness identity over the past month. In this transdiagnostic population, illness identity was related to the number of conditions the participants experienced and how well they were coping with their chronic conditions, supporting previous findings on the impact of co-occurring conditions (Warner et al., 2010) and the relationship between coping and illness identity (Oris et al., 2018). Further details regarding these findings can be found in Tables 9 – 17.

How Does Illness Identity Relate to Preferences for Group Therapy?

For the participants of this study, the experience of chronic illness was related to group therapy preferences. The number of conditions they experienced, how well they believed they were coping, and the condition that affected their life the most all appeared to play a role in what they wanted from group therapy. In contrast with previous suggestions that the time spent with a chronic condition may determine group therapy needs (Leszcz, 2020), participants' preferences were more often related to self-rated illness identity, coping, and the number of conditions reported than the time they lived with the condition that affected their lives the most.

Participants who self-rated their illness identity as being in the states of *engulfment* or *rejection* expressed particular interest in long-term groups that spend ample time exploring the suffering associated with chronic illness, emphasizing a need for catharsis in these illness identity states (Yalom & Leszcz, 2020). These participants also placed high importance on having a leader with firsthand experience with chronic illness, supporting the use of the therapeutic factors of belonging and universality (Yalom & Leszcz, 2020).

In contrast, those who self-rated their illness identity as being in the states of *acceptance* or *enrichment* expressed a stronger desire to learn to understand their emotions and support their overall wellness. These participants also showed that they were open to exploring topics that do not directly relate to chronic illness. Like the participants described in the study by Oris and colleagues (2018), the individuals in these states of illness identity appeared to be able to appreciate parts of themselves beyond chronic illness. Further details regarding the relationship between illness identity and preferences for group therapy can be found in Tables 18 – 20.

Thus, according to the results of this study, illness identity appears to relate to preferences for group therapy in multiple ways, especially surrounding the topics explored in

group. Moreover, these preferences seem to align with the descriptions of the illness identity states provided by Oris and colleagues (2018). This study has provided a novel approach to exploring what adults with chronic health conditions want from group therapy. In the following sections, I will present what I believe to be the strengths and limitations of this thesis.

Strengths

It is my contention that this thesis offers the profession great value and I hope it will be of use to those working with clients experiencing chronic health challenges. To support this contention, I will outline the strengths of this thesis, including: (a) achieving a large sample size, (b) highlighting client voices, (c) offering a unique approach, (d) choosing a unique sample population, (e) utilizing a collaborative survey design, and (f) adapting to online research.

Sample Size. This survey received a total of 387 recorded responses, and after data cleaning, resulted in a sample size of 213 participants—a sample over two times larger than my anticipated goal. I believe this is an impressive sample size for a master’s level research study, especially because this was my first time engaging in research. This sample size is also comparable to some of the previous studies cited in my literature review. For example, Van Bulck and colleagues (2018) reported a sample size of 216 adults in their study of illness identity and congenital heart disease.

Client Voices. As reported in my literature review, the firsthand perspectives of individuals with chronic illness are scarce within the research. This study provided a platform for this population to have their voices heard by researchers and clinicians in terms of their firsthand perceptions and what they want from group therapy. The significant response rate for this study could speak to the willingness of the chronic illness community to provide feedback for mental health professionals to improve their services.

Unique Approach. An exhaustive literature review revealed that this study is likely the first to explore the topic of illness identity within the context of psychotherapy. How an individual's relationship with their illness could influence their preferences for group therapy had not yet been described in the literature. Thus, this study brings a unique approach to addressing the psychological wellbeing of individuals living with chronic illness in both research and practice. Later in this chapter, I will elaborate on the potential applications of this unique approach to future research and clinical practice.

Unique Sample Population. While many studies focus on homogenous populations with a single diagnosis, this appears to be the first study to examine illness identity and group therapy preferences with participants who have reported a wide range of chronic health conditions and symptoms. In total, there were 201 different conditions and symptoms reported, and 79.8% of participants in this study reported having more than one chronic health condition. Moreover, this study was not limited to individuals who had received diagnoses for their chronic illness. I consider this unique sample population to be a strength of this study, as it has the potential to contribute a broad perspective to the literature. I believe this could open many potential avenues for future research, as I will discuss below.

Survey Design. The novel approach taken for this thesis required a unique survey that was generated by combining original survey items with items created by previous researchers. This survey was designed through collaboration with professionals from multiple backgrounds to tailor the questions to this distinct sample population. Thus, while adding client voices to the literature, this study also offered a new tool for exploring illness identity and group therapy preferences in adults with chronic health conditions.

Original Images. One of the strongest aspects of the unique survey design was the original images created for participants to self-rate their illness identity (see Q2 in Appendix E). Prior to this study, assessment of illness identity had been limited to research settings using more detailed quantitative questionnaires such as the IIQ. I believe that offering a novel approach to assessing illness identity translates well to practice settings and enhances the application of the results for mental health professionals, as I will discuss in the Recommendations section below.

Adapting to Online Research. This study was designed and completed during the COVID-19 pandemic, during which the entire world was forced to adapt to unprecedented times. At the time of writing this Discussion chapter, many individuals with chronic health conditions have continued to remain vigilant about the current public health risks. Accordingly, this study was conducted online and utilized social media platforms to connect with a population that may have otherwise been unable to participate in research. Remaining flexible, continually adapting to unpredictability, and harnessing the latest technology trends allowed me to collect a significant sample size for this important research.

Limitations

Despite the significant strengths of this thesis, I have identified several limitations within my research. These limitations include: (a) the absence of formal pilot testing, (b) the recruitment strategies used, (c) elements of the survey design, (d) the cross-sectional nature of the study, (e) the complexities of identity, and (f) the scope of the data and analysis. While these limitations impact the generalizability of the thesis findings, they also provide direction for how this type of study could be improved in the future. Thus, I will outline each of these limitations in further detail and include recommendations for mitigating each limitation.

Missing Pilot. Although informal testing of the survey was conducted at multiple points during the process of designing the survey, a formal pilot test to evaluate participant responses was not conducted for this study. This was due to the time limitations imposed by the duration of my master's program. Consequentially, there may have been elements related to comprehension, structure, or format of the survey that were overlooked prior beginning the study. Further, while the survey for this study included many items adapted from the work of previous researchers, many of the items were original. Therefore, the absence of formal pilot testing also made it impossible to know the validity or reliability of some of the survey items prior to the study. Further studies with greater time allowances should utilize pilot studies to create surveys that are clear and comprehensive.

Recruitment Strategies. In examining the success of the four recruitment strategies utilized for this study, it appears that the chronic illness support groups on Facebook brought in the most participants, while very few participants reported that they found the survey through the survey distribution pages. Upon reviewing the other studies that are commonly distributed through the pages designed for survey distribution, many of them appear to have more broad target demographics. Thus, it is possible that my target population could have been too specific for the purposes of these groups. While I am satisfied with the number of participants I recruited for this study, it may have been helpful to focus my efforts on sharing my survey in more chronic illness support groups. For example, I could have explored support groups on other social media platforms, such as Twitter, Instagram, Tumblr, or Reddit, to find more places to share my invitation.

Representation. In hindsight, I would have liked to put more time into utilizing recruitment strategies that would collect a more representative sample. Most of my study

participants identified as female, which limits the generalizability of my results to other gender identities. Thus, I believe I could have taken some more specific approaches to my recruitment strategies, including exploring the possibility of sharing my survey within Facebook groups for certain demographics (e.g., chronic illness support groups for men, transgender people, or nonbinary people). The generalizability of the findings is also limited by the fact that most of the participants reported living in Canada or the United States, so individuals from other countries were underrepresented in this sample. As mentioned in previous chapters, the experience of living within certain social systems, including healthcare systems, plays a role in the experience of living with chronic illness, and could therefore influence the development of illness identity. Thus, future recruitment strategies should include methods for reaching a greater number of individuals in countries outside of Canada and the United States. For instance, distributing the survey in groups specific to certain regions of the world could help to target the individuals who were underrepresented.

Survey Design. This was my first time designing a research survey, and while I received extensive support from my thesis committee in designing the questionnaire, there are elements of the survey that may have limited the efficacy of this study. These include the survey length, the survey items, the accessibility of the survey, the survey incentive, and cultural factors.

Survey Length. The scope of this survey was limited by its length. In hopes of minimizing survey fatigue, I tried to keep the survey as concise as possible. Therefore, the survey questions captured more breadth than depth for these topics, and further research will be needed to gain more in-depth understanding. In future studies, I would like to take a more focused approach to explore the perceptions of this population. Certain demographic data were also sacrificed to meet this goal. Consequentially, the descriptive characteristics of this sample

were limited, which may prevent more concrete conclusions related to participants' identities beyond their chronic health conditions.

After analyzing the data, I noted that 41.3% of the participants took longer than 10-15 minutes to complete the survey. It is possible that, for some participants (especially the 160 respondents whose responses were removed for being incomplete), despite my best efforts, the survey was too long. Thus, in designing my survey, I could have examined the survey length more carefully. Taking a more focused approach would have allowed me to shorten the survey, which may have resulted in a lower rate of dropout. For example, I could have chosen to include only one subscale of the Illness Identity Questionnaire, such as the Acceptance subscale, rather than the questionnaire in its entirety, or gathered preferences for only one category of group therapy preferences. While I believed I had made my survey as concise as possible, I now see that it may have been helpful to make the survey even shorter to minimize dropout. Based on this, future studies should keep in mind the varying degrees of time needed to complete a survey for individuals in this population.

Survey Items. I believe that several limitations could be drawn from the survey items themselves. As it was my first time designing a survey, the original items I designed may not have been as strong as items that were previously validated. While informal pilot testing and consulting with my thesis committee helped to design the original items, more formal pilot testing would have helped to determine the reliability and validity of my survey items. Further, the Illness Identity Questionnaire (IIQ) has been previously validated for use with individuals with certain chronic conditions; however, my study explored a transdiagnostic population in which many people had multiple conditions and/or conditions that had not been explored with the IIQ in previous studies. Therefore, further research is needed to validate this questionnaire

for use with transdiagnostic populations. Lastly, as with any questionnaire, the ordering of the questions could have influenced individuals' responses. This may be particularly true for the questions that provided many survey items in a row (e.g., Q6, Q7, Q9). It may have been helpful to present the items on these questions in a more randomized order to attempt to mitigate these effects.

Accessibility. The accessibility of the survey may have been limited due to certain technological features in Qualtrics. For example, some question formats may not have been compatible with text readers that assist individuals with visual impairments. These considerations could have been examined more carefully prior to releasing the survey. In future studies, it will be important to utilize the tools available to design surveys that are easily accessible for all individuals.

Moreover, as this study was conducted online, the individuals who participated in this study all had access to the technology needed to engage with the survey (e.g., computers, tablets, smartphones). Therefore, this sample may fail to represent individuals who do not have or choose not to access these devices. Further, the individuals who completed the survey were among those who had the physical capability to respond. Thus, the sample may not be representative of those whose conditions are too severe to allow them to respond to the survey. Future studies could ensure a more representative sample by exploring additional avenues of survey distribution, such as in-person (face-to-face or voice-to-voice) opportunities to engage in the survey that would give individuals the option to answer on paper or have their responses transcribed for them.

Offering an Incentive. It is possible that offering an incentive to complete the study may have biased my sample. For instance, if an individual were motivated to get to the draw at the

end, they could have selected random responses without taking the time to complete the survey honestly. I could have added attention check questions or reverse-coded items to test for this type of bias in the survey responses. In considering the type of incentive to offer, I chose to opt for fewer larger incentives (i.e., two \$50 gift cards) rather than a higher number of small incentives (i.e., one smaller gift card for every participant); however, it is possible that the latter could have attracted more participants. In the future, if offering a higher number of smaller incentives, I believe it would be even more important to add the items that could check for bias in the sample. I believe it is important to note that the optional raffle draw received 142 entries, which equates to 66.7% of the 213 participants. This could suggest that some individuals may not need an incentive to participate in these types of studies beyond having their voices heard.

Cultural Factors. Due to the nature of the distribution processes for this study, the survey reached individuals from all over the world. However, this study was designed by educated researchers in a Western culture with English as their first language. Therefore, there may have been some language and cultural pieces that were not accounted for in the survey design. For instance, the concepts of chronic illness and group therapy may have different meanings in different cultures, or the meaning of the questions could have been lost in translation. In the future, it may be helpful to ensure that the survey is available in a broad range of languages to be more accommodating for participants. Further, consultation with individuals from different cultural groups may have assisted in ensuring that the study would be received as intended across cultures. Thus, in future studies, I plan to address cross-cultural factors more closely.

Cross-Sectional Data. The results of this study reflect the firsthand perspectives of the participants at the time that they took the survey. There are many contextual factors that could have influenced the participants' responses, including, but not limited to, their mood and

symptom levels at the time they responded. In line with the Shifting Perspectives Model, these responses may provide “only a snapshot” of the participants’ experiences (Paterson, 2003, p.992). Therefore, the participants’ responses may not be generalizable to other contexts. Further studies could utilize a longitudinal cohort design to explore how these perceptions may vary across time and across different contexts.

Complexities of Identity. As mentioned in earlier chapters, I acknowledge that this study has only begun to scratch the surface of the complexities of identity in this population. I invited participants to share any additional identities that were relevant to them, and this invitation gave valuable insight into the types of identities that overlap with the participants’ chronic conditions. The survey question I used to invite participants to share their identities was intended to be open-ended, however, this was at the expense of collecting more specific demographic information to describe my sample. In my literature review, I mentioned the intricacies that other identities, such as gender, culture, age, race, ethnicity, religion, and socioeconomic status often add to life with chronic illness. Diving deeper into these identities within this population was beyond the scope of this study; however, future research should explore the multidimensionality of identity within the context of chronic illness, specifically in non-dominant and marginalized groups.

Scope of Data and Analysis. Based on the time limitations of my master’s program, I chose to conduct a quantitative survey to begin to explore this topic. However, I am aware that a mixed-methods or qualitative approach may have provided more detailed responses and allowed a deeper exploration of illness identity and group therapy preferences. In future studies, I would like to further explore the open-text responses provided by my participants using thematic analyses. Moreover, I believe future studies involving a qualitative focus-group would provide a rich exploration of the firsthand perspectives and preferences of individuals with chronic health

conditions. Future qualitative studies could allow for connection into the cognitive and emotional experiences of this population, which would provide invaluable insight for mental health professionals.

Lastly, I would like to acknowledge that engaging with this study was the first time that I have managed and analyzed research data. Although I was careful with the data analysis process and ensured that I worked closely with my thesis committee to mitigate as many errors as possible, I had to engage in a quick learning process. Thus, it is possible that I made errors in my work. However, I am grateful to my thesis committee member, Dr. Thelma Gunn, for guiding me in the process of analyzing my data. This foundational knowledge will serve me well in my future studies. I will now discuss potential future directions and treatment implications based on the results of this thesis.

Future Directions and Treatment Implications

Additional Areas for Future Research

In addition to the ideas for future research described above, I would like to outline additional recommendations for expanding the findings of this study and the current literature available. I find it exciting to consider the extensive opportunities for exploring the topics of illness identity and group therapy preferences, as there are many avenues to be investigated. The following will describe my perspectives on future directions for research based on this thesis.

Expanding Validity of Illness Identity Assessment. Since this study was the first to explore the concept of illness identity in a transdiagnostic population, future research should seek to validate the Illness Identity Questionnaire for use with a wider variety of chronic conditions, and for those who report multiple conditions. Further, in future studies, I hope to explore the validity of the illness identity self-rating tool created for this questionnaire. Doing so would

allow greater application of this questionnaire to future research studies and open more doors for exploring illness identity.

Differential Impacts of Conditions. I believe it would be valuable to explore the differential impacts on illness identity for those who experience multiple conditions. Some individuals may experience each condition in a different way (e.g., one may be more debilitating while another is more well-managed), so I would presume that different conditions could be integrated differently into their sense of self. For instance, a potential research question could ask: *How is illness identity shaped by different chronic conditions in a multi-diagnostic population?* Understanding the differential impacts and how they influence the individual's general sense of wellbeing could help to better understand the complexities of identity.

Measures for Group Therapy Preferences. In creating the survey used in this study, it was challenging to find existing measures that explored group therapy preferences. I am grateful that I was given permission to modify the questionnaire used by Sherman and colleagues (2007) to explore the group preferences of adults in a cancer support group. However, I believe it would be beneficial to create a standardized measure of group preferences that could be used in future research or practice settings. Doing so could allow researchers and practitioners to make between-group comparisons more easily and use participants' responses to inform best practices.

Exploring the Impact of Group Experiences. An earlier version of this survey planned to investigate the participants' experiences with groups (e.g., past and/or present participation in a support group or group therapy). However, as I narrowed down my research question, these survey items were eliminated. It would be interesting to explore whether past and/or present group experience plays a role in group therapy preferences (e.g., *How does previous group experience relate to preferences for group therapy in adults with chronic illness?*). I would

speculate that having past experiences with groups would shape an individual's preferences, either positively or negatively; however, this does not appear to have been explored in previous studies. Further research on the influence of previous experiences on group preferences could be valuable for gaining more insight into what individuals with chronic illness want from group therapy.

Longitudinal Studies. As mentioned in my limitations section, this study was a cross-sectional snapshot of the illness identities and group therapy preferences of these participants at a particular moment in time. Thus, several contextual factors could have played a role in the results of this study. Knowing that the experience of chronic illness is a dynamic and multidimensional process, future research should seek to employ longitudinal designs in further exploring the relationship between illness identity and group therapy preferences (e.g., *How does the relationship between illness identity and preferences for group therapy shift over time?*). These studies could uncover more of the contextual factors that influence the Shifting Perspectives of an individual's sense of self and how this impacts what they would want from group supports.

Therapeutic Change and Illness Identity. In the early stages of planning this thesis, I had considered exploring the differences in illness identity between individuals who had received professional mental health support (e.g., attending therapy with a counsellor/psychologist) as compared to those who had not (e.g., receiving social support alone). While the topic of my thesis shifted significantly before my study began, I maintain that it would be interesting to uncover how the therapeutic process may impact illness identity. In considering potential directions for my future research, I hope one day to explore illness identity using a pre- and post-measure surrounding an intervention, such as group therapy. For example, a future research

question could be: *Does group therapy contribute to changes in illness identity in adults with chronic illness?* I believe that exploring illness identity in this way would increase the collective understanding of illness identity as a construct and uncover whether actively engaging in therapeutic change could shift the way illness is incorporated into one's sense of self.

Focus Group. In my future research, I hope to conduct a focus group to gather the qualitative responses of individuals living with chronic illness. I believe a qualitative approach to exploring illness identity and group therapy preferences would help to elaborate on the “why” behind the results of this study (e.g., *Why do individuals with chronic conditions prefer a group leader with lived experience with chronic illness? Why do individuals with chronic conditions prefer individual therapy over group therapy?*). While the open text responses on my survey did provide context to some participants' responses, many individuals chose not to answer these optional survey items. This thesis has begun to bring client voices into the literature, and I believe that a qualitative analysis of the firsthand perspectives of this population could provide a deeper understanding of the emotional and cognitive experiences that explain what an individual would want from mental health supports. In turn, these responses could guide a more comprehensive application of the results to clinical practice.

Anonymous Design. Of course, in following ethical research practice, I made this online survey anonymous. However, it is possible that this aspect of the study also encouraged participation, as the multifaceted experience of chronic illness is often a sensitive topic that may not be given space to be expressed. Particularly in the context of giving feedback to service providers, there may be hesitancy to speak up about one's preferences in more direct face-to-face contexts. Those who have had harmful experiences with service providers in the past may not be encouraged to give their input to improve services very often. Perhaps the anonymous design of

my survey provided a safe place for individuals to share their perspectives without feeling judged or evaluated. Thus, I contend that it is important for future research with this population to uphold this type of safety wherever possible.

Recommendations for Group Therapists

While I will be providing recommendations for group therapists to implement changes in their approach to group therapy for chronic illness, I believe I would be remiss if I did not mention the potential barriers that group therapists may face in creating change.

Advocating for Systemic Change Wherever Possible. In 2002, the World Health Organization released a global report on *Innovative Care for Chronic Conditions*. Through this report, they acknowledged that many healthcare systems are not made for managing chronic health conditions, as they are typically meant to address acute concerns (World Health Organization, 2002). They advocated for action and integrative care on multiple levels, through changes in policies, healthcare organizations, and communities. Thus, while mental health practitioners may be in a unique position to create change in the care of this population, there are many other factors to consider. While many of these factors are beyond the scope of this thesis, I consider acknowledging them to be worthwhile.

In considering the potential limitations to implementing the recommendations in this thesis, I must note that in some circumstances the practitioner themselves may not be tasked with deciding certain aspects of group offerings, such as the time, location, or content of the group. Further, I acknowledge that many agencies may have limited availability of practitioners or peer volunteers with the appropriate training or experience for these specialized groups. As discussed in previous chapters, there may also be limitations in collaborative care with professionals in other disciplines. Large-scale developments in providing care to specialized populations often

happen slowly over time; however, these developments often consist of the cumulative impacts of smaller-scale changes that practitioners can incite at individual and community levels. With this thesis, I hope to empower practitioners to advocate for change wherever possible, no matter how small those changes may be.

Incorporating Client Preferences. Based on the results of this study, this population may prefer other treatment alternatives over group therapy. Thus, I believe that incorporating client preferences is an important factor for providing support that would appear more helpful to this population. According to the existing literature, the preferences of therapists and the preferences of clients often differ significantly (Cooper et al., 2019). Thus, the first recommendation that I hope to provide from my research is for group therapists to engage in open dialogue with their clients regarding their therapy preferences. Incorporating client preferences in the mechanics of group therapy (i.e., the structure, activities, duration, membership, etc.) will likely assist in the development of the therapeutic alliance, which is essential for supporting therapeutic change (McLeod, 2012).

Further, while the results of this study may point toward some general trends of therapy preferences for this population, it is important to account for individual perspectives and preferences. I believe that best practice in counselling is informed by both research and lived experience. Thus, in addition to incorporating empirical research into designing group programs, therapists should also seek to gain information from the unique individuals they serve. This is particularly important at the beginning of a group but should also be implemented throughout the course of the group (McLeod, 2012), and it may include utilizing quantitative surveys, feedback forms, open conversations, or anonymous methods of receiving client input (Swift et al., 2018).

Based on the results of this study, I would advise practitioners to prioritize having at least one group leader who has lived experience with chronic illness. Where it is not possible to have a professional with a chronic health condition lead the group, practitioners should enlist the help of peer volunteers to co-lead the group. Moreover, practitioners should engage in collaborative care whenever possible to incorporate specialist perspectives into the group experience.

By actively seeking the preferences of their members, group leaders can expand the possibilities within group by exploring different approaches, such as holistic alternatives or expressive arts therapy. Further, I would advise that group therapists offer long-term groups with multiple options for group delivery (i.e., both online and in-person groups) and frequency of group meetings to account for individual differences in preference and accessibility. My hope is that group therapists can create meaningful offerings tailored to the unique needs of this population.

Understanding the Impact of Chronic Health Conditions. As mental and physical health are deeply intertwined, professional support is often needed to navigate the challenges of living with chronic illness. I contend that all mental health professionals should seek continued education to understand the unique experiences of individuals with chronic health conditions. I believe this training would allow practitioners to provide a higher quality of care, even for clients whose presenting concerns involve topics beyond their chronic conditions.

Using Illness Identity in Practice. My motivations for pursuing this topic included my belief that illness identity could be a useful construct to conceptualize clients' relationships with their chronic conditions. Thus, I have identified multiple ways that counsellors could utilize the concept of illness identity in practice settings.

Illness Identity Self-Rating. The illness identity self-rating created for this study could be utilized in a group counselling setting in a variety of ways, including check-ins at the beginning of sessions or to monitor progress throughout the course of the group. Further, this type of self-rating could be used to gauge the differential impacts of multiple conditions for group members. Alternatively, these images could illustrate the concept of illness identity when providing psychoeducation. Regardless of the method of application, I believe that using illness identity self-ratings during group sessions could be an effective way for the group leaders and members to better understand themselves and each other.

Exploring Topics Based on Illness Identity. When the group leaders understand the members' illness identities, the topics explored in group can be chosen accordingly. For instance, if group members begin the group in the state of engulfment, the leaders can hold space for spending ample time exploring the suffering the members are experiencing. Activities in the beginning of the group may focus on emotional support and building coping skills for dealing with chronic illness. As the group progresses and members become more accepting of their conditions, leaders may begin incorporating education on emotional literacy and wellness while exploring themes of hope and change. If group members experience a shift into acceptance as they near the end of the group, leaders can give the option to explore topics that do not directly relate to chronic illness. My best hope for this application of my research is that group therapists choose to meet their clients exactly where they are on their chronic illness journey.

Actively Addressing Identity. Working directly with issues of identity in group therapy for chronic illness may assist individuals in reconciling their illness within their sense of self. Actively exploring the topics surrounding identity, such as values, internalized messages and narratives, self-talk, or the importance of the relationship with oneself, could help to bring these

perceptions to the forefront of group sessions. It is possible that group leaders will encounter individuals in a wide range of illness identity states, and I contend that all four states should be welcome within the group.

Normalizing Rejection and Engulfment. Group therapy provides the perfect setting for the therapeutic factors of universality and belonging to normalize the difficult thoughts and feelings associated with rejection and engulfment. Group leaders can encourage members to explore these states of illness identity and validate their experiences. I encourage therapists to cultivate a culture of openness and common humanity, rather than aiming to rush individuals away from these “maladaptive” states.

Exploring Acceptance and Enrichment. Given the dynamic nature of chronic illness, it is possible that acceptance and enrichment could appear as fleeting moments rather than long-term states of being for some individuals. Group therapy can provide an excellent opportunity for members to learn to recognize these states of illness identity when they arise and find joy in these moments, even if they are rare. This type of exploration could help members begin to shift away from seeing their experiences strictly through the lens of engulfment.

Reflection

Before concluding my thesis, I would like to provide a reflection on the impact that this thesis has had on my experience of chronic illness. I completed this thesis while navigating personal challenges of seeking new diagnoses, trying out new treatment options, and gaining new skills to manage my symptoms of chronic pain. While my personal experiences increased the inherent challenge of completing a master’s thesis, I believe they have also increased my passion for studying this topic. This research has motivated me to seek new connections within the chronic illness community that I may not have otherwise pursued. Through this thesis, I have

received the opportunity to learn more about myself as I researched and lived firsthand the complexities of chronic illness.

One of the models that has been foundational in formulating this thesis is Paterson's (2001) *Shifting Perspectives Model of Chronic Illness*, through which she suggested that it is the individual's perception of the situation, and not the situation itself, that will determine how well they cope with their illness. Because illness and wellness continually shift between the foreground and the background of the individual's perception, there is no "ideal end point toward which all people with chronic illness should strive" (Paterson, 2003, p.988).

As mentioned in Chapter 1, although rejection and engulfment are considered "maladaptive" illness identities, I would argue that they may be inevitable and necessary parts of living with chronic illness. My perception has certainly fluctuated continually between all four states of illness identity in the process of writing this thesis. The entirety of the human experience involves both positive and negative emotions, and emotions are suggested to be full-body experiences that are evolutionarily adaptive and essential for processing information (Schulkin et al., 2003). Experiencing a physical health condition requires the individual to emotionally, social, and cognitively adapt to their experience (Alshami, 2019).

Bowman (2001) emphasized viewing emotions toward illness as healthy responses to potential survival threats. In the case of chronic illness, what the body sees as a threat to survival is continually present. Thus, it appears unrealistic to expect someone with chronic illness to strive only for the experience of acceptance. I believe that mental wellness involves experiencing the entire continuum of emotions and sensations without getting stuck in one state. Through this thesis, I have learned to show myself compassion and understanding through the difficult

thoughts and feelings associated with chronic illness. It is my belief that this compassion will serve me well as I move on to my career as a psychologist.

Conclusion

This thesis has explored the overlap between mental and physical health, and while the focus of this discussion is on mental health professionals, there are also potential applications for other healthcare professions, including increasing referrals to mental health support when diagnosing physical health conditions. Thus, not only does this research study contribute to the literature it will be expanding, but it also has the potential to directly impact the practice of service providers, and in turn, the lives of individuals seeking support. Moreover, completing this thesis has contributed to my own personal and professional growth by serving as evidence of enrichment in action. Overall, this thesis has left me with a true appreciation for the potential impact that mental health professionals can have on the lives of individuals with chronic health conditions.

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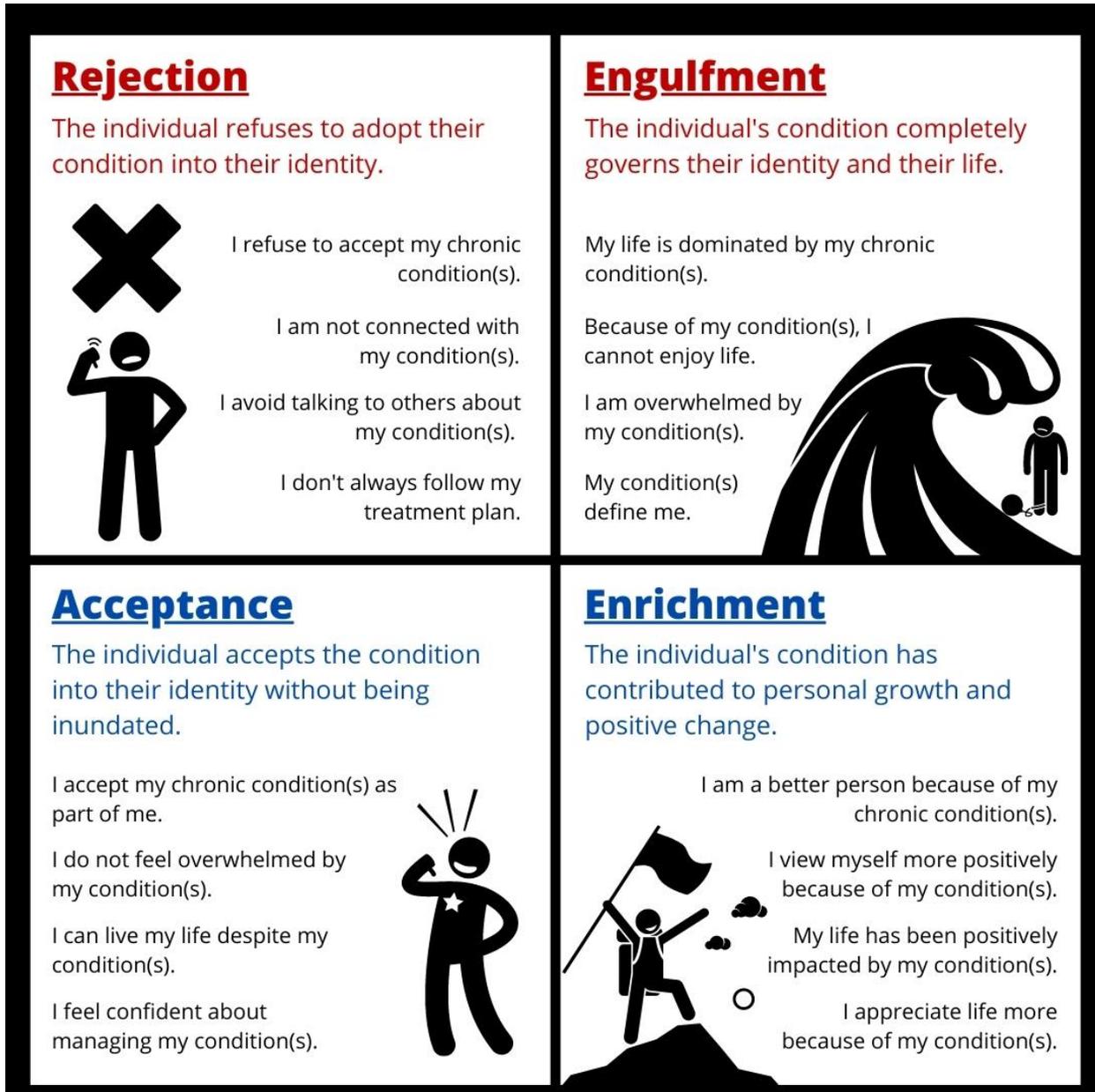
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Appendix A: The Four States of Illness Identity

The Four Illness Identity States Proposed by Oris and Colleagues (2016)



Note. Figure created by D. Kubik (2021) using Canva for Education. (anatolir, n.d.; Gan, n.d.-a; Gan, n.d.-b; Gan, n.d.-c; Gan, n.d.-d; milkghost, n.d.).

Appendix B: Requests for Permission

Permission to use Illness Identity Questionnaire (IIQ)

October 5, 2021

RE: Request for Permission to use the Illness Identity Questionnaire (IIQ)



Koen Luyckx [REDACTED]
Tue 10/5/2021 11:42 PM
To: Kubik, Dalaine
Cc: McBride, Dawn



Caution: This email was sent from someone **outside of the University of Lethbridge**. Do not click on links or open attachments unless you know they are safe. Suspicious emails should be forwarded to phishing@uleth.ca.

Dear Dalaine,

Please find in attach the questionnaire. Good luck with your research!

Best,
Koen

From: Kubik, Dalaine [REDACTED]
Sent: Wednesday, October 6, 2021 12:17 AM
To: Koen Luyckx [REDACTED]
Cc: McBride, Dawn [REDACTED]
Subject: Request for Permission to use the Illness Identity Questionnaire (IIQ)

Hello Dr. Luyckx,

I hope you are well.

I am writing to you because of your valuable research on illness identity in individuals with chronic illness. I am an aspiring researcher, and I am currently working on the proposal for my Master's thesis. I have CC'd my supervisor, Dr. Dawn McBride, on this email.

Your studies on illness and identity have been the inspiration for a large amount of my thesis proposal. Under the supervision of Dr. McBride at the University of Lethbridge, I am designing a study to gain the perspectives of those living with chronic illness to inform group counselling. I am interested to know how illness identity plays a role in these perspectives. The articles you have published intrigued me because of their implications for clinical practice. I was hoping you might be willing to grant me permission to use the Illness Identity Questionnaire as part of my survey. I recently attempted to contact Leen Oris regarding this questionnaire, but I was unable to reach her through the email address provided on the illness identity articles.

Under the careful supervision of Dr. McBride, I would be sure to give you and your research team's meaningful work the credit it deserves. With ethics approval, I would also be more than willing to share my results with you following the completion of my study. I plan to defend my thesis in the summer of 2022. If I receive your permission to use your questionnaire, I will include your permission in my ethics application and thesis, but I will remove any personal information other than your name.

I look forward to hearing your thoughts.

With sincerity,

Dalaine Kubik

(she/her)

M.Ed. Counselling Psychology Student

Education Representative, GSA Council

University of Lethbridge

Permission to adapt Illness Identity Questionnaire (IIQ)

October 11, 2021

Re: Request for Permission to use the Illness Identity Questionnaire (IIQ)

From: Koen Luyckx [REDACTED]
Sent: Monday, October 11, 2021 2:32 PM
To: Kubik, Dalaine [REDACTED]
Cc: McBride, Dawn [REDACTED]
Subject: RE: Request for Permission to use the Illness Identity Questionnaire (IIQ)

Caution: This email was sent from someone **outside of the University of Lethbridge**. Do not click on links or open attachments unless you know they are safe. Suspicious emails should be forwarded to phishing@uleth.ca.

Dear Dalaine,

This is of course fine for me
Good luck with your research,
Koen

From: Kubik, Dalaine [REDACTED]
Sent: Monday, October 11, 2021 9:49 PM
To: Koen Luyckx [REDACTED]
Cc: McBride, Dawn [REDACTED]
Subject: Re: Request for Permission to use the Illness Identity Questionnaire (IIQ)

Hello Dr. Luyckx,

Thank you once again for your permission to use the Illness Identity Questionnaire in my thesis project.

I was hoping you might be willing to grant me permission to adapt the wording of the IIQ questions to better fit my research. This would involve replacing the term "illness" with "chronic condition."

If I receive your permission to adapt your questionnaire, I will include your permission in my ethics application and thesis, but I will be sure to remove any personal information other than your time.

I look forward to hearing from you.

Take care,

Dalaine Kubik

*Permission to adapt Support Group Perceptions Questionnaire (Sherman et al., 2007)
October 21, 2021*

Re: Request to Adapt Questionnaire

From: Sherman, Allen C [REDACTED]
Sent: Thursday, October 21, 2021 9:14 AM
To: Kubik, Dalaine [REDACTED] McBride, Dawn [REDACTED]
Subject: RE: Request to Adapt Questionnaire

Caution: This email was sent from someone **outside of the University of Lethbridge**. Do not click on links or open attachments unless you know they are safe. Suspicious emails should be forwarded to phishing@uleth.ca.

Hi Dalaine. Goodness, thought I had responded, my apologies. Yes indeed, feel free to make whatever modifications seem useful. Will look forward to hearing about your experience.

As a minor aside, the name of the measure was the "Support Group Perceptions Questionnaire." (The title on the document provided to patients was simply a placeholder, to help us distinguish the patient version from the family caregiver version.)

Good luck with the data collection.

Allen

Allen C. Sherman, Ph.D.
Chair, UAMS Institutional Review Board
Associate Editor, *Head & Neck*
Director, Behavioral Medicine
Professor, Otolaryngology
Winthrop P. Rockefeller Cancer Institute
University of Arkansas for Medical Sciences

From: Kubik, Dalaine [REDACTED]
Sent: Tuesday, October 5, 2021 2:03 PM
To: Sherman, Allen C [REDACTED] McBride, Dawn [REDACTED]
Subject: Request to Adapt Questionnaire

Hello Dr. Sherman,

I hope all is well with you.

Thank you once again for sending me your Support Group Survey for Patients questionnaire. Your survey has turned out to be very relevant to my topic. There are very few studies like the one you conducted, and I truly believe your work is invaluable to this body of knowledge.

I am emailing you to request your permission to adapt some of your survey questions for my thesis. As mentioned in our previous correspondence, with ethics approval, I would be happy to share my results with you following the completion of my study. I plan to defend my thesis in the summer of 2022. I have included my supervisor, Dr. Dawn McBride, as a recipient of this email.

If I receive your permission to adapt your survey questions, I will include your permission in my ethics application and thesis, but I will remove any personal information other than your name.

I look forward to receiving your response.

Sincerely,

Dalaine Kubik

(she/her)
M.Ed. Counselling Psychology Student
Education Representative, GSA Council
University of Lethbridge

Permission to share survey: Chronic Illness Support (Facebook)

October 10, 2021

The screenshot shows a Facebook Messenger chat window. At the top left is a profile picture of Jessica [redacted] and the name Jessica [redacted]. At the top right are icons for voice call, video call, and information. The chat history shows a message from Dalaine at 10:59 AM. The message is in a blue bubble and contains the following text: "Hello Jessica! I hope you are well. I messaged Kathleen too, but she hasn't had a chance to open my message yet, so I thought I would try you as well. My name is Dalaine, and I have been a member of Chronic Illness Support for a little while now. While I have not made posts of my own, reading others' posts and seeing the support in the comments sections has been really helpful to me. I often don't feel like I am 'sick enough' to contribute to these groups, but I want you to know that this community has still made a big difference for me. I am a Counselling Psychology Master's student, and because of my personal experiences, I am really passionate about improving mental health care for people with chronic illness. I decided to channel this passion into my thesis project by designing a survey that will help mental health professionals better understand what people with chronic illness actually want from group therapy. Not a lot of research asks for the firsthand perspectives of people with chronic illness, so I am hoping it will make a difference for the way group therapists adapt their programs for our needs. I was hoping you might be willing to allow me to include the survey link in a post that invites people in this support group to participate. The survey will be ready to go within the next few months, and I think the members of this group would have some great perspectives to contribute. If I receive your permission to make the post, I would include your permission in my ethics proposal and thesis, but I will be sure to remove any private information beyond your first name. Please let me know what you think 😊". Below this is a response from Jessica at 2:24 PM: "Hi Lainey! I'm so happy you're enjoying the group. You're welcome to post anytime you like." followed by another message from Jessica: "I spoke with Heather, we are ok with allowing these occasionally. We just ask that you limit it to one post as not to spam." A system message follows: "You can now message and call each other and see info like Active Status and when you've read messages." At 2:43 PM, Dalaine replies: "Perfect, thank you so much! I really appreciate it 😊". Jessica replies: "You're welcome 😊". At the bottom is the input field with icons for attachments, emojis, and text input.

Admins and Moderators: Chronic Illness Support (October 10, 2021)

The screenshot shows the Facebook group page for "Chronic Illness Support". At the top, there is a group profile picture, the name "Chronic Illness Support", and buttons for "Joined", "Invite", "Search", and "More". Below this is the "Admins & Moderators - 4" section. It lists four individuals: Jessica [redacted] (Admin) with an "Add Friend" button; Heather [redacted] (Admin) with an "Add Friend" button; Broken but Beautiful (Admin) with a "Liked" button and a note "Personal Blog · 1,141 people like this"; and Kathleen [redacted] (Moderator) with an "Add Friend" button.

*Permission to share survey: Coping with Chronic Illness and Chronic Pain (Facebook)
October 10, 2021*

A screenshot of a Facebook private message conversation. At the top, the sender is identified as 'Traci' with a profile picture and the text 'Active 17m ago'. The message is timestamped 'Thu 3:58 PM'. The message content is as follows:

Hello Traci! I hope you are well.

My name is Dalaine, and I have been a member of Coping with Chronic Illness and Chronic Pain for a little while now. While I have not made posts of my own, reading others' posts and seeing the support in the comments sections has been really helpful to me. I often don't feel like I am "sick enough" to contribute to these groups, but I want you to know that this community has still made a big difference for me.

I am a Counselling Psychology Master's student, and because of my personal experiences, I am really passionate about improving mental health care for people with chronic illness. I decided to channel this passion into my thesis project by designing a survey that will help mental health professionals better understand what people with chronic illness actually want from group therapy. Not a lot of research asks for the firsthand perspectives of people with chronic illness, so I am hoping it will make a difference for the way group therapists adapt their programs for our needs.

I was hoping you might be willing to allow me to include the survey link in a post that invites people in this support group to participate. The survey will be ready to go within the next few months, and I think the members of this group would have some great perspectives to contribute. If I receive your permission to make the post, I would include your permission in my ethics proposal and thesis, but I will be sure to remove any private information beyond your first name.

Please let me know what you think 😊

The message is timestamped '6:46 PM'. Below the message, there are two system messages:

You may post the link to your survey once in the comments section below the announcement that is pinned to the top of the page.

You can now message and call each other and see info like Active Status and when you've read messages.

Advertising another group is not permitted at all.

The second system message is timestamped '7:20 PM'. At the bottom right, there is a response from the sender: 'That's great! Thank you for letting me know 😊'. The bottom of the screenshot shows the Facebook messaging interface with icons for adding attachments, voice recording, GIFs, and a text input field containing 'Aa'.

Admins and Moderators: Coping with Chronic Illness & Chronic Pain (October 10, 2021)

A screenshot of the Facebook group 'Coping with Chronic Illness and Chronic Pain'. The group name is at the top left, and the status 'Joined' is at the top right. Below the group name, there is a list of 'Admins & Moderators - 3'. The list includes three members:

- Rhonda [redacted] Admin
- Traci [redacted] Admin
- Britani [redacted]

Next to the names of Traci and Britani, there are 'Add Friend' buttons. The group name 'Coping with Chronic Illness and Chronic Pain' is also visible in the top left corner of the screenshot.

*Permission to share survey: Science-Based Chronic Illness Support (Facebook)
October 10, 2021*

Shannon [redacted]

Sun 11:02 AM

Hello Shannon! I hope you are well. I messaged Tovara too, but she has not had a chance to open my message yet, so I thought I would try reaching out to you as well.

My name is Dalaine, and I have been a member of Science-Based Chronic Illness Support for a little while now. While I have not made posts of my own, reading others' posts and seeing the scientific discussions has been really helpful for me. I often don't feel like I am "sick enough" to contribute to these groups, but I want you to know that this community has still made a big difference for me.

I am a Counselling Psychology Master's student, and because of my personal experiences, I am really passionate about improving mental health care for people with chronic illness. I decided to channel this passion into my thesis project by designing a survey that will help mental health professionals better understand what people with chronic illness actually want from group therapy. Not a lot of research asks for the firsthand perspectives of people with chronic illness, so I am hoping it will make a difference for the way group therapists adapt their programs for our needs.

I was hoping you might be willing to allow me to include the survey link in a post that invites people in this support group to participate. The survey will be ready to go within the next few months, and I think the members of this group would have some great perspectives to contribute. If I receive your permission to make the post, I would include your permission in my ethics proposal and thesis, but I will be sure to remove any private information beyond your first name.

Please let me know what you think 😊

Sun 9:06 PM

Hi, Lainey. Thank you for your message! I am glad that you find the group helpful. Please don't feel like you aren't "sick enough" to post This isn't a competition. I want everyone to feel comfortable to seek advice, help, knowledge, or even just a place to vent.

You can now message and call each other and see info like Active Status and when you've read messages.

You can certainly post the survey in the group When you do, I will also post and encourage people to participate. I'll be interested to see it! Take care, Shannon

Sun 9:27 PM

Thank you so much 😊 I really appreciate it!

Admins and Moderators: Science-Based Chronic Illness Support (October 10, 2021)

Science-Based Chronic Illness Support

Joined | + Invite | Search | More

Admins & Moderators · 2

- Tovara [redacted] Admin Add Friend
- Shannon [redacted] Admin Add Friend

Survey Sharing Groups

LinkedIn:



POST YOUR SURVEY HERE

Very soon you'll find more survey participants.

Survey Exchange – Find participants for research studies (for dissertation, thesis, market research)

Listed group

About this group

Description

An international group for students, PhD candidates, researchers, startups, founders and all others who need participants for their empirical studies (online surveys, online experiments, research studies, market research, questionnaires). The group is meant to encourage mutual support among its members so that everyone gets a chance to find more respondents and get a larger sample size for their study. Everyone is welcome to join, all languages are welcome!

Facebook:

Survey Exchange / Survey Group / Survey Participants - Dissertation, Thesis

Public group · 11.4K members

Joined



+ Invite



About

Discussion

Announcements

Topics

Members

Events

Media

Files



About This Group

A group to act as a subject pool for research projects, especially for students and PhD students. The group may also serve as a database for a wider range of people who are willing to participate in current or future research and may serve as an outlet for students anywhere to advertise for participants, or post links to their online surveys. If you are a willing participant, or budding researcher in any discipline, feel free to join! :)

If you need a larger and more diverse participant pool, feel free to join SurveyCircle at www.surveycircle.com. It's free and based on the concept of mutual support, too. [See Less](#)



Public

Anyone can see who's in the group and what they post.



Visible

Anyone can find this group.



General

Facebook:

Research Participation - Dissertation, Thesis, PhD, Survey Sharing

Private group · 37.3K members



Joined



+ Invite



About Discussion Announcements Topics Members Events Media Files



About This Group

You are visiting this Group or have joined this group because you are interested in Psychology Research. Either you are a researcher, or have conducted a research earlier, or you are just interested to know about researches and get information about how psychologists understand human behavior. This group serves both these purposes. This Group is for Research-minded individuals.

The group has following purposes:

1) It is an opportunity for all Researchers out there.

--- Sometimes it becomes difficult to get the participants for a research. That may be due to a big sample, due to non-availability of enough friends and acquaintances, or may be due to inclusion/exclusion criteria required by the researcher. Moreover, research needs to be done in time for which participants are required urgently.

Therefore, a common platform is needed where researchers can get participants who are willing to participate in their researches. For this purpose, this group has been created to aid researchers in getting the participants for their projects.

Another benefit for researchers is that they can interact with each other and provide suggestions to others. They can discuss their projects too. They can share research articles and questionnaires too.

2) Not only researchers, this group is for Participants too.

--- That means, you can join this group even if you want to become a participant only. Only a researcher in psychology knows the importance of a participant. So if you have done a research before, or are going to do it in near future, or have never done a research earlier, and want to help others in their projects, you can join the group and participate in as many researches as you want.

There is a benefit in becoming a participant. You can get yourself assessed on various factors through researchers. Since you will get an opportunity to fill several questionnaires and do many tasks, you can get the results from researchers about your performance. So there is an opportunity to know yourself better. You can ask for some useful material in return of your participation too.

3) The group is for those who like to know and discuss about researches. Psychology researches inform us about human behavior. Anyone would be interested to know about their own behaviors and how humans behave generally. For this, information should be gathered with empirical basis, as such data would provide a neutral view of behavior. So its an aim of this group to increase our knowledge about what researches have found out how humans behave. One can discuss with other members about various findings.

ALL THE BEST to all the Researchers and Participants. Join the group and maximize your sample size. Help others in their research projects. Discuss and share anything related to Psychology Research. In case you need survey participants from outside the group, feel free to check out the research website SurveyCircle at www.surveycircle.com. **See Less**



Private

Only members can see who's in the group and what they post.



Visible

Anyone can find this group.

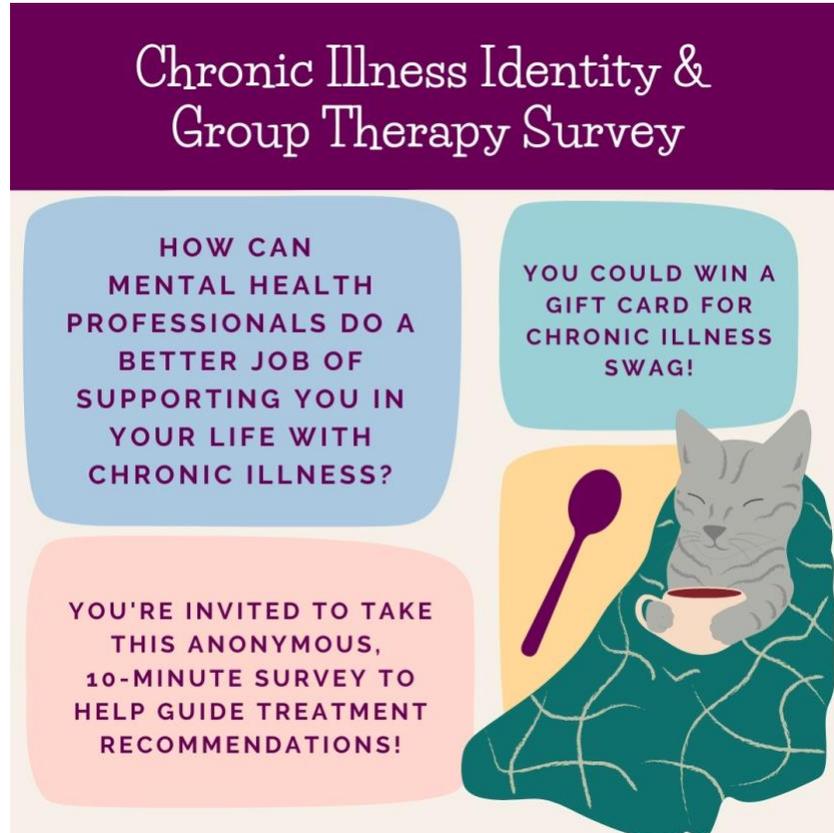


General

Appendix C: Survey Invitations

Survey Invitation Graphic

This graphic was included in all survey invitation posts to draw attention to the invitation.



Note. This figure was created by D. Kubik (2021) using Canva for Education. (kristinachistiakova, n.d.-a; Slidesignus, n.d.)

Survey Invitation: Chronic Illness Support (Facebook)

This invitation was posted once (with the invitation graphic) on the main discussion feed for this group.

Hello fellow humans! 🙋😊 As we all know, chronic illness impacts so much more than just our physical health. As I pursue a career in counselling psychology, I am advocating for more opportunities for mental health support for people living with chronic illness!

For my master's thesis, I have created an anonymous, 10-minute survey that will help inform mental health professionals how they can better support people living with chronic illness. If you are living with a chronic health condition, you are invited to take part in this survey to share your perspectives on chronic illness and group therapy!

Are you interested in participating in my study? Follow this link for more information 😊
https://uleth.qualtrics.com/jfe/form/SV_dbxDZo237aID1Hw

To thank you for participating, you will have the option to enter a draw to WIN one of two \$50 gift cards for some awesome chronic illness swag from the Unchargeables Shop! 😊 (www.theunchargeablesshop.com)

Survey Invitation: Coping with Chronic Illness and Chronic Pain (Facebook)

This invitation was posted once (with the invitation graphic) on the pinned comment thread dedicated to survey sharing.

Hello fellow humans! 🙋😊 As we all know, chronic illness impacts so much more than just our physical health. As I pursue a career in counselling psychology, I am advocating for more opportunities for mental health support for people living with chronic illness!

For my master's thesis, I have created an anonymous, 10-minute survey that will help inform mental health professionals how they can better support people living with chronic illness. If you are living with a chronic health condition, you are invited to take part in this survey to share your perspectives on chronic illness and group therapy!

Are you interested in participating in my study? Follow this link for more information 😊
https://uleth.qualtrics.com/jfe/form/SV_dbxDZo237aID1Hw

To thank you for participating, you will have the option to enter a draw to WIN one of two \$50 gift cards for some awesome chronic illness swag from the Unchargeables Shop! 😊 (www.theunchargeablesshop.com)

Survey Invitation: Science-Based Chronic Illness Support (Facebook)

This invitation was posted once (with the invitation graphic) on the main discussion feed for this group.

Hello everyone! 🙋😊 As we all know, chronic illness impacts so much more than just our physical health. As I pursue a career in counselling psychology, I am advocating for more opportunities for mental health support for people living with chronic illness!

For my master's thesis, I have created an anonymous, 10-minute survey that will help inform mental health professionals how they can better support people living with chronic illness. If you are living with a chronic health condition, you are invited to take part in this survey to share your perspectives on chronic illness and group therapy!

To thank you for participating, you will have the option to enter a draw to WIN one of two \$50 gift cards for some awesome chronic illness swag from the Unchargeables Shop! 🎁
(www.theunchargeablesshop.com)

Are you interested in participating in my study? Follow this link for more information 😊
https://uleth.qualtrics.com/jfe/form/SV_dbxDZo237aID1Hw

Survey Invitation: Survey Sharing Groups (Facebook and LinkedIn)

This invitation was posted (with the invitation graphic) once on the main discussion feeds for these groups.

Do you have a chronic health condition? Me too! As we know, chronic illness impacts so much more than just our physical health.

For my master's thesis, I have created an anonymous, 10-minute survey that will help inform mental health professionals how they can better support people living with chronic illness. If you are living with a chronic health condition, you are invited to take part in this survey to share your perspectives on chronic illness and group therapy!

Are you interested in participating in my study? Follow this link for more information 😊
https://uleth.qualtrics.com/jfe/form/SV_dbxDZo237aID1Hw

To thank you for participating, you will have the option to enter a draw to WIN one of two \$50 gift cards for some awesome chronic illness swag from the Unchargeables Shop! 😊 (www.theunchargeablesshop.com)

Survey Invitation: Personal Social Media Pages

This invitation was posted (with the invitation graphic) once at the beginning of data collection and once every two or three weeks until data collection was completed.

Facebook, Instagram, and LinkedIn Pages:

Hello everyone! 😊 I am pursuing my master's degree in Counselling Psychology, and my personal experiences with chronic illness have inspired me to advocate for opportunities for mental health support for people living with chronic health conditions.

For my master's thesis, I have created an anonymous, 10-minute survey that will help inform mental health professionals how they can better support people living with chronic illness. Anyone living with a chronic health condition (or chronic symptoms) is invited to take part in this survey to share their perspectives on chronic illness and group therapy! No diagnosis is required!

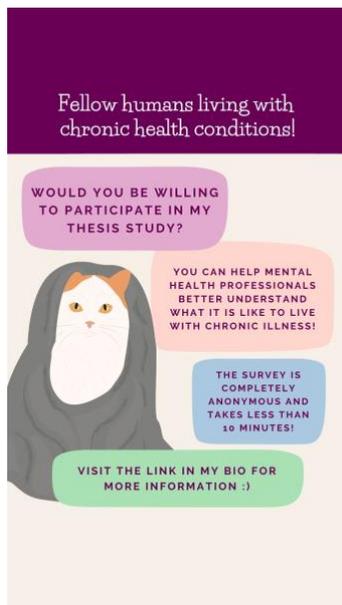
If you or someone you know might be interested in participating in my study, follow/share this link for more information and to participate 😊
https://uleth.qualtrics.com/jfe/form/SV_dbxDZo237aID1Hw

To thank them for their time, participants will have the option to enter a draw to WIN one of two \$50 gift cards for some awesome chronic illness swag from the Unchargeables Shop! 😊
www.theunchargeables.com

Thank you in advance for your support 😊

Instagram Story:

Slide 1



Slide 2



Note. Graphics created by D. Kubik (2021) using Canva for Education. (kristinachistiakova, n.d.-a; kristinachistiakova, n.d.-b; Slidesignus, n.d.)

Appendix D: Informed Consent

Chronic Illness Identity & Group Therapy Preferences Survey

(This survey will be available until February 25, 2022)

How can mental health professionals do a better job of supporting you - a person living with chronic illness?

Your participation will help guide treatment recommendations! 😊

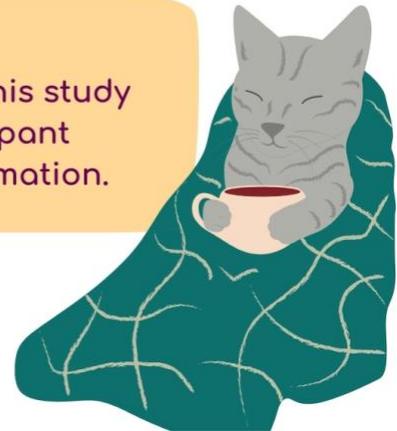
It is an anonymous survey that will take you about 10 minutes!

To say thank you for your input, you could WIN one of two \$50 GIFT CARDS to The Unchargeables Shop! (www.theunchargeablesshop.com)

Are you interested?

If so, please learn more about this study and your rights as a participant by reading the following information.

~ Dalaine 😊



Note. This graphic was created by D. Kubik (2021) using Canva for Education. (kristinachistiakova, n.d.-a; kristinachistiakova, n.d.-b)

SEEKING RESEARCH PARTICIPANTS **LIVING WITH CHRONIC ILLNESS**

(Chronic illness from any chronic physical health condition – no diagnosis is needed)

What is this research study about?

This study, which has been approved by the University of Lethbridge Human Participant Research Committee, is about learning from those with chronic health conditions how their illness has impacted their identity and their views about group therapy.

Who can participate in this research study?

Anyone **18 years of age or older** living with **chronic physical illness** (any chronic physical health condition(s); **no diagnosis is required**).

Chronic illness includes, but is not limited to: *chronic pain* (e.g., fibromyalgia, migraine), *joint and bone disorders* (e.g., arthritis, osteoporosis), *autoimmune diseases* (e.g., lupus, celiac disease), *respiratory conditions* (e.g., asthma, COPD), *gastrointestinal diseases* (e.g., Crohn's disease, IBS), *gynecological conditions* (e.g., endometriosis, PCOS), *hormonal disorders* (e.g., hyper/hypothyroidism), *nervous system disorders* (e.g., POTS, epilepsy), and/or *cardiovascular diseases* (e.g., congenital heart disease).

What will be expected of me if I participate?

Complete an online, anonymous (approximately) 10-minute survey. Your responses will be given in multiple-choice format and will require very little typing (with the option to elaborate upon some of your answers if you desire).

Will I win a gift card if I participate in this study?

Maybe – as you will be given the option to enter your email into a draw to win one of two gift cards if you click on the submit button of the survey. The gift cards are good to use at **The Unchargeables Shop** – an online community that raises awareness for chronic illness through apparel, stickers, homeware, and more! (www.theunchargeables.com)

FYI: *Your email address will not be associated with your survey responses. The odds of winning the draw are approximately 1 in 100 (depending on the number of survey participants).*

Are you someone with a chronic health condition who is interested in participating in this study?

If so, thank you!

The first thing is to learn about your rights and details about the research study. If you remain keen to participate, then you will be given access to my research survey 😊



Chronic Illness Identity & Group Therapy Preferences Survey

CONSENT FORM

If you would like to download a copy of this consent form, please **[CLICK HERE!](#)**

Title of the study: Illness Identity and Preferences for Group Therapy in Adults with Chronic Illness

Principal Investigator: Dalaine Kubik
M.Ed. (Counselling Psychology) Thesis Student
Faculty of Education
University of Lethbridge
Lethbridge, AB
laine.kubik@uleth.ca

Supervisor: Dr. Dawn McBride, Ph.D., R.Psych.
Professor
Faculty of Education
University of Lethbridge
Lethbridge, AB
dawn.mcbride@uleth.ca
403-317-2877

Thesis Committee: Dr. Thelma Gunn, Ph.D.
Professor
Faculty of Education
University of Lethbridge
Lethbridge, AB

Dr. Lisa Howard, Ph.D.
Professor
Faculty of Health Sciences
University of Lethbridge
Lethbridge, AB

Invitation to Participate: Anyone 18 years of age or older living with chronic physical illness is invited to participate in this study (*any* chronic physical health condition(s); no diagnosis is required).

Chronic illness includes, but is not limited to: *chronic pain* (e.g., fibromyalgia, migraine), *joint and bone disorders* (e.g., arthritis, osteoporosis), *autoimmune diseases* (e.g., lupus, celiac disease), *respiratory conditions* (e.g., asthma, COPD), *gastrointestinal diseases* (e.g., Crohn's disease, IBS), *gynecological conditions* (e.g., endometriosis, PCOS), *hormonal disorders* (e.g., hyper/hypothyroidism), *nervous system disorders* (e.g., POTS, epilepsy), and/or *cardiovascular diseases* (e.g., congenital heart disease).

Purpose of the Study: To learn from those with chronic health conditions how their illness has impacted their identity and their views about group therapy. This study is being conducted in partial fulfillment of the principal investigator's master's thesis.

Participation: If you wish to participate in this study, please complete the anonymous survey. The survey should take you approximately 10 minutes to complete. You do not have to answer any questions that you do not want to answer. Once you have completed the survey, please submit your responses. This survey will be available until February 25, 2022.

Benefits: You will have the opportunity to reflect on your relationship with chronic illness and your current mental health. In addition, you will have the ability to add your voice and opinions to the mental health community to inform treatment practices.

Risks: Although the survey questions are not expected to cause any emotional distress, it is possible that reflecting on your experiences with chronic illness could bring up strong emotions. You are welcome to skip questions or stop completing the survey at any time. If you experience emotional distress as a result of completing this survey, please reach out to someone you trust or one of the services in your area that provide support in difficult times. If you are in need of mental health support, follow this link to find resources near you: <https://checkpointorg.com/global/>

Confidentiality and Anonymity: No specific direct identifying information associated with your responses will be collected. However, as with any online survey, complete protection of privacy cannot be guaranteed due to the risk of unauthorized third-party access. Only the researcher, supervisor, committee members, and consultants involved in this study will have access to the raw data collected in this survey. Once you complete the survey, you will be given the option to provide your email address to be entered into an anonymous draw. Your response to this optional question is not tied to the responses you provided earlier in the survey. The email address you provide will be used for the sole purpose of contacting you if you are one of the winners of the raffle. All records containing email addresses will be destroyed once the raffle is complete (on or before September 25, 2022). This survey is being hosted on Qualtrics, and their privacy policy can be found at: <https://www.qualtrics.com/privacy-statement/>

Data Usage: Only anonymous data will be used in the principal investigator's Master of Education (Counselling Psychology) Thesis. Anonymous, aggregate data will also be used in articles in journals and professional publications; presentations at scholarly meetings, professional conferences, and during counsellor training workshops; and future studies involving the principal investigator.

Data Storage: The data collected in this study will be stored on an encrypted external hard drive. Only the researcher, supervisor, committee members, and consultants involved in this study will have access to the raw data collected. When not in use by one of the researchers involved in this study (see list below), the encrypted external hard drive will be kept in a locked filing cabinet within a private office. The encrypted external hard drive will be kept for a period of 7 years. After this time, the files will be deleted, and the external hard drive will be cleared of any study data.

Compensation: As a token of appreciation for your time, you will be given the option to enter your email into a draw to win one of two gift cards if you click on the submit button of the survey. The gift cards are good to use at The Unchargeables Shop – an online community that raises awareness for chronic illness through apparel, stickers, homeware, and more! (www.theunchargeables.com). Your email address will not be associated with your survey responses. The odds of winning the draw are approximately 1 in 100 (depending on the number of survey participants).

Voluntary Participation: Participation in this study is voluntary. You are under no obligation to participate, and if you choose to participate, you may refuse to answer questions that you do not want to answer. Should you choose to withdraw midway through the study, simply close your browser and no responses will be included. Given the anonymous nature of the survey once you have submitted your responses it will no longer be possible to withdraw them from the study.

Information about the Study Results: For a summary of the results (available September 2022), please visit the thesis supervisor's website (<https://www.dawn-mcbride.com/>) within one year of completing the survey to download.

Contact Information: If you have any questions or require more information about the study itself, you may contact the principal investigator or the supervisor using the contact information provided above.

The Plan for this study has been reviewed by a Research Ethics Board at the University of Alberta. If you have any questions regarding your rights as a research participant or how the research is being conducted, you may contact the Research Ethics Office at 780-492-2615.

Please download and/print this form to keep for your records.

Completion and submission of the survey means your consent to participate.

By participating in this survey, you can help therapists learn how to best support people with chronic illness!

Do you want to participate in this study?

Please click on the response that best represents your answer:

- I agree.** I understand my rights and the purpose of the study. I am willing to help therapists learn more about working with chronic health conditions 😊 I know that I can stop the study at **any time**, and I attest that I am **at least 18 years old**. (This answer will give you access to the research survey)
- No, thank you.** I do not wish to participate in this study. (This answer will automatically close this browser)

Display this question if “Do you want to participate in this study?” – I agree is selected

Do you identify as someone living with chronic physical illness or a chronic physical health condition?

- Yes, I am living with chronic physical illness or a chronic health condition.
- No, I do not have chronic physical illness or a chronic health condition.

Appendix E: Survey

Q1

Welcome to the survey! 😊

Chronic illness involves physical symptoms that may come and go but are part of your life for at least six months.
Diagnosed = formally by a healthcare professional
Undiagnosed = no diagnosis, seeking a diagnosis, or unknown cause

Please list and describe the chronic physical health condition(s) you experience. If you do not have a diagnosis/label for your condition(s), you may choose to list the symptoms you experience.

Example:

1. My condition(s):	2. Is this condition currently <i>diagnosed</i> or <i>undiagnosed</i> ?		3. How long have you experienced this condition? (in years)	4. On a scale of 1-5, how well are you coping with this condition?
	Diagnosed	Undiagnosed		
Lupus	<input checked="" type="radio"/>	<input type="radio"/>	10-15 years	4 - Good
Stomach Pains	<input type="radio"/>	<input checked="" type="radio"/>	6 months - 1 year	2 - Poor
Migraines	<input checked="" type="radio"/>	<input type="radio"/>	2-5 years	3 - Acceptable

Dropdown lists

3.

- 6 months - 1 year
- 1-2 years
- 2-5 years
- 5-10 years
- 10-15 years
- 15-20 years
- 20-25 years
- 25-30 years
- 30-35 years
- 35-40 years
- 40-45 years
- 45-50 years
- 50+ years

4.

- 5 - Extremely well
- 4 - Quite well
- 3 - Acceptable
- 2 - Poorly
- 1 - Very poorly

1. My condition(s):	2. Is this condition currently <i>diagnosed</i> or <i>undiagnosed</i> ?		3. How long have you experienced this condition? (in years)	4. On a scale of 1-5, how well are you coping with this condition?
	Diagnosed	Undiagnosed		
<input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input style="width: 50px; border: 1px solid black; font-size: 8px; text-align: right; padding: 2px 5px;" type="text"/> v	<input style="width: 50px; border: 1px solid black; font-size: 8px; text-align: right; padding: 2px 5px;" type="text"/> v
<input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input style="width: 50px; border: 1px solid black; font-size: 8px; text-align: right; padding: 2px 5px;" type="text"/> v	<input style="width: 50px; border: 1px solid black; font-size: 8px; text-align: right; padding: 2px 5px;" type="text"/> v
<input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input style="width: 50px; border: 1px solid black; font-size: 8px; text-align: right; padding: 2px 5px;" type="text"/> v	<input style="width: 50px; border: 1px solid black; font-size: 8px; text-align: right; padding: 2px 5px;" type="text"/> v
<input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input style="width: 50px; border: 1px solid black; font-size: 8px; text-align: right; padding: 2px 5px;" type="text"/> v	<input style="width: 50px; border: 1px solid black; font-size: 8px; text-align: right; padding: 2px 5px;" type="text"/> v
<input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input style="width: 50px; border: 1px solid black; font-size: 8px; text-align: right; padding: 2px 5px;" type="text"/> v	<input style="width: 50px; border: 1px solid black; font-size: 8px; text-align: right; padding: 2px 5px;" type="text"/> v
<input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input style="width: 50px; border: 1px solid black; font-size: 8px; text-align: right; padding: 2px 5px;" type="text"/> v	<input style="width: 50px; border: 1px solid black; font-size: 8px; text-align: right; padding: 2px 5px;" type="text"/> v
<input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input style="width: 50px; border: 1px solid black; font-size: 8px; text-align: right; padding: 2px 5px;" type="text"/> v	<input style="width: 50px; border: 1px solid black; font-size: 8px; text-align: right; padding: 2px 5px;" type="text"/> v
<input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input style="width: 50px; border: 1px solid black; font-size: 8px; text-align: right; padding: 2px 5px;" type="text"/> v	<input style="width: 50px; border: 1px solid black; font-size: 8px; text-align: right; padding: 2px 5px;" type="text"/> v
<input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input style="width: 50px; border: 1px solid black; font-size: 8px; text-align: right; padding: 2px 5px;" type="text"/> v	<input style="width: 50px; border: 1px solid black; font-size: 8px; text-align: right; padding: 2px 5px;" type="text"/> v
<input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input style="width: 50px; border: 1px solid black; font-size: 8px; text-align: right; padding: 2px 5px;" type="text"/> v	<input style="width: 50px; border: 1px solid black; font-size: 8px; text-align: right; padding: 2px 5px;" type="text"/> v
<input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input style="width: 50px; border: 1px solid black; font-size: 8px; text-align: right; padding: 2px 5px;" type="text"/> v	<input style="width: 50px; border: 1px solid black; font-size: 8px; text-align: right; padding: 2px 5px;" type="text"/> v
<input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input style="width: 50px; border: 1px solid black; font-size: 8px; text-align: right; padding: 2px 5px;" type="text"/> v	<input style="width: 50px; border: 1px solid black; font-size: 8px; text-align: right; padding: 2px 5px;" type="text"/> v
<input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input style="width: 50px; border: 1px solid black; font-size: 8px; text-align: right; padding: 2px 5px;" type="text"/> v	<input style="width: 50px; border: 1px solid black; font-size: 8px; text-align: right; padding: 2px 5px;" type="text"/> v

Q2

Out of these four images, which one best describes your experience with chronic illness overall in the past month?

A I refuse to accept my chronic condition(s).

 I am not connected with my condition(s).

 I avoid talking to others about my condition(s).

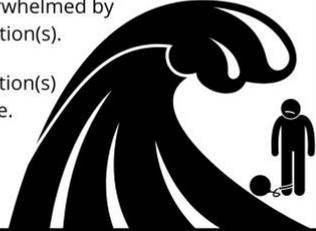
I don't always follow my treatment plan.

B My life is dominated by my chronic condition(s).

Because of my condition(s), I cannot enjoy life.

I am overwhelmed by my condition(s).

My condition(s) define me.



C I accept my chronic condition(s) as part of me.

I do not feel overwhelmed by my condition(s).

I can live my life despite my condition(s).

I feel confident about managing my condition(s).



D I am a better person because of my chronic condition(s).

I view myself more positively because of my condition(s).

My life has been positively impacted by my condition(s).

I appreciate life more because of my condition(s).



Q3

Out of the chronic conditions you experience, which one affects your life the most?

Q4

Please feel free to explain your choice 😊

Q5

Of the supports listed below, please select the ones you believe would be helpful for improving your mental/emotional wellbeing. (Assume all the services are offered at no cost and there is no waiting time to access each service)

- Individual therapy in person** (meeting one-on-one to talk with a mental health professional)
- Individual therapy online** (meeting one-on-one to talk with a mental health professional through an online video platform, e.g., Zoom)
- Group therapy in person** (meeting face-to-face *in person* with others who have chronic illness, led by a professional)
- Group therapy online** (meeting face-to-face with others who have chronic illness, led by a professional on an online video platform such as Zoom)
- Peer support group** where there is no leader, or if there was a leader, it would be someone who also has chronic illness (e.g., Facebook support group)
- Physician** (family doctor)
- Medication to treat mental/emotional wellbeing**
- Alternative holistic approaches** (e.g., yoga, meditation, acupuncture)
- Creative expressive arts therapy** (e.g., art therapy, music therapy)
- Other** services that would help you improve your mental/emotional wellbeing (please be as specific as you can, thank you):

- I would not seek support to enhance my mental/emotional wellbeing.**

Q6

Group therapy is usually led by therapists who share little about themselves, as the focus is to have the group members share and learn from each other. Groups are designed to enhance one's quality of life by learning new skills, knowing they are not alone, and expanding their coping skills.

Assume you are interested in attending group therapy for chronic illness. To what degree do you believe these topics would be helpful if you chose to attend group therapy?

	Very helpful	Somewhat helpful	Slightly helpful	Not at all helpful	I'm not sure
Receiving medical education about my illness/treatment.	<input type="radio"/>				
Receiving emotional support for chronic illness.	<input type="radio"/>				
Discussing topics that do not directly relate to chronic illness. (e.g., how to improve self-esteem)	<input type="radio"/>				
Discussing coping skills for dealing with chronic illness.	<input type="radio"/>				
Being given information to support my wellness. (e.g., nutrition, stress management, exercise)	<input type="radio"/>				
Learning how to understand my emotions.	<input type="radio"/>				
Discussing existential topics. (e.g., life's purpose/meaning, death/mortality, spirituality)	<input type="radio"/>				

Q7

This question includes statements about chronic conditions. Please think about the chronic condition that affects your life the most when you answer the statements in these four questions 😊

How much do you agree or disagree with these statements?

	Strongly agree	Somewhat agree	Somewhat disagree	Strongly disagree	Neither agree nor disagree
I refuse to see my chronic condition as part of myself.	<input type="radio"/>				
I'd rather not think of my chronic condition.	<input type="radio"/>				
I hate being talked to about my chronic condition.	<input type="radio"/>				
I never talk to others about my chronic condition.	<input type="radio"/>				
I just avoid thinking about my chronic condition.	<input type="radio"/>				
My chronic condition simply belongs to me as a person.	<input type="radio"/>				
My chronic condition is part of who I am.	<input type="radio"/>				
I accept being a person with a chronic condition.	<input type="radio"/>				
I am able to place my chronic condition in my life.	<input type="radio"/>				

I have learned to accept the limitations imposed by my chronic condition.

My chronic condition dominates my life.

My chronic condition has a strong impact on how I see myself.

I am preoccupied with my chronic condition.

My chronic condition influences all my thoughts and feelings.

My chronic condition completely consumes me.

It seems as if everything I do is influenced by my chronic condition.

My chronic condition prevents me from doing what I would really like to do.

My chronic condition limits me in many things that are important to me.

Because of my chronic condition, I have grown as a person.

Because of my chronic condition, I know what I want out of life.

Because of my chronic condition, I have become a stronger person.

Because of my chronic condition, I realize what is really important in life.

Because of my chronic condition, I have learned a lot about myself.

Because of my chronic condition, I have learned to work through problems and not just give up.

Because of my chronic condition, I have learned to enjoy the moment more.

Q8

Please add anything else you would like to share about your chronic condition(s) 😊

Q9

Assume you are interested in attending group therapy for chronic illness.
Please rate your preferences for these options:

	Strongly prefer	Somewhat prefer	Somewhat disprefer	Strongly disprefer	No preference
A group that meets face-to-face in person .	<input type="radio"/>				
A group that meets face-to-face online . (e.g., Zoom)	<input type="radio"/>				
A group where members have the same health condition(s) as me.	<input type="radio"/>				
A group where members have different types of health conditions.	<input type="radio"/>				
A drop-in group where members can come and go as they please. (i.e., there may be different members each week)	<input type="radio"/>				
A group that includes the same members each time for a fixed number of meetings .	<input type="radio"/>				
A short-term group that meets for only a few sessions and wraps up more quickly. (e.g., 4 sessions)	<input type="radio"/>				
A long-term group that meets for many sessions over a long period of time. (e.g., 10 sessions)	<input type="radio"/>				

A group that meets less often. (e.g., once per month/once every two months)	<input type="radio"/>				
A group that meets more often. (e.g., once per week/once every two weeks)	<input type="radio"/>				
A group with fewer members. (e.g., 8 or less)	<input type="radio"/>				
A group with more members. (e.g., 10 or more)	<input type="radio"/>				
A group that meets during the weekday. (i.e., morning/afternoon)	<input type="radio"/>				
A group that meets in the weekday evening.	<input type="radio"/>				
A more structured group with many activities. (e.g., planned lessons, practicing skills, worksheets, homework)	<input type="radio"/>				
A more unstructured group with fewer activities. (e.g., more talking, less lesson content)	<input type="radio"/>				
A group led by one professional.	<input type="radio"/>				
A group led by two professionals.	<input type="radio"/>				

A group led by at least one professional **with a chronic health condition(s)**.

A group led by professionals **without chronic health condition(s)**.

A group led by **one professional and one peer specialist** (someone with lived experience with chronic illness).

A group led by **two mental health professionals** (e.g., counsellors/therapists, social workers, psychologists).

A group led by one **mental health professional and one medical professional** (e.g., doctor, medical specialist).

A group that meets in a **healthcare facility**. (e.g., hospital, doctor's office)

A group that meets in a **community setting**. (e.g., community hall, counselling agency)

A group that emphasizes **hope and change**.

A group that spends ample time exploring **the suffering associated with chronic illness**.

Q10

Please add any additional comments or opinions you may have about group therapy 🗨️

Q11

Only a few questions left 😊

What is your age as of today?

v

Q12

What gender identity best describes you?

- Male
- Female
- Non-binary
- Transgender
- Third gender (e.g., Two-Spirit)
- I do not identify as any of the above, I identify as:

- Unsure
- Prefer not to disclose

Q13

Please share any other identities that are important to you (e.g., ability, culture, religion, spirituality, sexuality, ancestry):

Q14

What country do you live in?

Display this question if "What country do you live in?" – Canada is selected

Q14.1

What province/territory do you live in?

Q15

How did you hear about this survey?

- Facebook via Chronic Illness Support Group(s)
- A person told me about this survey and/or sent me the link
- Social media page (e.g., Instagram) including Dalaine's (researcher) social media page(s)
- Survey-sharing group/website (e.g., groups for survey sharing on Facebook)
- Other (please tell me how you found out about this survey):

- I do not recall where I heard about this survey.

Q16

Is there anything you would like to clarify about your responses?

Please add any other details you would like to share 😊

THANK YOU FOR YOUR RESPONSES!
JUST ONE MORE STEP 😊

To thank you for sharing your opinions,
you will have the option to enter a draw to
WIN one of two **\$50 gift cards** to
The Unchargeables Shop
at the bottom of this page.

BEFORE YOU GO...

You are invited to **share this survey** with anyone you know
who has also been impacted by chronic illness!

To share this survey with friends and family,
Please copy the link below:

https://uleth.qualtrics.com/jfe/form/SV_dbxDZo237aID1Hw

(this study will be available until February 25, 2022)

**Would you like to enter the draw to win one of the two \$50 gift cards
to The Unchargeables Shop?**

If you select YES: *Please do not close your browser until you have been taken to a
separate page inviting you to provide your email address.*

*Your survey results will remain anonymous. Your email address will only be used to
contact you if you are the winner of the draw.*

Please select your answer and click the button below to continue.

- Yes, please** 😊 - I would like to provide my email address and enter the draw.
- No, thank you** 😊 - I would not like to enter the draw. Please take me to the end of the survey.

Skill Testing Question

If you wish to enter your email address to enter the raffle, please answer the following question:

$(10 + 20) / 3 = \underline{\quad\quad} ?$

- 3
- 5
- 10
- 15

Display option to enter email address if “(10 + 20) / 3 = ? – 10 is selected

Raffle Entries

Please provide your email address to enter the draw to **WIN** one of two **\$50 gift cards to The Unchargeables Shop!** 😊

Your email address is not linked to your previous survey responses.

Only the winners of the draw will be contacted.

**Please note: the settings of this survey prevent individuals from participating more than once*

THANK YOU FOR PARTICIPATING IN MY STUDY! 😊

I am so grateful for your time and willingness to help!

BEFORE YOU GO...

You are invited to share this survey with anyone you know who has also been impacted by chronic illness!

**To share this survey with friends and family,
please copy the link below:**

https://uleth.qualtrics.com/jfe/form/SV_dbxDZo237aID1Hw

(this study will be available until February 25, 2022)

Need someone to talk to about your mental health?

Follow this link to find resources near you:

[CheckPoint Global Mental Health Resources](#)

Interested in learning more about group therapy or attending a group?

Follow this link to find a therapy group near you:

[Group Therapy Central - How to Find Group Therapy Near Me](#)

Want to receive a summary of the survey results?

(available September, 2022)

Please visit my thesis supervisor's website (<https://www.dawn-mcbride.com/>) within one year of completing this survey to download a summary of the results.

THANK YOU AGAIN

**for your willingness to help me make a difference
in mental health support for chronic illness**



Take good care,

Dalaine Kubik

M.Ed. (Counselling Psychology) Thesis Student

University of Lethbridge

laine.kubik@uleth.ca

Appendix F: Human Research Ethics Approval Form



RESEARCH ETHICS OFFICE
Health Research Ethics Board

2-01 North Power Plant (NPP)
11312 - 89 Ave NW
Edmonton, Alberta, Canada T6G 2N2
Tel: 780.492.0459
www.uab.ca/reo

Approval Form

Date: January 7, 2022
Study ID: 2022-001
Principal Investigator: Dalaine Kubik
Title: Illness identity and preferences for group therapy in adults with chronic illness.
Approval Expiry Date: January 6, 2023

Thank you for submitting the above study to the Health Research Ethics Board - Health Panel. Your application has been reviewed and approved on behalf of the committee. The following documents form part of this approval:

- Ethics Application (footer date January 7, 2022)

Any proposed changes to the study must be submitted to the REB for approval prior to implementation. A renewal report must be submitted next year prior to the expiry of this approval if your study still requires ethics approval. If you do not renew on or before the renewal expiry date, you will have to re-submit an ethics application.

Approval by the REB does not constitute authorization to initiate the conduct of this research. The Principal Investigator is responsible for ensuring required approvals from other involved organizations (e.g., Alberta Health Services, Covenant Health, community organizations, school boards) are obtained, before the research begins.

Sincerely,

A handwritten signature in blue ink that reads "Carol Boliek".

Carol Boliek, PhD
Associate Chair, Health Research Ethics Board - Health Panel



Appendix G: Chronic Conditions Reported by Participants

ICD-11 Category	Chronic Condition	<i>n</i>		
		Total	Diagnosed	Undiagnosed or Not Specified
01 Certain infectious or parasitic diseases	Lyme Disease	2	2	0
02 Neoplasms	Intraductal Papillomas	1	1	0
	Mast Cell Activation Syndrome (MCAS) (Systemic Mastocytosis)	16	12	4
	Myelofibrosis	1	1	0
	Papillary Thyroid Carcinoma	1	1	0
	Vaginal Cancer	1	1	0
03 Diseases of the blood or blood-forming organs	Hemolytic Anemia	1	1	0
	Pernicious Anemia	1	1	0
04 Diseases of the immune system	Allergies	4	4	0
	Epstein-Barr	1	1	0
	Unspecified Autoimmune Disease/Condition	3	2	1

ICD-11 Category	Chronic Condition	<i>n</i>		
		Total	Diagnosed	Undiagnosed or Not Specified
04 Diseases of the immune system	Behçet's Disease	1	1	0
	Immunoglobulin G (IgG) Deficiency	1	1	0
	Lupus	6	5	1
	Mixed Connective Tissue Disease	1	1	0
	Primary Immunodeficiency	1	1	0
	Sjogren's Syndrome	4	3	1
05 Endocrine, nutritional, or metabolic diseases	Addison's Disease	1	1	0
	Adrenal Dysfunction	1	1	0
	Adrenal Insufficiency	1	1	0
	Chronic Iron Deficiency	1	1	0
	Diabetes	14	14	0
	Gilbert Syndrome	1	1	0
	Graves' Disease	1	0	1
	Hashimoto Thyroiditis	12	12	0
	Hyperinsulinemia	1	1	0
	Hyperthyroidism	1	1	0

ICD-11 Category	Chronic Condition	<i>n</i>		
		Total	Diagnosed	Undiagnosed or Not Specified
05 Endocrine, nutritional, or metabolic diseases	Hypokalemia Periodic Paralysis	1	1	0
	Hypothyroidism	12	11	1
	Metabolic Syndrome	2	1	1
	Mitochondrial Dysfunction	3	3	0
	Polycystic Ovarian Syndrome (PCOS)	20	20	0
	Porphyria	1	1	0
	Prolactinoma	1	1	0
	Relative Hypoglycemia	1	0	1
	Secondary Carnitine Deficiency	1	1	0
	Thyroid Disorder	1	0	1
Vitamin D Deficiency	1	1	0	
06 Mental, behavioural, or neurodevelopmental disorders	Attention-Deficit Hyperactivity Disorder (ADHD)	6	4	2
	Anxiety	15	15	0
	Autism	2	2	0
	Binge Eating Disorder	1	1	0

ICD-11 Category	Chronic Condition	<i>n</i>		
		Total	Diagnosed	Undiagnosed or Not Specified
06 Mental, behavioural, or neurodevelopmental disorders	Bipolar Disorder	1	1	0
	Borderline Personality Disorder	1	1	0
	Complex Post-Traumatic Stress Disorder (CPTSD)	3	3	0
	Conversion Disorder	1	1	0
	Depression	14	13	1
	Depressive Episodes	1	1	0
	Dyslexia	1	1	0
	Eating Disorder	1	0	1
	Generalized Anxiety Disorder	6	6	0
	Major Depressive Disorder	3	3	0
	Panic Attacks	1	1	0
	Persistent Depressive Disorder	1	1	0
	Post-Concussion Syndrome	4	4	0
	Post-Traumatic Stress Disorder (PTSD)	3	3	0

ICD-11 Category	Chronic Condition	<i>n</i>		
		Total	Diagnosed	Undiagnosed or Not Specified
07 Sleep-wake disorders				
	Delayed Sleep Phase Disorder	1	1	0
	Idiopathic Central Nervous System Hypersomnia	1	1	0
	Narcolepsy	1	1	0
	Sleep Apnea	6	6	0
08 Diseases of the nervous system				
	Cerebral Palsy	1	1	0
	Charcot-Marie-Tooth Disease	1	1	0
	Chronic Fatigue Syndrome [Myalgic Encephalomyelitis (ME/CFS)]	11	10	1
	Dysautonomia	13	10	3
	Epilepsy	3	3	0
	Migraine	66	60	6
	Multiple Sclerosis	2	2	0
	Nerve Compression	1	1	0
	Neuropathy	1	1	0
	Non-Epileptic Attack Disorder	1	1	0

ICD-11 Category	Chronic Condition	<i>n</i>		
		Total	Diagnosed	Undiagnosed or Not Specified
08 Diseases of the nervous system	Peripheral Neuropathy	2	2	0
	Postural Orthostatic Tachycardia Syndrome (POTS)	30	26	4
	Seizures	1	0	1
	Sequala of Apoplexy	1	1	0
	Tremors	1	0	1
	Trigeminal Neuralgia	1	0	1
09 Diseases of the visual system	Autoimmune Uveitis	1	1	0
	Irlen Syndrome	1	1	0
	Visual Snow Syndrome	1	1	0
	Wet Age Macular Degeneration	1	1	0
10 Diseases of the ear or mastoid process	Benign Paroxysmal Positional Vertigo (BPPV)	1	1	0
	Dysfunction of Eustachian Tube	1	1	0
	Vestibular Migraine	1	1	0

ICD-11 Category	Chronic Condition	<i>n</i>		
		Total	Diagnosed	Undiagnosed or Not Specified
11 Diseases of the circulatory system				
	Arrhythmias	1	1	0
	Atrial Fibrillation	1	1	0
	Blood Clotting Disorder	1	1	0
	Carotid Artery Disease	1	1	0
	Heart Disease	1	1	0
	High Blood Pressure	2	2	0
	Mitral Valve Prolapse	1	1	0
	Orthostatic Hypotension	1	1	0
	Raynaud's Syndrome	3	3	0
	Tachycardia	2	2	0
12 Diseases of the respiratory system				
	Asthma	20	19	1
	Chronic Obstructive Pulmonary Disease (COPD)	2	1	1
	Chronic Sinus/Lung Infections	1	1	0
	Rhinitis	2	2	0

ICD-11 Category	Chronic Condition	<i>n</i>		
		Total	Diagnosed	Undiagnosed or Not Specified
12 Diseases of the respiratory system	Sinusitis	2	2	0
13 Diseases of the digestive system				
	Appendicitis	1	0	1
	Bowel Disorder	1	0	1
	Celiac Disease	9	8	1
	Cirrhosis of the Liver	1	1	0
	Colonic Inertia	1	1	0
	Crohn's Disease	9	8	1
	Dysmotility of Digestive Tract	1	1	0
	Food Intolerances	1	1	0
	Functional Dyspepsia	1	1	0
	Gastroesophageal Reflux Disease (GERD)	2	2	0
	Gastroparesis	9	8	1
	Irritable Bowel Disease (IBD)	2	1	1
	Irritable Bowel Syndrome (IBS)	35	27	8
	Leaky Gut Syndrome	1	1	0

ICD-11 Category	Chronic Condition	<i>n</i>		
		Total	Diagnosed	Undiagnosed or Not Specified
13 Diseases of the digestive system	Lower Anterior Resection Syndrome	1	0	1
	Lymphocytic Colitis	1	1	0
	Microbial Colitis	1	1	0
	Small Intestinal Bacterial Overgrowth (SIBO)	1	0	1
	Temporomandibular Joint Disorder (TMJD)	3	3	0
	Ulcerative Colitis	4	4	0
14 Diseases of the skin	Angioedema	1	1	0
	Eczema	1	1	0
	Hidradenitis Suppurativa	2	2	0
	Hives	2	2	0
	Psoriasis	2	2	0
	Scleroderma	1	1	0
	Skin Disease	1	1	0
	Urticaria	1	1	0
Vitiligo	1	1	0	

ICD-11 Category	Chronic Condition	<i>n</i>		
		Total	Diagnosed	Undiagnosed or Not Specified
15 Diseases of the musculoskeletal system or connective tissue	Ankylosing Spondylitis	4	3	1
	Arthritis	8	8	0
	Bertolotti's Syndrome	1	1	0
	Bursitis	1	1	0
	Cervical Dystonia	1	1	0
	Cranio-cervical Instability	1	1	0
	Degenerative Disc Disease	3	3	0
	Dupuytren Contracture	1	1	0
	Herniated Cervical Discs	4	3	1
	Inflammatory Arthritis	1	1	0
	Rheumatoid Arthritis	9	8	1
	Osteoarthritis	3	3	0
	Osteopenia	1	1	0
	Patellofemoral Pain Syndrome	1	1	0
	Polyarthropathy	1	1	0

ICD-11 Category	Chronic Condition	<i>n</i>		
		Total	Diagnosed	Undiagnosed or Not Specified
15 Diseases of the musculoskeletal system or connective tissue	Psoriatic Arthritis	1	1	0
	Scheuermann's Disease	1	1	0
	Scoliosis	6	6	0
	Spondylolisthesis	1	1	0
	Tendinitis	1	0	1
16 Diseases of the genitourinary system	Chronic Urinary Tract Infections	1	1	0
	Dysmenorrhea	1	1	0
	Endometriosis	38	36	2
	Hemorrhagic Ovarian Cysts	1	1	0
	Interstitial Cystitis	1	1	0
	Kidney Stones	2	2	0
	Menopause	1	1	0
	Pelvic Floor Dysfunction	1	1	0
	Premenstrual Dysphoric Disorder (PMDD)	1	1	0
	Pudendal Neuralgia	1	1	0
	Renal Disease	1	1	0

ICD-11 Category	Chronic Condition	<i>n</i>		
		Total	Diagnosed	Undiagnosed or Not Specified
17 Conditions related to sexual health	N/A			
18 Pregnancy, childbirth, or the puerperium	N/A			
19 Certain conditions originating in the perinatal period	N/A			
20 Developmental anomalies				
	Ehlers-Danlos Syndrome (EDS)	31	29	2
	Hip Dysplasia	1	1	0
	Hypermobility Syndrome (HMS)	1	1	0
	Medullary Sponge Kidney	1	1	0
	Stickler Syndrome	1	1	0
21 Symptoms, signs, or clinical findings not elsewhere classified				
	Allodynia	1	0	1
	Back Pain	3	2	1
	Biotoxin Illness	1	1	0
	Chronic Cysts	1	1	0
	Chronic Exhaustion	1	0	1
	Chronic Fatigue	10	5	5
	Chronic Foot Pain	1	1	0

ICD-11 Category	Chronic Condition	<i>n</i>		
		Total	Diagnosed	Undiagnosed or Not Specified
21 Symptoms, signs, or clinical findings not elsewhere classified	Chronic Pain	11	8	3
	Chronic Pain Syndrome	2	2	0
	Complex Regional Pain Syndrome	2	2	0
	Fibromyalgia	37	31	6
	Gastrointestinal Issues	3	2	1
	Gynecological Pain	3	0	3
	Headache	9	9	0
	Heart Palpitations	1	1	0
	Hip Pain	1	0	1
	Hypermobility	5	2	3
	Inflammation	2	1	1
	Joint Inflammation	3	2	1
	Joint Instability	1	0	1
	Joint Pain	5	2	3
	Knee Pain	1	0	1
	Muscle and Tendon Pain	1	0	1
	Muscle and Nerve Pain	1	1	0
	Nausea	2	1	1

ICD-11 Category	Chronic Condition	<i>n</i>		
		Total	Diagnosed	Undiagnosed or Not Specified
21 Symptoms, signs, or clinical findings not elsewhere classified	Neck/Head Pain	1	0	1
	Nerve Damage	2	1	1
	Nerve Pain	1	0	1
	Pain Related to Hypermobility	1	1	0
	Recurrent Fevers	1	0	1
	Sciatica	1	1	0
	Sinus Pain	1	1	0
	Sore Throat	1	0	1
	Stomach Pain	9	4	5
22 Injury, poisoning, or certain other consequences of external causes	Shoulder SLAP Tear	1	1	0
	Torn ACL	1	1	0
	Whiplash	1	1	0
25 Codes for special purposes	Post COVID-19 Condition	3	3	0

Note. The chronic conditions reported by participants have been categorized according to the ICD-11 for Mortality and Morbidity Statistics (Version: 02/2022) Retrieved from <https://icd.who.int/browse11/l-m/en>