THE TREATMENT OF YOUTH ANXIETY:
HISTORICAL AND CURRENT NARRATIVES

A Thesis
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for the Degree of Master of Applied
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ABSTRACT

This master’s thesis is a qualitative analysis of youth mental health journeys in Atlantic Canada, asking how youth experience treatments in the mental health system. Participants (N=8), aged 13-18, identified with anxiety disorders and had sought services within the mental health system. Semi-structured qualitative interviews were conducted with participants. Youth narrative summaries were presented providing rich youth perspectives in mental health research. A thematic analysis detailed both positive and negative experiences, which acted as facilitators and barriers for treatment often in contradictory forms. The central themes were: therapeutic relationships, treatment in school, medicalization, wait times, and being stuck in the margins. Communication and trust issues, a lack of comprehensive treatment options, and the complexity of navigating the system, pervaded the narratives. A social historical framework also informed the design, analysis, and findings of this thesis, which tracked the rise of anxiety in the twentieth century and contextualized current day treatments. This thesis has produced insights regarding the importance of youth perspectives in evaluating mental health care given the marginalization of these perspectives in past psychiatric discourses and present-day narratives.

Keywords: youth, qualitative, anxiety, treatment, social history, mental health.
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This research was supported by the Atlantic Canada Children’s Effective Service Strategies for Mental Health (ACCESS-MH; http://access-mentalhealth.ca/) and funded by the Canadian Institutes of Health Research (CIHR). Correspondence concerning ACCESS-MH should be made to Dr. Kate Tilleczek, Young Lives Research Lab, UPEI. Phone: (902) 620-5127. Email: ktilleczek@upei.ca

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CHAPTER 1: INTRODUCTION

This thesis integrates narrative analysis and critical social history to understand how youth anxiety disorders are treated, now and in the past. Patient journey narratives from eight (N=8) Atlantic Canadian youth who have a diagnosis of anxiety (n=7) or identify as having anxiety (n=1) were collected and analyzed to map the barriers and facilitators faced during treatment. Additionally, a literature review of selected social historical texts regarding the treatment of youth, mental disorders, and anxiety were reviewed and synthesized to provide social historical background to the current phenomenon of youth anxiety. This study is an interdisciplinary approach that deconstructs and contextualizes the treatment of youth anxiety, both how it has been understood through time and how it is understood from voices of youth today. This approach is grounded in individual experiences and illustrates how social systems impact treatment over time.

In this introductory chapter the rationale and background of the study are outlined. First, the subject background is introduced: Why is anxiety an important problem to study at this time? And, what are the current trends in youth anxiety disorders? Second, the background project is outlined as a source of data for this thesis research. This work is part of the Atlantic Canada Children’s Effective Service Strategy for Mental Health (ACCESS-MH; http://access-mentalhealth.ca/), a multi-method, interdisciplinary, five-year project in Atlantic Canada that is assessing the efficacy of youth mental health services. Third, the research questions are listed along with the
design used to explore the topic and potential implications of this work. Lastly, an overview is provided of the remaining thesis chapters.

1.1. Subject Background

In Canada, youth have been labeled one of the most at-risk populations for mental disorders, both nationally (Kutcher & McLuckie, 2010; Mental Health Commission of Canada [MHCC], 2015) and regionally in Atlantic Canada (Muzyychka, 2007). Anxiety is the most common and earliest onset mental disorder for young people with an estimated lifetime prevalence ranging from 15 to 30 percent (Beesdo, Knappe, & Pine, 2009; Essau & Gabbidon, 2013). According to the Mental Health Commission of Canada an estimated 12 percent of young people have been living with a mood or anxiety disorder is this country (MHCC, 2013). Further, a 55 percent increase was shown in youth anxiety related Emergency Department (ED) visits between 2007-2014 making anxiety the most frequent mental disorder for youth visiting the ED (Canadian Institute for Health Information [CIHI], 2015). Elsewhere, 32 percent of youth in the US reported clinically significant levels of anxiety at some point in their life (Merikangas et al., 2010). Youth mental health strategies have identified the debilitating effects of anxiety on the population and have stressed the importance of youth inclusion in service design moving forward (Burns & Birrell, 2014).

These trends indicate that anxiety is the most common mental disorder diagnosis for youth today with the sharp rise in ED visits reflecting an increased need to evaluate anxiety related services and treatments. There is a need then to talk with those youth who are experiencing this system, to untangle the complex systems youth face when navigating mental health treatments. In Canada, the mental health system youth face has
been reported to be fragmented and under-funded, with a lack of mental health professionals available in many regions of the country and interventions often occurring too late (Kirby & Keon, 2006). Qualitative pathways research has displayed the fractured, paradoxical, and almost labyrinthian nature of the youth mental health system in Canada (Boydell, Pong, Volpe, Tilleczek, Wilson, & Lemieux, 2006; Tilleczek & Lezeu, 2014). Therefore an exploration into the journeys of youth seeking treatment for anxiety from a critical qualitative perspective is both timely and insightful given the current climate of mental health in Canada.

1.2. Project Background

The qualitative data collected for this thesis is part of the Atlantic Canada Children’s Effective Service Strategy for Mental Health (ACCESS-MH; http://access-mentalhealth.ca/) project and is funded by the Canadian Institutes of Health Research (CIHR). ACCESS-MH is an interdisciplinary multi-method project studying how mental health services are provided to, and experienced by, youth, parents, and service providers in Atlantic Canada. It explores the gaps initially documented by Out of the Shadows at Last, the Canadian Senate Committee Report by Kirby and Keon (2006) and more recently the Mental Health Commission of Canada national strategy (2012). These reports called for more comprehensive mental health research, better communication among stakeholders, stigma reduction, and to improve mental wellbeing from a social determinants model.

The qualitative data collected by ACCESS-MH asks participants to map their journeys through the mental health system in order to analyze the barriers and facilitators when accessing services. As a graduate student working on the ACCESS-MH project I
conducted interviews in Atlantic Canada with youth, parents, and services providers. This thesis is a secondary analysis from the qualitative data set of ACCESS-MH. Of the 46 child and youth journeys collected in Phase I by the research team, across a range of mental disorders, eight interviews (N=8) from youth with who identified with anxiety disorders have been examined for this thesis.

1.3. Research Questions

My thesis explores the following research questions:

1. What are youth perspectives accessing and receiving treatment for anxiety in the mental health system? What has facilitated positive experiences throughout this process? What barriers have impeded their treatment and produced negative experiences?

2. What are the social and historical developments in understanding youth and anxiety over time? How can this social history inform our understanding of youth and anxiety treatment today?

The first group of questions is explored through the analysis of youth narratives collected from the ACCESS-MH project. The term treatment here is applied broadly and includes experiences accessing treatments in the medical, community, and school mental health systems. The second group of questions is explored through the analysis of social historical works on the treatment of mental disorders through time. These two sets of research questions guided the methodological design and analysis of this thesis. Both lines of questioning are rooted in critical and social constructivist approaches, which underlie the work done in this study.
1.4. Thesis Outline

This thesis includes six chapters and four appendices. The second chapter presents the literature review of this thesis. The literature reviewed defines anxiety disorders of youth, maps the recent trends in diagnostic criteria and prevalence, and discusses the themes and debates for the treatment of these disorders. The third chapter is the methodological overview of the thesis, which discusses the social constructivist epistemic stance, critical youth studies and social history as theoretical framework, narrative analysis and critical ethnography methodologies, sampling and interviewing methods, considerations in youth ethics, and lastly the thematic analysis carried out for the qualitative interviewing data. The fourth chapter presents the social historical findings, which outlines the rise of anxiety in the twentieth century marking the major social, cultural, and economic influences on the disorder’s diagnosis and treatment, which points to gaps in historical anxiety literature relating to youth and lays the groundwork for how social structures impact the lives of youth over time. The fifth chapter provides narrative summaries from each of the eight youth participants in this study, summarizing their journeys of access to treatment in the system. The sixth chapter is the results of the narrative analysis, presenting themes regarding barriers and facilitators participants experienced in their journeys. The seventh chapter is the discussion, which outlines the implications and recommendations from this work, and offers reflections and discussion points moving forward.
CHAPTER 2: LITERATURE REVIEW

2.1. Chapter Outline

The current chapter reviews the surveyed literature and discusses potential gaps and the important themes and debates when understanding youth anxiety research. First the scope of the literature review is outlined and inclusion/exclusion criteria are discussed, followed by the definition of youth anxiety disorders, the diagnostic criteria for anxiety disorders, prevalence, services and treatments including subsections on psychotherapy and pharmacotherapy, and a summary of how this literature impacts the current work in this thesis. The social historical literature review is presented in chapter four.

2.2. Scope of Review

The UPEI Robertson Library OneSearch engine was used for the initial literature review. This engine was selected because it covers a wide range of literature across many disciplines and journal types. OneSearch includes the UPEI print and online collections, EBSCOhost, JSTOR, WILEY, SAGE, and more. The aim of the first search was to paint the picture of the prevalence, treatments, and services for youth anxiety disorders today.

The first OneSearch review was conducted using the terms *anxiety disorders, youth/adolescents/young people, treatment/services, and prevalence/incidence.* Parameters were set to search only for peer-reviewed articles between 2014-2017 in order to find current statistics and treatments. This search produced 911 peer-reviewed articles. Most of these articles did not fit my criteria because they did not discuss youth specifically. The articles primarily focused on other diseases or mental conditions, the articles were experimental design such as testing randomized control trials for new
treatments, and the focus was the anxieties of specific groups such as veterans with PTSD, etc. From this search 10 relevant articles were selected and used in the literature review. From these 10 articles there were nine highly cited or specifically relevant studies, which discussed prevalence, treatment, services or diagnostic criteria for youth anxiety that were used in the literature review.

There was limited Canadian literature on youth anxiety therefore reports by the MHCC, CIHI data, best practice information from Health Canada, diagnostic information from Medical Council of Canada, and prevalence data from Atlantic Canada produced by Public Health Agency of Canada were reviewed and provided additional information on youth anxiety statistics and treatments in this country. Most of the data found from these Canadian reports however grouped anxiety and mood disorders together. Grey literature was then collected from sources such as the Anxiety and Depression Association of America, National Institute of Mental Health, the American Psychiatric Association (APA) along with World Health Organization (WHO) to provide additional information for anxiety disorders.

A second OneSearch review was completed searching the terms anxiety disorders, youth/adolescents/young people, and qualitative/research. The goal here was to find qualitative studies that would be similar in content or design for this thesis. This search produced 193 peer-reviewed articles. None of these qualitative studies related specifically to youth anxiety disorders or experiences of treatment and services. One article was found regarding barriers/facilitators in youth help-seeking behaviour (McCann, Mugavin, Renzaho, & Lubman, 2016) and regarding mental health detection in
primary care (Knight, Vickery, Fiks, & Barg, 2015). These two articles were used in the methodology section and contributed to the design of this thesis.

The youth mental health pathways research of Boydell, Pong, Volpe, Tilleczek, Wilson, and Lemieux (2006) and the critical youth studies and narrative research of Dr. Kate Tilleczek and her team (Tilleczek, 2011; Tilleczek, 2014; Tilleczek & Kinlock, 2013; Tilleczek & Campbell, 2014; Tilleczek & Lezeu, 2014; Tilleczek, Ferguson, Campbell, & Lezeu, 2014) added context, themes, and debates in these areas. These studies contributed significantly to project design and methodology and are discussed further in chapter three.

2.3. Defining Anxiety Disorders

Anxiety has been defined as the “brain response to danger, stimuli that an organism will actively attempt to avoid” (Beesdo, Knappe, & Pine, 2009, p. 484). To differentiate between normal anxiety and pathological anxiety has proven difficult, both in health research (Creswell, Waite, & Cooper, 2014) and for social historical analysis tracking anxiety over time (Horwitz, 2013). The reason for this is that anxiety occurs naturally in the body, is generally adaptive and non-pathological, and only when it interferes with our daily life functioning such as “extensive degrees of anxiety or avoidance” does it become necessary to address it as a disorder (Beesdo et al., 2009, p. 484). It may be difficult to classify the severity of anxiety in youth due to communication barriers. Communication is “vital to the application of the diagnostic classification system” yet this may be more difficult for youth depending on their cognitive or emotional state (Beesdo et al., 2009, p. 484). In other words, it can be difficult for youth
to express their symptoms to service providers and how these symptoms are communicated affects what is diagnosed and then how it is treated.

2.4. Diagnostic Criteria

The World Health Organization (WHO) has classified mental disorders in the International Classification of Diseases (ICD), now in its tenth edition (WHO, 2016). In the US the American Psychiatric Association (APA) has defined the classification and diagnosis of mental disorders through use of the Diagnostic and Statistical Manual of Mental Disorders, currently in its 5th edition (DSM-5) (APA, 2013). The DSM is regarded as the medical and legal authority on mental disorders in the US (Mallet, 2006). In Canada, the DSM is also considered the primary guideline for diagnosing mental disorders and is used by psychiatrists, paediatricians, and psychologists (Health Canada, 2002). The Medical Council of Canada has transitioned its language and testing criteria from DSM-4-TR to DSM-5 diagnostic criteria (Medical Council of Canada, 2015).

Current categories for anxiety disorders in the DSM-5 are; separation anxiety disorder, selective mutism, specific phobia, social anxiety disorder, panic disorder, agoraphobia, generalized anxiety disorder, anxiety disorder due to another medical condition, other specified anxiety disorder, unspecified anxiety disorder (APA, 2013). For youth many anxiety disorders have been “grouped together irrespective of age” with little explicit guidelines for “developmentally appropriate assessments” (Beesdo et al., 2009, p. 484-485). Yet it has been recommended that individualized, age specific, approaches to diagnosis and treatment be implemented for youth anxiety disorders (Creswell et al., 2014). Other reporting scales such as Revised Children’s Anxiety and Depression Scale (RCADS) and the Spence Children’s Anxiety Scale (SCAS) have been
used for children with anxiety (Creswell et al., 2014). Despite the development of more detailed interviewing and assessment, comorbidity is the norm not the exception for the diagnosis of youth anxiety disorders (Essau & Gabbidon, 2013). There appears to be a gap in literature regarding the application of youth specific anxiety nomenclature, both in Canada and beyond.

The DSM diagnostic process has relied primarily on patient information of their symptoms, making communication and interpretation by the physician the key tool for diagnosing mental disorders (Beesdo et al., 2009). As younger children may have difficulty “communicating information about internally experienced affective states” often other sources are sought, such as teacher reports, to “distinguish among normal anxiety, subclinical, and pathological” levels of anxiety (p. 485). Determining appropriate youth specific nomenclature and diagnostic guidelines is critical for all sub-clinical, clinically significant, and severe cases of anxiety disorders in youth, and the literature points to a gap in readily available criteria (Beesdo et al., 2009). How patients portray their histories and their life stories is important when determining diagnosis and treatment, therefore communication, language, and underlying assumptions by the practitioner come into play (Gross, 2009). Beesdo et al. have also reported that a “substantial degree of phenotypical diversity or heterogeneity” exists between patient symptoms within the narrow categories for anxiety disorders (2009, p. 484). Further, Beesdo et al. have explained that by adding the other and unspecified categories, the more recent DSMs have created high rates of inter-anxiety and mood disorder comorbidity among children and adolescents.
2.5. Prevalence

Variations in data collection methods, diagnostic and clinical thresholds, age, and geography make prevalence data for youth anxiety difficult to chart with Canadian statistics often having grouped mood disorders and anxiety together. The MHCC has estimated that 12 percent of young people in Canada live with a mood or anxiety disorder (2013). Another Canadian study estimated four percent of children and youth had an anxiety disorder that was clinically significant and required treatment (Waddell, Shepherd, Schwartz, & Barcian, 2014). In 2009 the Canadian Chronic Disease Surveillance System reported a prevalence rate of seven percent for mood/anxiety in youth aged 15-19 (O'Donnell, Vanderloo, McRae, Onysko, Patten, & Pelletier, 2016).

Meta-analyses placed the worldwide prevalence rate for anxiety at seven percent among children and adolescents (Polanczyk, Salum, Sugaya, Caye, & Rohde, 2015). In the UK surveys indicated 15 to 30 percent lifetime prevalence in children and adolescents (Essau & Gabbidon, 2013). In a national survey, considered the first statistically representative sample of US children and adolescents for incidence of mental disorders, 32 percent of youth had been affected at some point by an anxiety disorder, with eight percent having registered as severely distressed and impaired (Merikangas et al., 2010).

The onset of anxiety appears earlier than other mental disorders as well, with separation and phobias appearing earliest and panic, social, and generalized anxieties appearing later in adolescence (Beesdo et al., 2009). Despite the “variation in prevalence estimates… likely due to method variance” (Beesdo et al., 2009, p. 5) a high number of youth have clinically significant levels of anxiety.
Primary care data in the UK reported that anxiety symptoms from children and youth tripled from 2003-2011 yet anxiety diagnoses remained stable (John et al., 2015). This suggests that more young people were exhibiting symptoms yet formal diagnoses did not take place. However the National Longitudinal Surveys of Children and Youth in Canada reported that anxiety rates have remained relatively stable from 1995-2008 and contributing to the escalation of anxiety were methodological differences in studies, increased treatment seeking behaviour, and changes in diagnostic criteria (McMartin, Kingsbury, Dykxhoorn, & Colman, 2014). The explanation in the rise of youth anxiety is not clear and is beyond the scope of this thesis. However, being attuned to these themes and issues is important in understanding the social landscape of youth anxiety.

### 2.6. Services and Treatments

“Children may receive mental health services from many agencies whose primary responsibilities do not include mental health care” (Costello et al., 2014, p. 360). In fact this research reported that most services were provided in schools (24 percent), with mental health service providers (23 percent) and general practitioners (10 percent) coming in second and third respectively (Costello et al., 2014). Adequate treatment and support by the school system is very important. Research has shown that youth with anxiety disorders displayed academic impairment in school. After effective treatment and symptom relief, however, academic performance improved (Nail et al., 2015).

Another gateway into the mental health system is the Emergency Department (ED). CIHI reported a 45 percent increase in all mental health related ED visits from 2006-07 to 2013-14, while other medical conditions remained stable or declined (2015). Anxiety related visits had increased by 55 percent over the same time period (CIHI,
2015). This dramatic increase may reflect a lack of psychological and social treatment options available to youth in Canada.

The results of national comorbidity surveys in the US have indicated that approximately 40 percent of youth with an anxiety disorder did not seek professional treatments or services (Costello, He, Sampson, Kessler, & Merikangas, 2014). This data suggests that the majority of youth who have or have had clinically significant levels of anxiety did not receive treatment. A lack of youth recognition and literacy of mental disorders has been shown to be a barrier for seeking care and could explain the lack of help seeking behaviour (Coles, Ravid, Gibb, George-Denn, Bronstein, & McLeod, 2016). Additional barriers to treatment have included a lack of local appropriate services, lack of trained professionals, wait times, and competing family and time commitments (Creswell et al., 2014). In Canada, gaps in service availability, integration, continuity, and wait times were reported as barriers for treatment of mental health problems for youth (CIHI, 2015).

2.6.1. Psychotherapy. It is often difficult to separate anxiety and depression treatment literature for youth due to a lack of age specific data, high rates of comorbidity, and similarities in treatment options (Birmaher, Yelovich, & Renaud, 1998). Therefore depression medication dosage and side effects are often cited when establishing the criteria for youth anxiety treatments (Birmaher et al, 1998). American paediatric research on depression treatment for youth reported that psychotherapy was the most common prescription for youth while psychotropic drugs were second at approximately 50 percent of cases, higher than the recommended level for this age group (Olfson, Gameroff, Marcus, & Waslick, 2003).
A review of fifty years of evidence-based therapy for child and adolescent anxiety disorders showed that cognitive-behaviour therapies (CBT) and exposure therapies were the most well established treatments, with CBT being generally accepted as the most effective first-line option (Higa-McMillan, Francis, Rith-Najarian, & Chorpita, 2016). Despite its efficacy there are still many young people who do not respond to traditional CBT or do not have access to practitioners; as a result considerable research has recently looked at the success of Internet interventions and video teleconference sessions (Rialon Berry, 2016). Positive results have been shown from low intensity CBT through “bibliotherapy” i.e. parent and youth workbooks and through e-therapies (Creswell, et al., 2014).

2.6.2. Pharmacotherapy. The Anxiety and Depression Association of America (ADAA) have recommended that CBT, medication, or a combination of both be used for treatment of youth anxiety disorders (2015). Selective serotonin reuptake inhibitors (SSRIs, such as Paxil, Zoloft, and Prozac) were reported as the medication of choice for paediatricians (ADAA, 2015). Other adult anxiety medications such as benzodiazepines (e.g. Xanax, Valium, and Ativan) have not been recommended for children and youth due to side effects and addictive qualities (ADAA, 2015).

In 2004, the Food and Drug Administration (FDA) issued a public warning and applied the black-box label, its strongest warning, for use of SSRIs among children and adolescents (National Institute of Mental Health [NIMH], 2015). The concerns were cited over increased suicidal tendencies for youth taking the medication. However SSRIs have shown fewer side effects compared with other psychotropic medication and in combination with psychotherapy are considered the most effective medication (NIMH,
2015). The FDA had only approved fluoxetine (Prozac) for treating mood disorders for children and youth yet the rise in SSRI prescriptions in recent years means that physicians have been issuing the drugs off-label, thus circumventing the black-box warning (NIMH, 2015).

As discussed earlier in the chapter, anxiety has become the most common mental disorder for youth visiting the ED in Canada and this rise has been coupled with a steady increase in prescriptions of anxiety and psychotropic medications (CIHI, 2015). In Canada, one in 15 of all youth were dispensed anxiety/mood medications in 2013-2014, marking a 23 percent increase from 2007-2008; whereas during the same period psychotherapy had increased only 10 percent (CIHI, 2015). Most (83 percent) of the new psychotropic prescriptions were for SSRIs, which has become the most commonly used medication for anxiety/mood related disorders for youth in Canada (CIHI, 2015). This increase is alarming and could signify psychotropic medication becoming a first-line treatment by family physicians, paediatricians, or psychiatrists.

More guidelines and health care research are required to explore these trends. There has been no clear minimum age limit for psychotropic medication and no longitudinal data has been established on the consequences of stopping these medications later in life (Creswell et al., 2014). It has been recommended that, “medication should not be routinely offered to children and young people and that psychological treatment should be considered the first-line treatment” (Creswell et al., 2014, p. 677). In the US over fifty percent of youth who sought treatment for anxiety received some form of medication, with antidepressants being the most common (Merikangas et al., 2013). This has marked an increase in recent years and although the authors do not point to an
overmedication problem they agree more clinical trials should be conducted (Merikangas et al., 2013). The position taken by CIHI is that there has not been enough long-term empirical data on side effects and any dramatic increase in prescriptions should be met with caution (2015).

2.7. Chapter Summary

It has been recommended in the literature that any young person with anxiety, along with their guardians, should receive comprehensive individualized interviewing by an appropriate healthcare professional to understand risks and side effects of their treatments and comorbidities of their condition (Creswell et al., 2014). However given the potential barriers discussed in this chapter including communication issues with youth, wait-times, limited access to local professionals, and a lack of youth specific nomenclature, coupled with the rise in pharmacological prescriptions over psychological treatments, one must consider that “comprehensive individualized interviewing” may be a luxury that youth are not afforded by the system.

Qualitative inquiries have established that the mental health system for youth is complex and difficult to navigate (Boydell, Pong, Volpe, Tilleczek, Wilson, & Lemieux, 2006; Tilleczek & Lezeu, 2014). These types of research are missing from the mainstream literature on youth anxiety. Given the recent trends and debates the question then becomes, is the system sensitive to the conditions facing youth and what would youth perspectives reveal about how anxiety is experienced and treated today? By implementing youth voice through a qualitative approach this thesis provides insight into an area of mental health that has been understudied.
The following chapter reviews the methodological approach taken for the youth interviews and narrative analysis. This approach stems from the research questions: What are youth perspectives accessing and receiving treatment for anxiety in the mental health system? What has facilitated positive experiences throughout this process? What barriers have impeded their treatment and produced negative experiences? The following chapter also outlines the data collection methods, the ethical basis of this research, and the analytic framework used to interpret this data and findings. The social historical research questions, methods, and findings are found in chapter four.
CHAPTER 3: METHODOLOGY

3.1. Chapter Outline

To begin this chapter I outline the social constructivism epistemic stance that informed this qualitative approach. The theoretical framework of the thesis is discussed outlining my integration of critical youth studies and social history. Next, the methodological approach, which includes narrative analysis and critical ethnographic approaches, is reviewed. The research methods are then outlined, which includes a description of the actions taken to collect the primary data for this thesis, along with sampling criteria, interviewing procedures, elements of qualitative rigour, ethical considerations, and lastly the steps taken during the thematic analysis of the interview data.

3.2. Epistemic Stance

The researcher’s epistemic stance has been defined as the justification for what constitutes valid knowledge within a particular paradigm through the author’s relationship to that knowledge in their work (Carter & Little, 2007). Knowledge formation in this thesis was rooted in the social constructivist paradigm; the design was inductive and emergent (Carter & Little, 2007). Research questions were developed and adapted over the course of the study and remained broad and open-ended so that meaning from participant experiences could be contextualized and interpreted within social and historical structures. The interpretative stance has been rooted in critical theory to critique institutions and their relationship with participants (Morrow & Brown, 1994). This approach acknowledges the cultural, social, and historical norms operating on individuals
to uncover inequalities and reveal marginalized experiences and voices (Madison, 2012; Morrow & Brown, 1994; Tilleczek & Kinlock, 2013).

3.3. Theoretical Framework

The theoretical framework of this thesis merged critical youth studies and social history. As has been explicated by Tilleczek, a critical youth studies approach analyzes how meaning is formed through “daily negotiations” across “physical, emotional, and cognitive developments” (2014, p. 19). In comparison to developmental and reductionist theoretical models, critical youth studies views individuals as social actors who create meaning throughout various cultural and social movements (Cahan, Mechling, Sutton-Smith, & White, 1993). This sociological approach has had an impact on developmental psychology, which once viewed children as a stable category irrespective of socio-historical context, but which has started to introduce concepts such as the invented child and the practice of childhood over positivistic developmental criteria (Cahan et al., 1993). Critical youth studies research has discussed ways young lives have been studied over time and how groups have historically been marginalized (Tilleczek, 2014). From this perspective it has been outlined that adult imperial understandings of young people have historically been corroborated by societal ideologies and empowered by the institutional values, which has marginalized youth voices in society (Cahan, Mechling, Sutton-Smith, & White, 1993).

From a social construction lens mental disorders are not considered “set in stone” but have been constantly “defined and redefined” throughout socio-historical periods (Gross, 2009, p. 124). The psychological concepts used to define and classify disorders are seen as pliable and are reified through scientific testing and quantitative records.
(Danziger, 2003). Yet psychiatric labels are often portrayed as “accurately reflecting the objective organization of the world they lived” (Danziger, 2003, p. 26). The lived experiences of youth are hidden in these reductionist approaches to youth mental health where labels may not accurately reflect youth biographies and may pathologize their behaviour.

A critique by social historians is that the classification of mental disorders was not constructed by those who “bestowed the label” yet “when people find themselves and their actions characterized in a particular way, their self-perception and their behaviour can be greatly affected” (Danziger, 2003, p. 27). Defining what is normal or abnormal is a powerful position to have and it has life altering consequences for those being classified as it affects the types of treatments made available from confinement to outpatient models of care (Foucault, 1988; Reaume, 2002). Critical youth studies and social history have formed the theoretical framework of this thesis, which in turn guided the research questions, project design, and analysis.

3.4. Methodological Approach

If the epistemic stance is a justification for what constitutes accepted knowledge formation, then methodology guides and offers theoretical justification for what methods are chosen to collect data and implement the research design (Carter & Little, 2007). The methodological approach included elements of critical ethnography and narrative analysis presented through a critical youth studies theoretical framework (Tilleczek & Kinlock, 2013). The emphasis was to understand deeper roots of problems and the connections between psychological, social, and institutional interrelationships. Socially a young person is not on equal footing with their teachers, counsellors, or psychiatrists. Being
aware of this relationship was important because among community role models and people of authority youth voice and autonomy has often been lost (Tilleczek & Kinlock, 2013). These critical approaches have challenged the standardized and statistical ways of knowing youth, which had become the status quo in education and health research (Tilleczek, 2014). Critical methodologies have uncovered how meaning within social, political, and economic systems revealed experiences of participants (Morrow & Brown, 1994). From this lens the structures that have impacted participants may be socially and historically situated with researchers being attuned to the subjective experiences of participants (Morrow & Brown, 1994).

3.4.1. Narrative analysis. Use of narrative analysis in my research has reflected what Larsson and Sjöblom (2010) described as narratives based in a sociological approach, grounded in social construction. These authors explained that narrative research has given marginalized groups a voice when “recapitulating what happened to them” (Larsson and Sjöblom, 2010, p. 274). The analysis of narratives proposed by Chase (2005) is relevant because it outlined how paradigmatic reasons have enabled and constrained participants (i.e. barriers and facilitators) by their social resources (i.e. services for mental health) as understood through how the narrators develop their interpretations (i.e. youth narrative experiences).

The inclusion of narrative summaries in this thesis, found in chapter five, ensured participant journeys were not fractured and interpreted out of context. It is important to honour the effort and courage of each participant in sharing these individual stories. For example, previous narrative inquiries into the barriers and facilitators of mental health pathways revealed tensions and contradictions youth faced throughout complex,
sometimes paradoxical, journeys to care (Boydell, Pong, Volpe, Tilleczek, Wilson, & Lemieux, 2006; Tilleczek & Lezeu, 2014). Through self-narrative, youth have created biographical stories of meaning over time and place (Tilleczek, 2014). The stigmatization and marginalization of youth have been addressed in these works “through life stories, biography, and narratives of young people and their communities” (Tilleczek, Ferguson, Campbell, & Lezeu, 2014, p. 63).

3.4.2. Critical ethnography. The narrative analysis was merged with critical ethnography, which represented a “responsibility to address processes of unfairness or injustice within a particular lived domain” (Madison, 2012, p. 5). Critical ethnographic research has aimed to change conditions toward more freedom or equity for those who experienced the phenomena of study and to ultimately disrupt the status quo and underlying operations of power and control (Madison, 2012). Critical ethnographies have provided politically active critiques of the data through cultural critiques of marginalized situations in relation to public policy processes (Foley & Venezuela, 2005). Youth voice plays a vital role and the researcher presents stories that would have otherwise been “restrained” or “out of reach” (Madison, 2012, p. 6). Critical ethnographic perspectives with, for and by youth have unveiled the dynamic individual and institutional relationships youth have with their environments (Tilleczek, 2014; Tilleczek & Kinlock, 2013). For this thesis, the goal was to bring marginalized voices to youth mental health research to provide valuable insight for policy and social change.

The inclusion of both narrative and critical ethnographic methodologies is congruent with the constructivist epistemic stance of this study and the research questions explored. The work of Taber (2010) discussed the power of combining narrative and
ethnographic methodologies to understand how personal stories and experiences fit into the greater organizational and social structures. In health research, ethnographic work has produced insights into medical value systems, the culture of medical schools, and insights into everyday life of medical workers (Atkinson & Pugsley, 2005).

3.5. Methods

The current section outlines the research methods taken to collect and analyze the primary data for this thesis. Patient journeys data was collected from eight (N=8) youth aged 13-18. Participants were diagnosed with anxiety (n=7) or self-identified as having anxiety (n=1) and had received some type of treatment for anxiety from the mental health system. As discussed in the introduction, the ACCESS-MH interview protocol, consent forms, and survey were used during participant data collection (see Appendices 1, 2, and 3). The guiding research questions from the qualitative ACCESS-MH data are: What are youth perspectives accessing and receiving treatment for anxiety in the mental health system? What has facilitated positive experiences throughout this process? What barriers have impeded their treatment and produced negative experiences?

3.5.1. Sampling criteria. The research design was inductive and emergent. The decision to focus on youth anxiety disorders developed over time after conversation with educators and stakeholders regarding the major issues facing youth mental health in communities. The target sample was for youth, aged 13-18, with any anxiety related disorders, either formally diagnosed, still seeking formal diagnosis, or who self-identified. This could be described as criterion purposeful sampling where youth needed to fit these conditions to be included in the study (Miles & Huberman, 1994). Stakeholders in the mental health community, including medical professionals,
community mental health workers or groups, educators, parents and youth organizations were all contacted to help with recruitment. Snowball sampling was used during recruitment as mental health champions and advocates in various communities referred willing participants who were comfortable sharing their story to the project. A table listing the participants sampled is presented at the beginning of chapter five.

3.5.2. Interview data. The sample of narratives used for this thesis was a combination of interviews I conducted (n=4) and interviews conducted by colleagues on the ACCESS-MH project (n=4). The ACCESS-MH team created the research instruments used to collect this data such as, the interview protocol (see Appendix 2), the consent forms (see Appendix 1), and the survey where participants provided information such as diagnosis, age, and gender (see Appendix 3). The interview process was designed to be open-ended and conversational following the semi-structured interview protocol. For further information on the qualitative data collection approach of ACCESS-MH see Tilleczek and Lezeu (2014) and Tilleczek, Bell, Munro, and Gallant (in press). The analysis of the narratives for this thesis (N=8) is considered a secondary analysis from the ACCESS-MH dataset.

3.5.3. Qualitative rigour. Rigour and effective design elements are important for qualitative research to be accepted as credible contributions to scientific knowledge. In reaction to the post-positivist critique of qualitative research, Lincoln and Guba (1985) proposed criteria to establish accountability and trustworthiness in qualitative research, outlining the framework for credibility (as compared with internal validity), dependability (as compared to reliability), confirmability (as compared with objectivity), and transferability (as compared with external validity). Some qualitative researchers
though have questioned these parallel terms with quantitative methodology stating that qualitative research is based on relativity and should resist having rigid standards (Barusch, Gringeri, & George, 2011). However, it is important to outline what criteria have been used to establish the legitimacy of the data analysis and to explain the choices made throughout the research process.

Measures to ensure rigour included engagement with the mental health community, field notes, peer debriefing, thick descriptions of the narratives, and reflexivity, as listed by Lincoln (1995). I engaged stakeholders at various levels of the mental health system, such as policy makers, educators, medical professionals, and community mental health workers, along with youth and parents to gain perspective on the central issues facing the youth mental health system today. Feedback from these communities helped focus the topic of this thesis to study youth anxiety treatments and services. The ACCESS-MH team peer debriefed and collaborated on initial findings and reviewed research methods and field notes throughout the data collection process. Pre- and post-interview field notes were taken to provide context and reflection during the interview process. Full descriptions of each interview narrative and direct quotes from participants are presented in chapter five to ensure stories were not analyzed out of context. This ensured that the results of this thesis remained grounded in the experiences of the participants. The thematic analysis is discussed later in this chapter and displays the analytic process and coding of the narratives.

3.5.4. Youth ethics. The ACCESS-MH project received Research Ethics Board (REB) approval from the University of Prince Edward Island (see Appendix 4), as well as approval from Saint-Mary’s University, University of New Brunswick, and Memorial
University. Additionally regional health authorities in PEI, NB, and NL provided REB approval for any recruitment through hospitals or community health. Any school boards contacted for recruitment also provided REB approval to recruit youth and parents through the education system. As a graduate student on the ACCESS-MH I received REB approval to use a sample of the data for this master’s thesis and for future publications. Participants who were the age of consent in their province (18 years old in PE, NS, NL; 19 years old in NB) signed their own consent forms and those who were below the age of consent had a form signed by their guardian. Participants consented that their data could be used in the analysis and anonymous quotes could be published (see Appendix 1).

The Research Ethics Board of UPEI classified this study as “minimal risk”, however youth with mental disorders were still considered a vulnerable population and the data collected for this project was considered extremely sensitive. Each graduate researcher on the project received patient journeys training by Dr. Tilleczek and the ACCESS-MH Principal-Investigation team regarding how to handle any disclosure of abuse or violence, contact information if any mental health crisis occurred, and specific criteria for dealing with mental disorders of youth, and steps to ensure consent (Tilleczek & Bell, 2014). Additionally I obtained the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2) ethics certification.

The Young Lives Research Laboratory UPEI managed the data storage of all ACCESS-MH interviews (for more information see http://katetilleczek.ca/). To adhere to the TCPS2 data management standards the qualitative data management protocols of Young Lives Research and UPEI Robertson Library were followed for ethical storage of all project data throughout analysis. Each piece of participant data was de-identified and
labeled with an ID code. All interview transcripts were scrubbed of identifying names, places, or programs including geographic information and the names of services used. Participants were given pseudonyms. Recruitment, data collection, and analysis were completed with complete confidentiality.

3.6. Narrative Analysis

As discussed in chapter two there were gaps found in recent mental health literature that documented qualitative experiences of youth in the mental health system. Two examples were found where thematic analyses of barriers and facilitators were analyzed, regarding youth help-seeking behaviour (McCann, Mugavin, Renzaho, & Lubman, 2016) and mental health detection in primary care (Knight, Vickery, Fiks, & Barg, 2015; McCann, Mugavin, Renzaho, & Lubman, 2016). More relevant to this thesis work from Boydell, Pong, Volpe, Tilleczek, Wilson, and Lemieux (2006) provided literature on barriers and facilitators of youth pathways to access mental health care in rural Ontario from the perspective of parents/families.

The results from Boydell et al. (2006) identified personal barriers (stigma, information, financial) and facilitators (word of mouth, advocacy), systemic barriers (human resources, policy, funding, wait times, invisibility) and facilitators (personalized and localized services), environmental barriers (distance) and facilitators (small size). These themes provided a template, or framework, from which to interpret the narrative data analyzed in this thesis. However my research questions focused specifically on how youth were treated in the system from their own perspective, which produced different coding and thematic criteria.
3.6.1. **Narrative summaries.** Interview transcripts ranged from 6 pages (15 minute interview) to 47 pages (1.5 hour interview) in length. Given the conversation style interviewing there was a broad range of content was covered when describing journeys through the mental health system. Full interview transcripts were shortened and summarized into narrative summaries, presented in chapter five. This stage of the analysis established a chronology of events for each narrative given that the raw interview transcripts naturally “jumped around” the timeline. The inclusion and exclusion criteria focused on treatments, services, and experiences in the mental health system. Narratives were focused on contextual information regarding early signs of anxiety, other comorbidities, how anxiety impacted various aspects of their lives such as in school, what important figures were involved in their journey, how they experienced being treated by the system, where they sought treatment, how they experienced barriers and facilitators, and ideal outcomes and improvements to the system. Narrative summaries were relatively inclusive of transcript materials in order to paint a portrait of their journeys to date.

Two participant narrative summaries included information provided from parents. In both cases these interviews were relatively short and the participants were not overly comfortable sharing full details of their journey. Although it was important to maintain youth perspectives in these narratives it was also beneficial that add parent input to contextualize journeys when the participants did not provide long interviews, i.e. they could not recall exact details of their journey or were not comfortable elaborating in great detail.

Presenting the narrative summary data in the main body of the thesis ensured that each participant’s individual story would be heard and displayed without fracturing his or
her experiences. “Narrative analysis attempts to hold lives and experiences in context and avoid fragmenting or reducing” in order to understand their unique journeys and see their own biographical interpretation (Tilleczek & Campbell, 2014, p. 53). I felt this to be an important aspect of my research aim to include youth voice in health care research. As an analytic tool this helped me visualize each participant’s journey, to contextualize the themes developed from this data while keeping themes grounded in the experiences of youth.

3.6.2. Thematic analysis. Next, a thematic analysis was completed, which organized common experiences around barriers and facilitators of participant treatment through the mental health system. These results can be found in chapter six. This analysis reflected what Braun and Clarke (2006) proposed as theoretical thematic analysis. From this perspective the researcher actively searches for patterns of meaning in the data “driven by an analytic interest in the research area” while still keeping interpretive depth (Braun & Clarke, 2006, p. 84). This thematic approach has been useful in health science research when a particular gap in health care needs answers (Crabtree & Miller, 1992).

Patterns of meaning were coded to document which treatments were accessed, where treatments took place, and with/by whom participants were treated. The term treatment was applied in a broad sense of how youth have been treated medically, therapeutically, and socially by the groups and institutions that provide mental health care. Treatments observed and coded included:

- Received through school/guidance counsellors.
- From family physicians and paediatricians.
- From psychiatrists.
• From psychologists, community counsellors, social workers.
• Through inpatient acute care programs or the ED.
• Group therapies.
• CBT and other psychological therapy.
• Pharmacotherapies.

Common treatments were observed across the sample of narratives. After this coding structure was established a second level of coding analyzed how the participant experienced each of these treatments and documented what meanings were attached to these events. For example, if the phenomenon was experienced as a positive step toward mental health care then I asked what facilitated this. Or if it was experienced as a negative step toward mental health care then what barriers were in place that prevented it? These results were grouped into barriers and facilitators included quotes from participants that expressed these experiences and how they were treated in the mental health system.

3.7. Chapter Summary

This chapter summarized the methodological approaches of the interviewing and narrative analysis components of the thesis. The data collected presents the stories of youth who have sought treatment for anxiety and highlights their common barriers and facilitators when being treated in the system. However, integral to the methodological approach, as discussed above, is the understanding that social historical structures impact our concepts and treatment of youth as well. The next chapter discusses the methods, scope and findings of the social historical component of this thesis.
CHAPTER 4: SOCIAL HISTORICAL FINDINGS

4.1. Chapter Outline

The current chapter presents the social historical methods, scope and findings and explores the social historical research questions outlined in the introduction, namely:

What are the social and historical developments in understanding youth and anxiety over time? How can this social history inform our understanding of youth and anxiety treatment today?

This chapter is unique and challenging because it belongs somewhere between the literature review, methodology, and results. The social historical framework has influenced the research design and analysis of results for this thesis and is congruent with the critical ethnographic methodologies that emphasize the power of social and historical structures operating on individuals in cultural, political, and economic ways (as outlined in chapter three).

The social historical review undertaken displays a gap in historical and contextual literature that traces the evolution of youth anxiety disorders in society. My work does not attempt to write this history and no primary historical data was collected for this thesis. Instead, a number of seminal historical works are introduced and synthesized specifically to paint a portrait of how mental disorders have been treated through modern history. Historical information presented in this chapter dates from approximately the turn of the twentieth century to the turn of the twenty-first century. However the goal of this chapter is not to report a timeline of events but rather to raise important themes and debates regarding how youth, anxiety, and mental disorders have been conceptualized,
diagnosed, and treated throughout modern history and how this might influence our understanding of the same criteria today.

This chapter begins by detailing the scope of the historical review and texts surveyed, followed by an introduction to the rise of anxiety in the twentieth century. Included in this section is a discussion of diagnostic and treatment developments over the same period. The subsequent section examines the psychiatric discourse or paradigm as presented through seminal works in the history of psychiatry and examines how this position affects patient voices and autonomy in the system.

4.2. Scope of Historical Review

Searching for literature on the history of anxiety in databases such as OneSearch was difficult because the term history often produced articles referring to someone with a “history” of a certain disorder. One article was found regarding the social construction of anxiety (Dowbiggin, 2009). The SAGE journal History of Psychiatry was chosen to find additional articles that could be relevant to contextualizing the history of anxiety disorders in youth. Terms youth and anxiety were searched. Of the 60 results produced, one article was included in the review (Mallet, 2006) and one book had been reviewed and therefore the book was selected for inclusion (Horwitz, 2013). Other articles were excluded because they did not discuss anxiety disorders specifically despite being posted in the search results.

Google Scholar was searched for additional articles, books, and grey literature that pertained to youth, anxiety, and history. Only one article (Treffers & Silverman, 2011) traced the history of youth anxiety research. This article is an introductory chapter to a child and adolescence anxiety textbook. Another article documented historical works
that impacted psychiatry (Martin & Rhodes, 2004). I did not identify other textbooks or articles that included sections on the history of anxiety disorders and youth. Next, the terms *social construction*, *anxiety*, and *youth*, were searched in Google Scholar. One peer-reviewed article (Beesdo, Knappe, & Pine, 2009) discussed social developments of anxiety disorder classification and was included in the review.

Following these reviews attention was given to seminal writings in the history of mental disorders to better understand diagnosis and treatment through time and in society. Writings in the history of psychiatry from Foucault (1988), Healy (2002), Reaume (2002), Szasz (2011), and writing from the history of psychology from Danziger (2003) and Harris (1979) were reviewed. I note that these are not traditional or great figure approaches to history (Furumoto, 1989) but are critical historical works in the field. They are therefore congruent with the critical methodology of this thesis. The aim was that these works would shed light on current themes and debates, and critique the status quo, in youth treatment today.

### 4.3. Rise of Anxiety in the Twentieth Century

Horwitz described that in the early twentieth century anxiety was considered the “malaise of upper-middle classes”, when people began expecting a medical name for their general worries and sadness in society yet did not want to be institutionalized or seen as “mad” (2013, p. 71). He explained that anxiety diagnostic criteria as we know it today became ubiquitous in the 1950s and has continued to gain more prominence ever since (Horwitz, 2013). The mid-century has been labeled the *age of anxiety* after decades of nuclear stockpiles, energy crises, disease outbreaks, genocides, and international terrorism posed potential threats to society (Dowbiggin, 2009; Horwitz, 2013). Coupled
rise of political rhetoric and instantaneous media, which occupied the minds and attention of more and more people the idea of fear became more prominent throughout Western societies (Dowbiggin, 2009; Horwitz, 2013).

The mid-twentieth century also brought the conceptualization of the term adolescence, which has been interpreted by some as a social reinforcement of the standardized categorization of abnormal behaviours in youth (Mallett, 2006). There was a significant rise in the classification of youth delinquency after the Second World War along with a rise in consumerism and expanded education models, which in many ways normalized and institutionalized what was considered “normal” adolescent behaviour (Elder et al., 1994; Tilleczek, 2011). These changes were reinforced by Erik Erikson’s popular work Children and Society (1963), which viewed juvenile delinquency in relation to public schooling and economic values (cited by Elder et al., 1994). What was lost in this era of rapid social change, according to Elder et al., was consideration for “time, process, and context” because young lives have always been changing in a changing society (1994, p. 11). Efforts to place youth back into social and historical contexts have carried into the present day in the “new” sociological studies of children and youth (for example see Leonard, 2015; Tilleczek, 2011, 2014). This kind of work calls for interdisciplinary approaches that move beyond medical and psychological research and understandings that have dominated the status quo.

4.3.1. Development of diagnostic criteria. According to Treffers and Silverman (2011), scholars have often referenced Freud’s (1909) Little Hans and Watson and Rayner’s (1920) Little Albert studies as early “pioneers” in youth anxiety research. Although these works gained wide traction academically and in the cultural zeitgeist,
critical histories of psychology have uncovered *origin myths*, which promoted certain pioneering works and their methodologies to validate the status quo of the discipline (Harris, 1979). For example, the literature that propagated Watson and Rayner’s work “painted an inaccurate picture of how Albert’s fear initially generalized” and “misrepresents the ease with which Albert was conditioned” (Harris, 1979, p. 156). Often classic studies have been misrepresented which has built a false sense of continuity in the histories of psychological disciplines (Harris, 1979).

In the early twentieth century new anxiety research began to focus on youth and anxiety. Research areas included the study of nervous temperaments, heredity, education system, family upbringing, panic attacks, and anxiety as a medical symptom of emotional disorders (Treffers & Silverman, 2011). Categories for panic, agoraphobias, obsessive-compulsive disorder, and social phobias became implemented in adult diagnostic literature, along with “shell shock” categorized as a result of the psychological impacts of the First World War (Horwitz, 2013).

Standardized categorization for youth mental disorders did not appear until the APA published the *Childhood Psychology Report* of 1964 (Mallett, 2006). This led to an expansion of both youth related disorders for the DSM-3 (1980). Youth specific nomenclature for anxiety was limited. The expansion from DSM-3 added to conduct and oppositional disorders, which made juvenile delinquent behaviours such as stealing, lying, and joining certain peer groups a diagnosable problem for the first time (Mallett, 2006). These developments aligned with the social and political climate of the time.

Mallett has challenged the peer review process taken by the APA during the twentieth century, citing low levels of scientific reliability and validity for the DSM
criteria expansion of conduct and oppositional disorder, pointing to a shift toward educational and organizational value systems in America during this era as the catalyst for change rather than empirical evidence to support the categorization of youth categories in the DSM (Mallet, 2006). That value system positioned young people who did not fit social norms as delinquents and conceptualized their behaviours as abnormal. This could be seen as further marginalizing particular groups of youth.

For much of the twentieth century psychodynamic and cognitive-behavioural paradigms co-existed as leading frameworks for etiological explanations of disorders and therapeutic options (Horwitz, 2013). With the publication of the DSM-3 (1980) anxiety and depression were split into specific disease states and all disorders were presented a-theoretically, only listing symptomatology with no etiology or suggested treatments (Horwitz, 2013). This opened the door for a market-driven response to treatment options and removed any theoretical discussion of the cause of mental disorders from the diagnostic process.

4.3.2. Development of pharmacotherapy. The rise of the biological and pharmacological paradigms toward the turn of the twenty-first century marked a major cultural shift in how mental disorders are treated. Pharmacology in the US in 1960s “made it appear to anxious people that relief was just a prescription away” (Dowbiggin, 2009, p. 432). After a continued increase in the use of psychotropic medication in the 1970s, the FDA attempted to crack down on this trend and determined that anxiolytic medications “must target a specific disease” not the “stress of everyday life” (Horwitz, 2013, p. 126). Librium and Valium were marked as schedule four drugs with strict
restrictions and they denied pharmaceutical companies the ability to market them as anxiety and depression medications (Horwitz, 2013).

According to Horwitz these restrictions by the FDA had the opposite effect. Marketing became more covert and less apparent to consumers by giving physicians samples of their products to offer to patients, and more specific disorders in the DSM allowed pharmacotherapy to continue to grow. The DSM-3 (1980) split anxiety and depression into specific disease states which made it easier for diagnosing and medicalizing despite the high amounts of comorbidity that resulted in this move (Horwitz, 2013). Further, this marked a major ontological shift in the nature of anxiety and its perceived causation. With pharmacotherapy not being prescribed for the anxiety of social life the causation became internalized into specific disease states that had chemical causes not social for which medication could be prescribed (Horwitz, 2013).

Some of the earliest psychotropic testing for youth was reported in the works of Nissen (1976) who proposed the possibility of drugs for behavioural disorders in children and Renshaw (1975) who researched psychopharmacology for children (as cited by Martin & Rhodes, 2004). Early youth testing of lithium as a treatment for bipolar and depressive disorders dates back to DeLong (1987). It was not until the 1990s that a wave of selective serotonin reuptake inhibitors (SSRI) began being prescribed for youth ushering in what has been considered the age of depression (Horwitz, 2013).

In the 1990s psychiatry became more involved with the medicalization of mood disorders for youth (Healy, 2002). This included youth with depressive or anxiety related issues becoming treated with severe personality disorders: “Given the large number of them they could not be abnormal in the sense of being outside the normal range for
personality variations or nervousness” (Healy, 2002, p. 348). Before this time it was “all but taboo” for psychiatric drug treatments to be prescribed for children and youth; “Clearly some change was to be welcomed, but mass treatment on the scale that developed by the mid-1990s indicates a profound cultural shift” (p. 348).

These moves had a marketing component as well. SSRIs were originally marketed for anxiety, but due to limited proof of efficacy and poor public uptake they were then marketed for mood disorders (Horwitz, 2013). As we have discussed in chapter two, SSRIs are now the number one mood and anxiety medication given to children and youth in Canada with approximately 1 in 15 young people in Canada receiving a prescription at some point in their life (CIHI, 2015). The rise of SSRIs and youth anxiety points to a new era of anxiety, one with a vested interest in the pharmaceutical developments of youth treatments within the cultural acceptance of medicating the rise of youth anxiety symptoms.

4.4. Psychiatric Discourse

In empirical research the discursive nature of psychiatry is often taken for granted yet it is the primary tool psychiatrists use to measure and diagnose disorders (Danziger, 2003). Diagnostic categories such as multiple personality disorder and post-traumatic stress disorder have not been constructed by those who “bestowed the label… that is the patients themselves have not been able to supply meaningful feedback to psychiatric institutions and are thus not integral to the diagnoses” (2003, p. 27). The social historical work of Foucault’s *Madness and Civilization* (1988) described the void between reason and madness. Foucault writes, “The language of psychiatry, which is a monologue of reason about madness, has been established only on the basis of such a silence” (1988, p. 38).
xi). Toward the end of the nineteenth century the powers of the doctor grew through the medical appropriation of madness and the rise of positivism in medicine and psychiatry shifted the power from the asylum to psychiatry (Foucault, 1988).

What can be taken from this work from the perspective of youth in today’s mental health system? It appears that there is a growing void between young people’s social lives and the psychiatric system that is trying to make sense of, diagnose, and treat the recent rise in anxiety. A lack of understanding or communication exists between these various positions of interest, which raises potential issues around the psychiatrization of anxiety in youth. If youth perspectives are not considered within this silent discourse or monologue delivered by psychiatry about youth, power inequalities that have plagued psychiatry historically will go unanalyzed.

4.4.1. Patient voice. Szasz wrote in The Myth of Mental Illness: 50 Years Later (2011) that we should view those with mental disorders as patients who are able to seek, reject, and negotiate diagnoses and treatments. This is what Szasz called the “ethical injunction” that Western treatment has been based on - to allow for choice and decision making - whereas the psychiatric model has functioned under the moral assumption that the patient was a danger to himself or herself and to society (p. 181). Szasz has been a staunch critic of the connotation of the term mentally ill. He has written that those afflicted by this “illness” removes liberty and responsibility whereas the term patient allows for more freedom and choice (2011).

The work of Szasz is controversial because labeling mental disorders as illnesses has proven important in the promotion of mental disorders as legitimate, fundable, and treatable aspects of our healthcare system (Kirby & Keon, 2006; MHCC, 2012). This has
undoubtedly helped in the de-stigmatization of mental disorders. The medicalization of the language may have contributed to the increased rhetoric surrounding the fight against the mental illness, a powerful metaphorical shift, which has also been seen in the fight against, and subsequent de-stigmatization of, cancer and AIDS (Childress, 2012).

What should be taken from the work of Szasz in relation to youth is that patient voice should be considered in research and the evaluation of anxiety treatment. Youth mental health patients and service users should have the opportunity to seek treatments and have power when negotiating care within these complex systems. It may be difficult for young people suffering from anxiety symptoms to communicate and advocate for treatment options, which is why the healthcare system must be sensitive to the unique ontological challenges youth face when seeking treatment and voicing these issues.

Reaume (2002) discussed the movement toward the end of twentieth century that saw those with mental disorders challenge the nomenclature and rhetoric around labelling diagnoses. He traced the evolution of terms such as lunatics, the insane, to inmates, patients, survivors, and eventually consumers or clients of the system (Reaume, 2002). These changes helped groups of mental “patients” to organize and advocate and escape the patronization and oppression from mental health institutions (Reaume, 2002). The trend has represented the move toward mobilized action and representation of groups who have been marginalized by the mental health systems through increased personal autonomy to advocate for changes in treatments. The rhetoric, nomenclature, and language used to define and conceptualize mental health have impacted the position youth have within the mental health system.
4.5. Chapter Summary

This chapter outlined social historical shifts throughout the twentieth century that have effected how youth, mental disorders, and anxiety have been constructed. The construction of these categories has implications for how anxiety and youth are treated within the system. These works also point to social, cultural, and economic factors that influenced anxiety diagnosis and treatment throughout the rise of anxiety in the twentieth century. An important theme that emerged from this discussion is the missing voices and stories of those who bestow psychiatric labels, marginalized within economic and psychiatric systems. In the next section, the narratives of youth who are currently seeking treatment for anxiety in Atlantic Canada are presented in the form of narrative summaries. It is instructive to see how the portrait painted by social historical literature is portrayed through current youth narratives.
CHAPTER 5: NARRATIVE SUMMARIES

5.1. Chapter Outline

A tremendous amount of gratitude goes out to the participants for the courage and energy to share their experiences for this research study. These journeys are snapshots of eight youth who are currently living with anxiety disorders and they have shared their experiences, to date, within the mental health system. Each participant is at different stages of their journey and these are ongoing stories. Some of the younger participants are just beginning while the older participants were able to reflect and better contextualize their experiences. Seven of the eight participants chose to have their interviews audio recorded and one chose not to. Below Table 1 lists the participant information by their pseudonym. Following this section, each participant’s pseudonym is listed followed by his or her narrative summary. Note, the Richard interview was conducted without audio recording and full direct quotes were not possible.

Table 1. Participant Sample

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Interview Date</th>
<th>Interview Age</th>
<th>Identified Gender</th>
<th>Diagnosis (Date)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mary</td>
<td>July 19/16</td>
<td>18</td>
<td>Female</td>
<td>Anxiety (2016), Social &amp; Generalized</td>
</tr>
<tr>
<td>Nicole</td>
<td>Dec 18/16</td>
<td>15</td>
<td>Female</td>
<td>Anxiety (2015)</td>
</tr>
<tr>
<td>Richard</td>
<td>April 5/16</td>
<td>14</td>
<td>Male</td>
<td>Anxiety (2005)</td>
</tr>
<tr>
<td>Al</td>
<td>April 18/16</td>
<td>18</td>
<td>Male</td>
<td>Anxiety (2008, Self ID)</td>
</tr>
<tr>
<td>Scott</td>
<td>July 13/15</td>
<td>18</td>
<td>Male</td>
<td>Anxiety (2013)</td>
</tr>
<tr>
<td>Elsie</td>
<td>July 13/15</td>
<td>18</td>
<td>Female</td>
<td>Anxiety (2013)</td>
</tr>
</tbody>
</table>
5.2. Mary

Mary recalled that her first troubles with mental health date back to grade 7. She was suspended from school for something she and her friend did but she did not fully explain what that was. Mary did not return to school until grade 11 however she did not elaborate on what took place in these years beyond the fact that she felt isolated from friends and began socializing less. Mary’s friends at that time got into drugs and partying and as a result Mary tried to distance herself from them. Her anxiety would manifest primarily in school and in social situations. Mary said:

I noticed that I would get really panicky in public and stuff, like I couldn’t talk to people, or I couldn’t order my own food. Like I still can’t, but I just noticed that there was something weird. And I just called myself socially awkward because I just thought I was weird. And then I kind of started like understanding it a bit more, and I would search up stuff and it would show, like, oh, you have anxiety, and I’m like, oh, okay, cool… I couldn’t do presentations, I couldn’t talk… everybody thought I was mute for a really long time.

Mary reflected, and explained that she had been, what she called, “mentally abused” at home and that she had a lot of family problems growing up. She would be really nervous to eat in front of her family and be around them so she “shut herself away” as she put it. At the point of the interview Mary lived with a guardian and had limited
relationships with her parents and grandparent, although they are aware she was having mental health issues.

After missing years of school she returned in grade 11. At this point her guidance counsellor stepped in and took a vested interest in her well-being. Mary would see her guidance counsellor daily at school, which built a very strong relationship and was an essential support for her going through school. Mary explained:

She just kind of got it. And she told me a lot about her experience with stuff too, and like her mom was crazy, and my mom was too. And she said like she dealt with some anxiety and stuff, she said not as severe as I did, but she just kind of like understood and, I don’t know, she just was always there when I needed it.

Mary worked hard to get good grades in school after missing so much time before high school. “I worked really hard at it. Because I found school kind of helped me take myself out of that and focus on something else.” Getting over the anxiety was not easy:

At the end of it, like at the end of this semester I was kind of like speaking up in my English classes and stuff, just so I could get the extra marks, because I knew if I didn’t I was going to fail. But it was really hard to do, and after it, like I would just sit there, like cry.

Her teachers sent out a note saying that Mary was not to do any presentations unless she was comfortable with it.

Mary’s anxiety required more support outside of school. She told her guidance counsellor she had suicidal ideation and then was quickly referred to community mental health for group therapy and eventually one-on-one sessions. Mary said:
I was in group therapy for six weeks… And then I had like a follow-up session with the mentors from it and they were just like, ‘oh well you can do another session of group therapy’. I’m like, ‘this is bullshit, like give me CBT or something because this isn’t working’. So they were like, ‘okay’. And then I was in with one therapist for like two months, and she wasn’t helping at all. So then I got referred out again, and I had to wait for like two months… I didn’t wait to be like her client anymore, but then I had to be referred out again. And then I had to meet with like a psychiatrist, and he retired and then- yeah, so it’s a big mess right now.

Before the psychiatrist retired, a few months before this interview, Mary did see him for three sessions and received a formal diagnosis. She said her other community therapists and guidance counselors couldn’t legally diagnose and told her to bring up issues of diagnoses with her psychiatrist. He diagnosed her with social anxiety, generalized anxiety and depression.

The sessions with a psychiatrist were not very productive and Mary described them to be “strange.” She explained:

Like the last time I was there he was like, ‘well what do you want from this?’ I’m just like, ‘I don’t know’. And he’s like, ‘well why did you come see me?’ I was like, ‘because you guys told me to’. So I don’t know; it was really strange. And then I was like ‘okay well just give me some medication or something’ just to shut him up. And he was like, ‘okay’.

First the psychiatrist prescribed Mary an SSRI but that did not go well: “I think it was Prozac. And that was just a shit show… everybody else seemed to think it was making,
like, my suicidal ideation a lot worse, so they just made me stop it completely.” Her psychiatrist took her off Prozac after a month and they tried a different SSRI, Zoloft, which she continues to take at the time of the interview.

Mary said that for many years she was against medication. She worried about what it would do to her. But she decided that it would be okay to try it. “I am trying everything, because it got so hard to handle on my own that it was like I couldn’t function enough to use the techniques to chill out. And instead I would just like have panic attacks all the time, or like anxiety attacks. And like, I just needed something to like calm me down enough that I could maybe start using those techniques to chill out.” At first the goal was to just have something to take when needed but now it is something that she takes every day in a low dosage. When asked if this had made a difference she responded, “It is not as good as I’d want it to be, but it’s definitely helpful, because if I don’t take it I notice a big difference.” Now that the psychiatrist is retired Mary is waiting to see a new psychiatrist who will be available in another month after the interview date.

Mary explained that she often thinks about jumping off a bridge. When she tells her therapist this she is adamant that Mary go to the hospital. “I told her all they’re going to do is pump me full of more drugs, and keep me in a room.” Mary has never been to the Emergency Department for her mental disorders but she has heard stories from friends that have made her not want to go. She explained:

My friend recently – just before school finished – she OD’d on 60 Tylenol, and she had to go get like her stomach pumped and stuff. And she self-harmed really, really bad. And she lost like way too much blood, she almost died. And they just gave her a bunch of drugs, and she was crazy for like three days, because it took a
while for it to kind of like come down in her system. And she was off the wall. So I don’t want to be like that.

The only other alternative offered to Mary was a crisis unit number to call if she felt suicidal but she said she hates talking on the phone so it is not an option for her.

Despite these differences of opinion Mary still feels her current community therapist is better than her previous one. She complained that her previous therapist would do therapeutic activities that she did not feel were legitimately helping her. The therapist told Mary to tap her fingers and think of my cloud and Mary responded, “all-righty bud”. She wanted something more concrete. Mary also described her first therapist as a “pill-pusher” and pushed medication from the start, “before she even like assessed me or anything”. The current therapist though, Mary feels, does more concrete tasks such as CBT. Mary wants to continue with these types of therapies and work toward goals to feel like she is developing better coping skills.

Wait-times have been a barrier at various points of the journey. Wait-time for her school guidance was only a week and once she got it she was able to see her counsellor anytime she wanted. For community therapy Mary said that it took her about three months to get into group therapy and another three months to see a one-on-one therapist. Her psychiatrist took three to four months. “You might have lesser symptoms than when you tried to receive mental health care, because you might just end up taking it into your own hands and dealing with it that way, but then sometimes it might be too late.”

Once Mary entered into the system she has had relatively consistent access to therapists, even though the treatment options have been limited. “I honestly think that, like, the school was better than therapy just because like you have access to it all the
time, like at all times…Guidance was awesome, just like everything like that. Yeah, I
didn’t have to make an appointment and she’d just like, here you go, I’ll see you
tomorrow, and I’m like okay.” Mary’s guidance counsellor went above and beyond her
job, at one point she paid for Mary’s application fees for university and even though she
is now out of school her counsellor still checks in to make sure things are okay. The
school would accommodate when Mary needed time to cope with class and stress.

At the point of the interview Mary had finished school and no longer had access
to their guidance counsellor. When asked where she would now go in a crisis situation
now she responded with laughter, “My bedroom…and hide away from the world.” When
asked if her other service providers have offered any viable options she said, “No, my
psychiatrist just told me to … he asked me one time if I had a good imagination and I
said, yeah. And then he asked me if I could ever think of pretending to be in the guidance
rooms, and I was like, I’m not that creative.”

Mary said that if there is a crisis you can get a bed at the hospital for what they
call a “72-hour hold” but if things are more severe they have to send you to a larger
mental health facility in another city in the province. “It would be good to have
something like that here, because it’s- like I would have an easier time going if I knew I
wasn’t going to be shipped to [larger city] tomorrow”. She continued, “So it’s- I don’t
know. It’s hard to have motivation to go and seek more help when you’re scared you’re
going to get shipped away.”

Mary said that the more severe you are the more help you get and she does not
think that is fair. “A lot of the time I was scared to even reach out and get help because
I’m like okay, I don’t think I’m sick enough… like it sounds stupid, but you want to be
sicker so you get the help that you need.” Mary was made a higher priority after she told people she was suicidal and that the wait time would have been much longer if she just said she had severe anxiety.

Beyond these barriers Mary feels there is not enough education on what mental disorders are. It wasn’t until she took a psychology course that she began to make sense of what was happening to her. She thinks youth need to speak up and become more active for changing the system. Mary said there is better understanding for those with special needs and who have physical disabilities but because you can’t see anxiety or depression people don’t know that it is happening. Schools need to come together to make mental health a priority. She said even something like “pride week” but for mental health would help a lot to educate and change the status quo of how it is treated.

5.3. Nicole

Nicole began the interview by recalling how in the seventh grade she was feeling depressed and was fighting at lot with her father. That year she went to her paediatrician and was prescribed “anger meds”, as she put it, but did not take this medication for very long because she did not like the way it made her feel. A year later, in the eighth grade, her mental health deteriorated and anxiety became a central issue. She thought, “Something is going on” and although she tried to “push it aside” she could not help but feel that “everything was taking over.” Nicole said, “I didn’t want to get out of bed… I’d sleep constantly and wouldn’t hang out with anybody…I’d just be so out of it at school and couldn’t concentrate” and she would get “really, like really, bad anxiety and would be so stressed” and later in the interview she added, “I cry a lot whenever I get in that mood and then I just can’t get out of bed.”
Nicole’s aunt, father and best friend all noticed something bad was going on. Her aunt told her “you’re taking anxiety attacks” and said she didn’t seem like herself anymore. Her aunt suggested she see a counselor for help. They called the local youth mental health centre and she was put on a wait list for both one-on-one therapy and group therapy. “Like I waited and I waited and they finally got back to me and said, like you’re on the waiting list”. At the date of the interview she was still on this wait list, which had been for over a year.

Nicole then decided to talk to her family doctor. The physician asked how long the anxiety had been happening, if she had lost interest in activities, if she had thoughts of harming herself, the basic symptoms and so on. She said the experience of seeing her family doctor was “fine” and “pretty quick”. Nicole did have thoughts of harming herself but the doctor’s evaluation was, “you sound like passive suicidal”. The doctor explained to her, “you think about it but don’t think you’d ever do it” however Nicole said it still “runs through my head all the time… I can’t do this anymore.”

The result of this visit to the physician was that she was prescribed Ativan, which was prescribed to primarily to help her sleep. Sleeping has been a major problem throughout her journey. “I can’t sleep and then I wake up because of my anxiety issues… I wake up and I just feel so sick and I shake and it’s really bad”. Nicole was also sent for blood work and tested for low iron. She was given a list of private counselors she could contact.

The doctor also gave her an anxiety workbook to help her through her daily anxieties. “It’s like a teen anxiety workbook. The first page was to interview your relatives and ask them about anxiety. There’s a bunch of questions and then answer them
yourself… And the next one was draw yourself standing at your bedroom door in the morning and then draw all your struggles throughout the day with anxiety and different things. So, like I did that and I’m still trying it. I’m hoping it’s going to get better, but I don’t know. It’s just not helping with anything, like drawing of my struggles”.

Nicole was offered group therapy but she was hesitant to join at first. She said, “I don’t really want to do group counseling, and then they’re not really going to help you. I don’t talk about my problems with everybody. Plus it’s like all girls, and I don’t want to talk to a bunch of girls about my problems I don’t know”. A few months later she reluctantly agreed to attend group therapy because it was the only option available and some other girls she knew were also going to try it. Unfortunately though they “kept putting it off for weeks and I was like, to my dad, can you talk to them or something? Because all the girls there have a lot of problems and stuff and like they were kind of putting us off to go and find more people with problems instead of just joining them in as we go. So, I feel like they shouldn’t have put us off like that. So I said screw this.”

Nicole has found it hard to cope with school and her anxiety. “We have a 15-day rule. If you miss 15-days you just get kicked out.” She does not feel this type of school system makes sense and wished that her teachers actually knew more about what was going through. She had recently got in a fight with a teacher. He said to her that he should know more about her health problems and Nicole replied, “I have anxiety and depression. So he knows about it but I feel like there should be a thing, if you have mental health problems…I don’t feel like it’s right if you miss that much school and they just kick you out. Like you’re just missing more school. It makes no sense to me. I feel like they should try and make you do more to catch up. Just makes no sense for me.”
School counselors have been a part of Nicole’s journey and she has spoken with them many times. However she has not had many positive results. “She talked to you but she didn’t really do anything about it. She was like, okay cool, whatever. I don’t really think schools really address mental health like the way they should. Like they just kind of like push it aside likes it’s nothing, basically. That’s how I see it at least.”

In terms of changes that can be made in schools Nicole feels that they should be more involved and know more about your problems. Nicole said:

I think they should just have to know honestly that some people with mental health problems have trouble with classes and stuff and sometimes if they miss extended periods of time there are reasons. Because I had a lot of doctor’s appointments and stuff, so I was missing a lot and they’re just like, it’s not good and yeah. Plus I feel they should sort of address mental health, like teach us about it a little bit but I feel like it should be more. You get me?

When asked if she was happy with the services she has received her answer was “No, because, just cause they took so long to try and get me in, and also how I didn’t do the group counselling.” In terms of her treatments, she explained:

Well, I wouldn’t really say that anything went well. I find that sometimes over like a short period of time I feel okay, like I’m not like happy or good, but I’m okay. I can cope with things for a tiny short period of time and then everything goes downhill and nothing’s working. So, I haven’t noticed the pills working yet. I still feel the same way. I haven’t been crying. I’m just thinking the same way, I’m just lying there emotionless. So, yes, I don’t know. I don’t really find them to be working.
When asked if she is still stuck in bed most days Nicole replied:

I think it might kind of be helping that way. I’m kind of getting more energy…

I’m just trying to just keep going. Get out of bed and just literally leave me alone
– I can’t do this. In my mind I’m like, I have to go to school and deal with all this.
It’s so hard to just have it all in your head and just try and focus on your life.

Wait lists were the major barrier Nicole saw in the system and would be the first place she would make changes. She believes that when the situation is dire you should not be left to wait. “If you’re depressed or anxious, things can go wrong so fast that I feel like we should be able to get help faster, right? So like somebody commits suicide, like I was on the waiting list for a year and things could have gone wrong fast, so I feel like they should try and get more counsellors, find a way to speed the process up”.

5.4. Richard

Richard was diagnosed with anxiety at the age of four from his family doctor in a rural Atlantic Canadian town. He did not recall many details from the initial visit because of how young he was at the time. He was not sure what symptoms he was experiencing at the time and why his parents took him to the doctor. He recalled blood work and that the doctor prescribed him anxiety medication at that time but did not recollect other forms of testing or treatments.

Richard continued to battle his anxiety in the years that followed. He missed a lot of time from school over the years. At the age of 11, his anxiety continued to worsen and he tried going to a therapist in his local town. He discussed how he “hated” this experience and only went to a few sessions before discontinuing. Later the same year his parents took him back to the family doctor and they did more testing, again blood work
but no psychological testing that he could remember. What resulted from this was a stronger medication dosage. He did not know exactly what kind of medication he was prescribed but he said they “tried the same ones as before” but “just stronger”. He explained that since the stronger dosage the last two years has been more stabilized and his anxiety levels have been manageable.

Richard described not feeling symptoms at home but explained that the anxiety would manifest itself primarily at school. Missed class time was a problem throughout his entire educational experience. He spoke of his anxiety symptoms being physically sick to his stomach rather than being more psychological or fear based. He understands that he now has created negative association between school and anxiety and one of his major goals is trying to break this cycle.

However there were many positive supports that came from his education as well. Richard has received much of support from his teachers, counsellors, and the administration. They have taken a vested interest in his health and wellbeing and although it is still a daily struggle to attend school comfortably his attendance and grades are improving. He was excited about the transition to High School because he found school relatively easy. He envisioned more advanced courses that will challenge him in new areas.

He also received considerable support and motivation through school by playing on the basketball team. He elaborated at length that playing on the basketball team has been very important for his physical and social activity. Because he cannot play games with the team when he is absent from school this has created a new motivation to attend class regularly. Further, he really wants to go to Medical School someday to become a
doctor. With this goal in mind he knows his marks are important so it is motivating him to miss less time and do well.

Friends and family did not play a primary role in Richard’s story. When asked he said he did not have a lot of close friends at school and his parents have always been supportive but had little detail to add.

Richard did discuss the role technology plays in his life. He has been saving money to upgrade and upkeep his computer. This has motivated him to work a part-time job throughout the school year. He explained that outside of school and basketball much of his time is spent online. He did not view this as alone time but rather social time with his online gaming community. He contrasted this with outdoor time saying he does not enjoy being outside.

5.5. Al

Al described how his first mental health issues started at school. “I think around grade five. I think and that was like when I got bullied a little, back then, and that is when it really started to take off from there.” He felt that something was wrong with himself and that kids were making fun of him. When asked if anyone stepped in to help he said, “I think I mostly just kept to myself. I didn’t really talk about it much”. “It was my fault”, he thought. Sometimes he would bring it up with his parents who tried to help him stick up for himself. The bullying was centred on his weight issues as he explained, “Like I used to be like really chubby back then and that they used to make fun of me saying I was fat”. Around grade 8 the bullying subsided a bit and his weight changed. “I used to be decently chubby, and then I got like really really skinny. I think it was from like believing that I was fat and not happy with myself”.

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Al described his anxiety symptoms by saying, “I just start shaking and I couldn’t, wouldn’t be able to talk. Like I go to say the word “do” or something and it would be like “d’, d’”, like I couldn’t get the words out of my mouth.” He emphasized his social and performance anxieties growing up. Specifically, presenting in class and taking tests were troublesome. His extreme perfectionism, his mother felt, had prevented him from getting through all the questions on tests. In Junior High he began to focus on his marks and learn the appropriate amount of time to take a test. His anxiety levels got better when he entered high school. His mother said that he created many stressors in his life that didn’t exist to the outside world. They later found out after having discussions with his family that there is a history of anxiety on his father side but this was not talked about openly and they hadn’t known this existed.

With regards to guidance counsellors, Al said, “Pretty sure I remember talking to some guidance counsellors” but had little detailed memory. His teachers were supportive and helped him in class. When it came time to speak or take tests they would ensure he felt comfortable and would adapt to suit his needs: “Like they give me an alternative route to do the project or whatever. It really like brought up my confidence, because of that.”

His journey did not feature the healthcare system much. He recalled seeing someone for “one-on-one” time about his anxiety when he was younger. His mother added that they utilized the community mental health in the area and faced little to no wait-time. The reason they got through quickly was because they knew an employee there and were able to bypass the wait-list. The counselling sessions created talking points, strategies, and coping skills that Al and his family were able to apply. It was a
long hard road of talking through everything. His mother added that he was prescribed a muscle relaxant in order to help with performance anxiety on tests, which he took for approximately six month during the eighth grade. He had not taken any psychotropic medication throughout his journey at the point of the interview.

Hockey and music are two outlets to put his energy into. “Sports, I don’t know I just found that hockey was always a good way to take out some aggression” and he said, “I play guitar. That was always a help, something to look forward to. Like get away from the stress of doing work, just go play guitar for ten minutes or so be right calm”.

Al believes that overall he is in a better place mentally and his anxiety is controllable. Despite having some triggers around school and work but he said, “Yeah I feel like it’s really, really good now… like now just found that I’m learning to control it kind of. And the things that trigger it I just try to stay away from”. He feels schools are an important part of dealing with mental health problems because there are a lot of kids who suffer and he sees a lot of classmates who have anxiety in school. He now tutors elementary students and wants to help others who have difficulty in school like him.

5.6. Scott

Depression started creeping in around 12-years-old when Scott was living in central Canada. He said:

I found my motivation, at the time I was doing well in and had a pretty good social base. You know, I didn’t really have too many problems. Just the motivation started to go down. I found things to be seen a lot more intimidating, a lot more difficult.
As the year went by things got worse. “I felt kind of out of place even with people that I know and felt comfortable with years beforehand… I dealt with depression and anxiety and what not probably pretty substantially.” Scott started hanging out with a new crowd, smoking marijuana, and getting into trouble with teachers. His family and close friends noticed something was off and he started to see a counsellor. He had sessions every week and he noticed that it helped but that challenges were continuing.

Scott’s substance abuse with drugs and alcohol started around 2011-2012. The same year he had a knee injury, which caused acute pain for months. He was not prescribed anything adequate for the pain and he started buying prescription drugs off the street. The reason for this he feels is that doctors are trained to know what drug users look like and he could not get a prescription even though he felt it was legitimate pain. So, “I switched over to hydrocodone because I just – it was getting too expensive and Tylenol 3s on the street are like more expensive than – it’s cheaper to buy Tylenol 3s at street value than it is to buy like cheap heroin.” He described this decline and how he became more and more strung out and could not think rationally. He had thoughts of self-harm and suicidal ideation. Eventually it led him to heroin. “I had my first experience with heroin in March of that year, which I smoked it. A couple of weeks later I had it through a needle and I ended up overdosing.” Through the hospital he entered into opioid-replacement therapy, which he did for three months.

At this point he and his family moved to Atlantic Canada. This gave him the opportunity for a clean slate. His substance abuse subsided and he started school. They received a family doctor pretty soon and after a short period on a wait-list he started seeing a social worker for mental health issues by February 2013. “That was really,
looking back, was the beginning of where the anxiety piece started to come out more.”

Scott began feeling suicidal and was admitted to the hospital on suicide watch.

Later that year he began to lose interest in school. He explained:

I think the huge downhill slide over the years leading up to that with not feeling school was for me. It didn’t feel that it taught me anything that I wanted to learn… I don’t think this province’s education system is an accurate reflection of intelligence.

He looks at universities and thinks that students wouldn’t be treated in such a “condescending manner, not so passive aggressive” but “you have to get through high school to get there. And that’s very difficult when you’re counting the motivation to get up every day.”

Scott left school and in 2013 at the age of 15 he entered a live-in psychiatric clinic run by the hospital. It was a four-month program but he stayed less than two weeks. He found this situation very difficult because there were patients aging from 13-18 with conditions such as schizophrenia, bipolar disorder and autism. “There was one or two people in particular there who were Autistic who I – the sympathy is there I just don’t have the patience for it, you know?” He added, “The administration did not know how to handle it.”

Events in 2014 did not go well either. After another suicide attempt he was admitted to the hospital again. He was released but not being in school his smoking got worse. “I had pretty good habits with things, smoking dope multiple times a day. I mean, I was kind of just perpetually stoned for the good portion of that winter. If it wasn’t weed, it was anti-anxiety medications.”
At this time Scott’s social worker felt that she did not have enough expertise in both the mental and substance abuse problems he was facing and decided to transfer Scott to someone else. He was referred to an addictions counsellor who he has been seeing since. “She switched me over to an addictions counsellor and that’s who I’ve been seeing since. But she covers the depression, anxiety pieces and we focus on that and if there’s substance abuse pieces we focus on that. So it’s all week-by-week, dependent on what’s most relevant”. Scott described the medications he has taken over the years:

Yeah, I mean, I started on – I’ve been on and off medication since I lived in [Canadian city]. Anti-depressants, anti-psychotics. So that’s been, it’s been like eight or nine of them; I couldn’t tell you when I started one and ended another because it’s always something, right? I had a Clonazepam script at one point, an Ativan script at another and other times I was buying Valium and Xanax on the streets.”

He later continued regarding his treatment:

Medication is only part of the piece. You still have to work on the coping mechanisms, but then at the same time I don’t actually care what they recommend for coping mechanism… I feel like there’s a lot of attempts to focus on multiple things at once and not locking down one issue… Youth with mental health concerns that you believe requires medication, your options are basically limited to walk-in clinics, your family doctor or seeing this child psychiatrist.

Scott hasn’t had much rapport with his family doctor who is there “on paper” and he does not like to prescribe psychotropics to patients he doesn’t have a lot of rapport with. Therefore it is his child psychiatrist who prescribes his medications.
When combined with wait times it can be hard to get what you need. “Even with [psychiatrist] because he’s so hard to make an appointment with - if you go to him seeking medication and he says – like he said to me last week, “I have to think about it for a little bit. Come back in two weeks.” Well, it’s not something that can wait.”

This relationship has been poor. Scott found the psychiatrist “pretentious” and “interrupting”. In fact with all psychiatrists he finds, “there is this omnipresent pretentiousness and sense of superiority… it’s incredibly clinical” and he does not find there is the same problem with social workers. “I’ve been involved with four five different psychiatrists over the course of my life. They all – it’s uncanny how similar the personalities are.” He has tried to get past the personality problems yet “it does get to the point where you feel like you can’t be heard. Like when I get interrupted and when I get this train of thought altered a lot” and “he makes conclusions very early before hearing the whole story… I find talking about the superiority complexes because there’s an obvious – you can see and you can sense the gap pretty clearly that he’s got the authority, he’s got the power… the control aspect is not hidden.” Later he said, “I don’t think to feel better I should have to feel worse… I don’t think I should have to go in and hate going in to an appointment and feel put down and feel put into place just to get my meds refilled for a couple of months.”

Beyond the communication problems the psychiatrist has been very difficult to book appointments with. Scott understands how busy physicians are and explained how the region had two psychiatrists and when one retired they did not replace him. The entire region’s caseloads fall on one person. “He’s swamped…I mean, you go into his office and he’s got lots of books and advertisements on ADHD meds, so that’s obviously where
his area of expertise is but he’s kind of forced to deal with every kid that’s got a mental health condition because he’s kind of mandated to. It’s what he’s got to do. I do think there’s an aspect because he’s so busy he gets bitter and he doesn’t put the effort in. And what I see is because it’s so hard to make appointments with him you can’t build that rapport. And it limits him and it limits the patient. And I find over years, every time I have to see this guy for medication it’s like I’m counting my words because I’m making sure every one of them counts. I wouldn’t - you couldn’t pay me to see him for an appointment unless I’m getting something out of it, to be honest. I don’t go in there and have any benefit to him about talking about things because I can do that with my social worker and actually feel listened to. If I’m going to see him it’s solely for the purpose of I need a refill of a medication, I need my medication altered in some way. That’s it… They can’t afford to invest as much time in everyone because it’s just too many appointments, it’s too many people to get to. I mean, I’ll get my appointments pretty much cut off right in an hour. If I’m in the middle of something, ‘Sorry, I’ve got to go.’” But he does not blame his counsellor because “you need to be fair to everyone.”

This is not a positive experience of the psychiatric services he has been offered. Scott feels there is a lack of professionalism and that things never happen smoothly. “I do actually find there’s a lack of professionalism, not just in the private fields but also at the hospital. You have to call multiple times to get these – to follow up on scheduling appointments or following up on getting a referral sent in. It’s par for the course. I don’t feel like anything is a smooth – I’m going to do this, it’ll get done.” Later he said that you always have to follow up, “When you’re having kids, for example, who are already kind
of ashamed or embarrassed getting the help in the first place. It’s asking a lot for them to follow up. It is, unfortunately”.

He then told the story of his most recent suicidal ideation. “So I came to the [hospital] late Saturday night with suicidal concerns. They told me, well they have a crisis team that meets during the days and stuff for youth but of course they don’t meet on Sundays… Because they only expect that kids will want to kill themselves on weekdays? [Laughter]” Entrance into the hospital is complex and time consuming, especially during times of crisis:

This has happened quite a few times, usually late at night or early in the mornings or stuff like that. I ultimately went home to my mom and spent the entire day of that Sunday sleeping because I didn’t have any drugs to cope with it and it was the only way I would be able to stay – keep myself alive which is to sleep and wait it out. They took me back in on Monday when the crisis team was in and the crisis team met with me for five minutes and determined, Okay, go to the [hospital].

When he arrived at the hospital he was admitted and spent three days in bed:

They pretty much ignored me. And that’s the thing that I struggle with, is that you have a kid who’s like me, who’s ruminating with these suicidal ideations and it’s like they’re just expecting you to wait it out… What did I get out of this? I’ve had to just convince these people multiple times that I didn’t feel suicidal anymore when I still did.”

He explained that these problems are “bureaucratic to the max… it’s following a mandate and not following any kind of human aspect. And so, I’m coming out and I’m
having an anxiety attack, yelling – they’re more focused on telling me, “Okay, you can’t talk to us like that,” and all this and just kind of trying approach an irrational situation rationally… autonomy’s the word. Complete disconnect. There is a prison-like aspect to it.” He understood that it was not an easy situation to handle and that he was acting irrationally but that it was not the way they should have been trained to communicate and de-escalate the situation. He also “felt trapped” because despite the fact he voluntarily entered he found out they had him on a 48 hour watch without telling him. This may have been what ethnically needed to be done for his safety but he did not agree with the dishonesty. “You go in seeking help and you end up feeling more trapped and isolated. Like at that point if all I’m going to do is sleep and not eat, I can do that home, you know?”

Scott explained how his mother has been with him throughout the journey. She has been very involved throughout the entire process and there is little secrecy between the two. Scott’s mother wants psycho-educational testing to be done to check for learning disabilities and she wants him to go back to school. This type of testing is also very expensive but it is something she has been saving for. “To her it’s worth it and I just don’t see what I’m getting out of it. But I mean the financial aspect is a barrier for sure.” She does everything she can to support him. “You have to drive an hour and go to the [hospital].

A larger societal barrier for Scott includes how Atlantic Canada is very complacent about drinking culture and does not take substance abuse seriously. He also said it is hard to build a support community because many of the youth groups in his area are religiously affiliated. His friends are also going through mental health troubles and
have banded together because they need each other to talk through what is happening to them. The system does not provide the social support according to Scott so you must find it elsewhere:

And that’s kind of the thing that I wondered was, does one take that kind of intrinsic energy of people with similar issues wanting to confide in each other. How do you do that and merge that, in my opinion, with the pre-existing infrastructure and staff and resources in one of these hospital settings or with government funding or whatever.

He feels that small towns have it tough because there are not people there to offer programs and funding is limited. “I really think it’s the small towns that get it bad. I don’t think it’s so bad in the city because there’s more people willing to offer it. When your numbers are so small, the isolation piece comes into play.”

Scott explained that group therapy might be an answer to pool resources however he isn’t a “group therapy kind of guy”. One positive way he has seen group therapy work was in school when they instituted a school run mental health program where students dealing with problems could go and hang out. Counsellors would visit this room and have a group of people to talk with and he thought this was very positive. The problem is now that he no longer goes to school he doesn’t have access to the school based supports.

Overall when he reflected what needs to be changed he said, wait-times and personnel, and, “It’s too many people needing service and not enough people offering them” especially in rural communities. He feels there is a stigma around medication and many young people do not want to take them. He thinks a skeptical attitude is good but medication plays an important role:
They don’t want the side effects or they don’t want to be zombies or whatever have you. And maybe sometimes, I think the attitude is good. It’s always good to have that kind of thing where you want to deal with things on your own without that but I’m the kind of guy, I guess, realistically I wouldn’t be alive today if I didn’t have medication.”

Further he thinks mental health education for all is important, regarding medication and therapies, or regarding coping mechanisms. He has been lucky and issues with social workers have been just personality based but they do their jobs well. His major critique is the communication and power relationship problems with psychiatrists. He remains worried about the gap in the system when he turns 19 and is not sure what services will be available. He is hoping that through healthcare they can afford private care and he said some of his previous services would be cut off, which is one more thing he has to deal with. He stated that he would “forever be baffled by the way society looks at age” and he has felt judgment and limited by age, not only in healthcare but also across society.

On the positive side he has had an incredibly supportive family he said and his mother has been involved about 90 percent of his treatments and problems throughout the journey as he is fully transparent with her. He said she is probably more frustrated with the health care professionals than he is. Also he has been engaged in public speaking to raise awareness about mental health problems for youth. This is something he will continue to battle his whole life. “I think stuff like some of the obsessive compulsive tendencies will be handled over time but I don’t think depression and anxiety, generalized anxiety will ever go away”. 
5.7. Elsie

The first memory Elsie had of needing help with mental health was in the eighth grade. Sleeping alone was always a problem growing up for Elsie:

I had like fears of things, like extreme fears… I always just had like a lot of anxiety just being alone I wouldn't be alone in the house like ever, I would never be alone…until probably grade nine I wouldn't stay in the house by myself. Sleeping was really hard and stuff for me and my mom was the one who said first like you definitely need to see somebody.

Elsie was home schooled until the ninth grade and she had severe anxiety returning to school. “I'd just never been academically well in school. I've always had learning problems with like reading and comprehension and stuff like that, so I just hated it and just like my self-image like I just would like hate going to school every single day.” The cycle this created throughout school was not good. The more time she missed the worse her anxiety around school got. “I wish I went to school more because it would create more anxiety if I skipped for like three days and then I went back and I didn't know what was going on”.

Her mother worked for a mental health organization and was able to connect with a therapist seemingly without much wait time due to her connection within the system. “Then we went to the hospital…to get a therapist for me and that was probably grade 9 that we went there.” She saw the hospital’s psychologist. “I went to her for about a year I found it was fine, but, then I didn't think that maybe it was her that wasn't helping me because we just didn't connect, so I went to one in town like a private one, but, I only went there like three months and then I went back to her at the hospital.” She continued
seeing her for a total of three years, sometimes as often as once a week. However she slowly went less and less, feeling like the psychologist could not relate to her problems and that the things she was being asked to do was not addressing the issues. “I found it always hard because… she didn’t tell me like ‘I can relate to you’ kind of, so I was like you can't really know.” Elsie felt that she could not be fully honest with her therapist. “Especially when I started having really bad problems with like eating and everything like that. She would make me do a journal and stuff and I would just like fake it.” Elsie often struggled to confide in her therapist and would hide parts of her story, and would report that things were getting better when they weren’t. The psychologist would often try to make jokes about her eating problems or her anxieties and although this sometimes lightened the mood it also made it hard to build trust, “I just felt like she didn't understand. The way she was talking to me at least she didn't really get it.” Her family physician prescribed her medication to help combat the anxiety in the tenth grade however she did not want to take the meds. She explained:

   Because I just felt like it wasn't helping me. I would just not take it so I really didn't give it a chance because I didn't like medication. And same with the therapy too I felt like it wasn't helping just because I had a negative kind of view on it I guess so I felt like it wasn't helping me.

   Her family physician said that a psychiatrist might be able to give her something better, something that will work for her, so she was referred to a psychiatrist in a larger city within her province. She did not recall a very long wait time. “I think it was a month and a half later”. The psychiatrist sessions as she recalled, “It was just a lot of questions I
think. More like just questions he asked me and then I just kind of answered them and then he would tell me, do you feel like this and then I would say yes or no kind of.”

Her problems with anxiety and depression continued throughout school and later in high school she began restricted eating and self-harming. “I exercised like three hours a day. I didn't throw up at all, during that time, but, I was just eating like really nothing.” She then added that in terms of self-harming, “I've done it on my legs and there's pretty big scars from that, but I didn't really do it anywhere else because I figured like my mom would see it… I feel like most of the things are because of just the way I feel about myself and like if I would just binge and I feel like lately too like I really don't do anything I just like eat all the time.”

When asked if anyone at school was helpful she responded, “High-school there was no one. Grade nine I had a counselor who was really helpful to me. I noticed at least here at [high school] there's like so many people that they're mostly for courses, they're not actually there to help you with mental health stuff, it's just courses and school.” She briefly tried talking to school counsellors but she felt that there were so many kids looking for help and that as she received was advice on her course work. She did not feel she could reflect and talk with them and did not go back for any help throughout high school.

Elsie missed a lot of class time. Although the school would inquire they did not show a lot of interest in why she was missing school. When she went over the missed class limit she would have to ask her teachers to let her back in the class, which often they would do. She reflected, “I remember a couple of times I'd go to the teacher and say is there any work I can catch up on, they'd be like no you weren't here so you don't get it
and they're kind of rude and I'd be like alright then.” Although she almost dropped out of her final year she was able to finish high school. But it was not easy. Elsie said:

I definitely wish that the school like had some kind of thing where you could like have an adaptation or whatever to do school some days in like a different place like not a classroom or something because I would walk into the class or like start to go into the class or walk down the hall and be like I can't go in the classroom. So then I would just skip and just leave because I would just or if I could even just like go in, get my work, go somewhere else. Like you can do that, but I just was already anxious enough to ask to do that. There was a learning center to do that in. I did some times, but I found it just made me anxious the whole thing about it.

In terms of friend and peer support she had one very close friend who helped her throughout the entire journey. “She was probably like my most closest friend because at school I didn't really have friends so she would just always talk to me and she had the same kind of problem as me stuff like that.” Beyond her close relationship she did not open up about mental health with others. Instead she would avoid it by “just trying to not talk about feelings… we didn’t talk about stuff like that, we were just hanging out.” Then she explained:

So I would just pretend like everything's okay and then I would go home and usually I wouldn't hang out outside of school with them because when I went home I didn't really want to like keep pretending to be like happy or whatever… I just was like I can't really pretend to be like okay or whatever. And I found at
least my friends were really judging and stuff like that on other people and I was like well they're probably like that to me.

Elsie’s relationship with her family throughout her journey was complicated. She described her relationship as a “rollercoaster” between fighting and not fighting. At first her parents would let her have mental health days, but then Elsie maybe took advantage of those days and was forced to attend school. This hurt their relationship. Her parents divorced while Elsie was in high school. That added stress to the family and although there were good times and she was supported and could talk to her parents there was also a lot of strain and fighting throughout the journey. She does attend community mental health groups through the local youth mental health organization. She said these sessions are more group related activities like talking circles. Elsie said:

And I find that really helpful because just hearing other people's experiences. That's what I've always thought, like if can relate to other people it just helps me battle alone more than just being told what to do I find. And people get emotional and get upset and stuff and then you can relate and everything, so I like that a lot better.

When reflecting on common themes throughout her journey the conversation was centered on how she would put on a positive face but not want to burden her family, friends and even therapists with what was going on inside. Being sad she said was “it's not somebody that I feel people want be around… like I don't want to have no friends so I would just pretend and same with at home too.”

Elsie offered some views on the system as a whole, and the struggles she has faced with connection and support. She would often hide parts of her story to her
therapists. Even though they were paid to hear her problems she felt that they did not empathize with her situations and she could not be fully honest about how she was feeling:

    I feel like they definitely are helpful, but, sometimes I wish that I could feel like they understood or could relate to me or like kind of give feedback or say like I understand because of this or like I know somebody like this. But, I know you're not supposed too because it's confidential, but, like for me I feel like that would help.

She also feels that school, whether or not you like it, is a second home. Students spend so much time there that she feels teachers should know people’s stories and be understanding. “They don't know, they don't know anybody's story, like somebody could be like getting abused or something at home and then they have to come to school because you have to.” Generally if people had more understanding and worked with youth on their level Elsie feels that better results could be achieved. “If there was some kind of just program for people, parents, any adult, because they teach kids a lot but adults don't maybe understand… some people don't learn as fast as others and stuff like that… just to be calm and to help, something like that, just to educate adults.”

Her perfect ending to the journey would be for herself and any youth going through these problems to:

    Just feel good about yourself, you don't always have to be happy but the majority of the time not to be thinking so much about yourself. Just live in the moment and not be thinking like ‘oh what about this’. My anxiety would be like thinking way beforehand on stuff and everything… You just didn't feel judged by the people
too so you didn't feel like there was something wrong with you I guess…just feeling like you're not alone.

**5.8. Catherine**

To begin the interview Catherine described the difficulties she faced throughout early adolescence, with her trouble at home and her difficulty dealing with life in general. Depression developed as a real problem by the age of 13. That same year Catherine went to see her first therapist but she did not recall the exact situation that caused the visit. She explained that those first couple of years her memory is not clear, she said perhaps she tried not to remember and blocked it out of mind. But she recalled her friends and their families were the ones that recognized something was wrong and that she needed help.

She explained:

So basically what had happened is I used to live in a small town called [small town]. And so my friend’s mom would take me to [larger town], which was about a ten-minute drive to that hospital, which is where I had got my first counselling, therapy, whatever. Then after I had lived with my mom – like moved out of my dad’s, lived with that family for six months, then lived with my mom for a summer, then moved in with my nan – then I was up there, and the school helped me try to get back into the mental health system again, where I ended up in [neighbouring town], which is like a five-minute drive from my hometown of [hometown]. So I ended up at the… In [larger town], it was at the actual hospital, but in [neighbouring town], they have the mental health centre…. I lived with my father and I don’t even think my father knew I was going to therapy… It was through a – like the hospital. Once a week, we would drive to… Our town didn’t
have a hospital, but the town next to us, we would drive to the hospital and I would sit down for an hour and talk about things going on

Catherine said she didn’t stay with her therapists for very long. “Over the course of those five years, I’ve been with probably five different therapists.” The first few sessions did not go well. “Even though I was young, I could tell I really just didn’t connect, and my friend’s mom suggested that, because I had said to her, ‘I don’t want to go. I don’t like talking to this lady.’ So she like asked them if I could have someone else to talk to”.

In high school the education system became more involved in Catherine’s treatments. “My school was aware that things weren’t great. Middle school, there wasn’t really any like help per se, but as soon as I went into high school, my friend’s mom had told the high school, and I had a counsellor from week one of ninth grade all the way up to twelfth grade. I think that’s how I survived high school.” She discussed her being bullied all through school and how the counsellors were crucial in dealing with that. By the twelfth grade, with only one course left and with bullying still being a problem, she “couldn’t handle it anymore” and they allowed her to finish her final course home online. This support through school was very helpful for Catherine’s wellbeing:

Even though I got to see a trained counsellor, it was every two weeks…if things got cancelled or snow days or things got mixed up. It was hard for my Nan to drive me there all the time, so being able to talk to someone when things were bad… Because I still self-harmed up until the eleventh grade, and I tried to kill myself in the like tenth grade I believe it was. So if I didn’t have those people at school, I think I definitely would not be here.
She explained that the school support was more reliable than her community mental health appointments:

Since like trained counsellors, they do have to make appointments with tons of other patients, they can only see people so often. It’s not like if you have a crisis, you can just go in and see them, you have to go to emergency services. Where if you’re at school and something happens and you feel like you’re going to have a breakdown, you can go to their office and request an emergency appointment.

She said her counsellors said she had depression and anxiety, but that she was referred to the psychiatrist “to get an official diagnosis and to get me on medications. I’ve been on a few different ones… I’m trying to think when I started taking pills. I’m not 100 percent sure.”

Other national mental health programs or phone-in mental health support Catherine has never found helpful because you always have to keep telling your story over again from the start. “Whereas if you already have someone, like a school counsellor there and know your story, they know the backgrounds.” Without your history it is hard to know how to support someone through difficult times. She said that emergency services fall in the same boat. “Those suck because then you have to tell your story all over again.” She said that her counsellors and psychiatrist shared her file so she had some history already when she changed hands. Now that she is in university the files have been shared with the mental health staff at her school.

At the point of the interview Catherine finished high school and no longer had access to her school counselling and she turned 18 which cut her off from her youth
services. This move put her on new wait lists for services and she had not seen anyone for therapy in the months leading up to the interview:

I am currently on a waiting list for the downtown mental health clinic to see a counsellor there. And I’m on a waiting list to see a psychiatrist at [provincial Health department]. I haven’t seen my psychiatrist in half a year, and I haven’t seen a therapist since June or July. It’s been hard.

The only other option while she is on these waiting lists is the emergency appointments, which she can access. However she tried this service three months earlier was told by the counsellor working that she does not need emergency service and that she needed long-term counselling, which she explained is how she got on the waiting list. She went on this list in October and was not called back until January.

When asked if she has been happy with the treatment she has received she said:

Sometimes… In the beginning it felt pointless, and I didn’t exactly like going. The past couple of years, I’ve liked going more, and I’ve found it more helpful than when I was younger, because to me, everything just felt really pointless and that I wasn’t going to get better. But it was nothing on their end. Like the treatment was fine. It was just me who wasn’t ready to accept the treatment, I think. So the past couple of years has been a lot easier.

When Catherine reflected on things she realized a lot of people have been involved in her journey and many people helped her along the way:

Most of the time, I find people extremely helpful. I find the problem that lies within the like free mental health services is – comes down to availability. For example, my mother has been on a waiting list for at least half a year, and my
mom is in a much worse state than I am. So even once you’re in the system, availability becomes extremely hard.

Later she explained that the services are not in place when she needs them:

I could have a breakdown for like three days, and then a week and a half goes by and I’m okay again. So by the time I’m seeing the counsellor, I’m saying, this happened a week and a half ago. But I never really got to see someone in the moment, which was difficult. Like if I was at school and it was happening, I got to see someone during the moment, but they were just school counsellors.

The largest barrier for Catherine was moving, finding a new therapist, and having to tell her story from scratch each time she went somewhere new:

They’re working on like ways to manage my anxiety, or like they’ll just start working on technique, and I’ll have to go to someone new. So that was the biggest barrier, which was me always having to move and start over. And the most helpful thing was, honestly, probably more the school systems care.

In terms of one-on-one therapy her advice is if a patient has a problem with therapy you have to listen, “If they’re saying that they don’t connect well with someone, find them somebody else, because being able to connect to someone is like the biggest part.

5.9. Beth

Beth began talking about her anxiety with a friend a little over a year before her interview, while she was in the seventh grade. Her friend too was going through mental health problems and they shared their experiences with each other. That summer, in 2015, Beth was feeling depressed and very anxious and she told her parents she was thinking of self-harming. Her parents brought her to their family physician where they
were told she should be admitted to the Emergency Department (ED). Beth spent five days in the ED and began her journey into the mental health system:

When I went to the hospital, there was like – because how it works there, if you’re like – there’s a place in [hospital psychiatric unit], so it’s four beds. So all of those are taken up, and then there’s two extra beds – those were also taken up. So we ended up staying in the ER for a long time, so that was a lot of waiting.

The initial wait at the ED was not ideal however her father added that since they entered through the hospital they were provided a therapist much quicker than if they were to find one on their own, and he is thankful for how relatively timely the services have been comparatively.

At the point of the interview Beth had only been in the system for a little over a year. She had seen three therapists. First, she felt that a female counsellor helped her to a point but she needed to go further. The second, a male psychologist, she saw for a few sessions but there has been a lack of connection and openness. Beth said, “You know, well, I haven’t been totally honest with him.” It was not easy opening up and letting adults into her experiences with anxiety and mood disorders. She is connecting much better with her current psychologist. They have made strides forward and have developed coping skills.

When asked if she has received any formal diagnoses, and if so how they went about evaluating her diagnosis, Beth replied that her initial therapist gave her a survey. “It was like a survey sheet thing with, like, the second – I saw more than once. Once I took it, she was like, she was saying I definitely scored higher for depression, but then there’s also a component of anxiety.” Then the psychiatrist did an evaluation and said she
had both depression but the anxiety ranked higher on the scale. When asked about this testing Beth said, “I don’t remember anything” even though the journey had only started a year before. She acknowledged what a blur the whole experience has been thus far.

Beth had not taken any medications although they were recommended. Her father explained that they had received conflicting information about whether medication would be suited for their daughter. Specifically their psychiatric nurse in the hospital did not feel Beth, at her age and with her conditions, should be prescribed medication where the psychiatrist felt she should be. It was difficult to know how to proceed. One mental health professional told her she needed to “tough it out” while another told her that she shouldn’t be suffering if she doesn’t have to. These messages can be hard to negotiate when seeking care.

Friends were a major part of this journey. Beth has had many friends who are going through similar experiences with depression and anxiety:

Well, one of my friends has like really bad anxiety, and she’s had it for a long time. And then, like, the friend that I talk to, she used to – I don’t think she does, but she used to, like, cut and she was depressed. She’s been to the hospital. I don’t think she sees a therapist anymore. And then, I have like a couple other friends who are – one has, like, anxiety and panic attacks and has been to the hospital because of that, a few times, and she’s depressed and stuff. It’s a cheery bunch of people.

When asked who in her class she also sees with anxiety issues she said, “Majority girls. It was like one guy, it was only like last year, mostly, but like he was suffering with
anxiety and stuff. But I don’t think that’s such a big thing for him now.” Beth discussed what she has seen in school and how they cope with their anxiety:

Well, there’s like three girls in my class, so it’s me and two other girls that we all, like, have talked to like doctors and stuff about anxiety, and the guidance counsellor and the teachers and the principal and all of our parents have said that, like, if we need to like leave the class and stuff, we can. So we do a lot of just working out in the hallway, which is just easier.

Beth’s journey is in its early stages and she did not have any recommendations for improvements and steps moving forward.

5.10. Chapter Summary

This chapter has profiled each of eight young participant journeys. These rich narratives provide insight into the experiences of youth today and how they have been treated within a complex mental health system. They navigate and negotiate their treatment with various people and systems along the way. Next, the results of the thematic analysis are provided which deconstructs the narratives into thematic categories based on common barriers and facilitators experienced regarding how they have received treatment.
CHAPTER 6: NARRATIVE ANALYSIS

6.1. Chapter Outline

This chapter provides the results of the thematic analysis. All participant narratives were analyzed and interpreted according to the various barriers and facilitators that impacted how participants experienced the mental health systems. These themes that emerged ranged from positive and caring treatment to neglectful and alienating experiences. Participant interviews reflect different stages of their journeys through the mental health system. This is important to note because they may have experienced different barriers or facilitators depending on their needs at different times, and those who are older may have had more reflection on their journeys as a youth. Despite these differences all participants have engaged with and negotiated treatment with many people within the mental health systems and networks. Many of the barriers and facilitators across the sample touch on the similar thematic areas but participants experienced them in different circumstances. This highlighted the paradoxical struggles participants faced negotiating between treatments that both facilitated and obstructed their paths toward care.

The thematic areas for facilitators in treatment include; positive therapeutic relationships, school supports, openness to treatment, and medications as stabilizers. Thematic barriers in treatment include; therapeutic disconnection, wait times, barriers in school, medicating the problem, and being stuck in the margins.
6.2. Facilitators for Treatment

6.2.1. Positive therapeutic relationship. “If they’re saying that they don’t connect well with someone, find them somebody else, because being able to connect to someone is the biggest part” – Catherine.

A positive therapeutic relationship was necessary for a participant to feel that treatments, services, and supports were constructive and comprehensive. This was not easy to accomplish and took time to navigate the system to find the right person or people to deliver this care. This was someone they could connect with and trust for therapy, counselling and/or guidance at a personal level. The experiences varied depending on the participant and their time spent seeking treatment, ranging from Beth who had just recently found a psychologist that she connected with to Mary who had a guidance counsellor go above and beyond the “call of duty” and helped with many elements of social and educational life throughout high school. Another example, Richard, who “hated” talking therapies had support in his school from the guidance counsellor, his teachers, and the principal who all knew of his anxiety diagnosis and worked closely with him. Catherine summarized this best by explaining that if someone does not connect with a service provider they should have the ability to find the right connection.

For Scott it was his current social worker that he felt could cover the complexity and individualized support he needed. “She covers the depression, anxiety pieces and we focus on that and if there’s substance abuse pieces we focus on that. So it’s all week-by-week, dependent on what’s most relevant”. Social workers filled an important treatment and support gap that psychiatry did not for Scott. He did not spend time opening up with
his psychiatrist because “I can do that with my social worker and actually feel listened to”.

Mary felt that her previous therapists did not get to the core of her problems but her current therapist began CBT, which helped her take positive steps toward living and dealing with anxiety. On the other hand, Elsie attended group therapy and had positive connections there and said, “I find that really helpful because just hearing other people's experiences… if can relate to other people it just helps me battle alone more than just being told what to do”. Al found that counselling sessions created talking points, strategies, and coping skills that he and his family were able to apply at home.

For Mary, who lacked family support in her journey, her high school guidance counsellor exceeded responsibilities and helped both in school and outside, communicating with Mary’s therapists and psychiatrists to ensure she received the treatment she needed. “She just kind of got it. And she told me a lot about her experience with stuff too… she just was always there when I needed it”. This created trust and understanding, something that was hard to find throughout much treatment in the system.

6.2.2. School support. “The most helpful thing was, honestly, probably more the school system’s care” – Catherine.

Schools were central in most participant journeys, either for the support they provided or contrarily problems youth had with school. Guidance counsellors and school supports were the most consistently accessible services available to youth participants. In many cases without this accessibility treatment and support would not have been possible, sometimes during times of crisis or sometimes the general support network that schools provided.
“I honestly think that school was better than therapy just because like you have access to it all the time, like at all times… I didn’t have to make an appointment”, said Mary. Catherine felt that school counselling is how she survived high school, “If you’re at school and something happens and you feel like you’re going to have a breakdown, you can go to their office and request an emergency appointment”. Richard also had the support of his school through his guidance counsellor; administration, teachers, and basketball coaches who have all helped him improve his attendance and reduce his anxiety around school activities.

The education system was consistently on the front line dealing with youth anxiety in the classroom. Richard explained that when he would arrive at school he would feel sick yet when he would go home symptoms went away. Beth explained that many people in her class have been experiencing high levels of anxiety. Absenteeism and anxiety at school were common in the journeys as well; although this posed problems some teachers were flexible about taking tests and doing presentations. “They give me an alternative route to do the project or whatever. It really like brought up my confidence, because of that,” said Al.

6.2.3. Openness to treatment. Some participants discussed their own personal growth and awareness over the course of their journeys, which helped them find treatments that worked for them. These were personal developments that helped facilitate positive treatment, be it more awareness of anxiety and mental disorders or being open to types of treatments being provided.

It was not until Mary started taking psychology courses that she realized she had anxiety. “And I just called myself socially awkward because I just thought I was weird.
And then I kind started like understanding it a bit more, and I would search up stuff and it would show, like, oh, you have anxiety”. A key theme to Al’s narrative was his path to understanding himself and recognizing the source of his anxiety triggers while building self-esteem and accomplishing social goals. Richard has become more aware and educated on what his anxiety is and how to deal with it. He understands that he now has created negative association between school and anxiety and one of his major goals is trying to break this cycle.

At first Elsie didn’t give therapy or medication a chance. She explained, “I really didn't give it a chance because I didn't like medication. And same with the therapy…I had a negative kind of view on it”. Eventually Elsie opened up and found that the therapies began to help. Although it was a constant battle she became more open to her treatments, which has helped her in recent years. Catherine shared a similar experience.

“Sometimes…In the beginning it felt pointless, and I didn’t exactly like going. The past couple of years, I’ve liked going more, and I’ve found it more helpful than when I was younger… Like the treatment was fine. It was just me who wasn’t ready to accept the treatment, I think. So the past couple of years has been a lot easier”.

6.2.4. Medication as stabilizer. “I guess, realistically I wouldn’t be alive today if I didn’t have medication” – Scott.

One of the more contradictory themes has been medicalization of anxiety disorders. Although it has been met with resistance (see discussion in barriers section) a small number of participants have also discussed its importance it has played to stabilize them at various stages.
Mary resisted pharmacotherapy at first but eventually she felt it was necessary. “Because it got so hard to handle on my own that it was like I couldn’t function enough to use the techniques to chill out”. It was not Mary’s ideal solution but it has been beneficial, “If I don’t take it I notice a big difference”. Nicole felt that medications have helped her get out of the house more. She said, “I think it might kind of be helping that way. I’m kind of getting more energy”.

Richard had been on psychotropic medication since approximately four years old and felt it stabilized him throughout school. Talking therapies were not successful for him and he felt that the medication has helped him although he does not remember a time before medication nor recall exactly what caused him to see the physician and receive a prescription at such a young age.

Scott explained that medication has been necessary to keep him functional throughout his journey. He explained that if you need medication “your options are basically limited to walk-in clinics, your family doctor or seeing this child psychiatrist”. He said that young people his age often are resistant to medicating anxiety and mood disorders because, “they don’t want the side effects or they don’t want to be zombies or whatever have you. And maybe sometimes, I think the attitude is good”. However medication has kept Scott stable throughout his journey: “Realistically I wouldn’t be alive today if I didn’t have medication”.

6.3. Barriers in Treatment

6.3.1. Therapeutic disconnection. “I’m counting my words because I’m making sure everyone of them counts” – Scott.
Participants felt a lack of quality time and meaningful relationships with counsellors and medical professionals were barriers when seeking treatment. Many participants did not feel heard, or cared for, during therapies, and experienced a system that was overburdened and not equipped for their individual needs. There was often a lack of support and understanding, and this sometimes created alienation. This led to instances where some participants did not trust their providers and held back when communicating their problems.

Power issues between patient and provider have been observed as well. Scott said, “There is this omnipresent pretentiousness and sense of superiority… it’s incredibly clinical… you can see and you can sense the gap pretty clearly that he’s got the authority, he’s got the power… the control aspect is not hidden”. When thinking about why this may be Scott said, “He’s so busy he gets bitter and he doesn’t put the effort in”. Here, there was not enough time or consideration to build trust and understanding.

Often communication broke down between doctor and patient. Mary said of her last visit with her psychiatrist, “He was like, ‘well what do you want from this?’ I’m just like, ‘I don’t know’. And he’s like, ‘well why did you come see me?’ I was like, ‘because you guys told me to’. So I don’t know; it was really strange. And then I was like ‘okay well just give me some medication or something’ just to shut him up. And he was like ‘okay’”. This example highlighted gaps in communication and the role medication sometimes plays.

Changing therapists and retelling your story also obstructed treatment: “That was the biggest barrier, which was me always having to move and start over” said Catherine. “Whereas if you already have someone, like a school counsellor there and know your
story, they know the backgrounds”. Seeking treatment with someone who does not know your personal history is difficult. She said that emergency services, like call-in lines or crisis teams fail because of this: “Those suck because then you have to tell your story all over again”.

Some participants found it hard to be honest with counsellors. Beth had difficulty connecting with her first psychologist. Upon reflection she said, “You know, well, I haven’t been totally honest with him”. Elsie said her therapist “didn’t tell me like ‘I can relate to you… so I was like you can't really know”. She often struggled to confide in her therapist and would hide parts of her story, and would report that things were getting better when they weren’t. “I just felt like she didn't understand... I wish that I could feel like they understood or could relate to me or kind of give feedback”. Creating a positive person-to-person connection with your therapist was not easily accomplished. Richard said he “hated” his experience with therapy and has not returned for many years.

Some participants had negative experiences with group therapy, especially if it was offered in lieu of one-on-one counselling. Mary said, “This is bullshit, like give me CBT or something because this isn’t working”. Nicole also resisted group therapy: “I don’t talk about my problems with everybody. Plus it’s like all girls, and I don’t want to talk to a bunch of girls about my problems I don’t know”. However these were the only options available while these participants were on a wait list for one-on-one counselling. Scott said, “It does get to the point where you feel like you can’t be heard… They can’t afford to invest as much time in everyone because it’s just too many appointments, it’s too many people to get to”.
6.3.2. **Wait times.** “I waited and waited and they finally got back to me and said, like you’re on the waiting list” – Nicole.

Therapeutic treatment barriers were compounded by wait times and the complexity navigating appointments and sessions. Many participants waited considerably long times for referrals and were left not knowing the status of their requests and where they should go for help. Others received more timely access entering through emergency or acute pathways however these treatments often were not well suited for their anxiety and mood related needs. Also wait times did not reflect the urgency some participants felt when requiring treatment and contributed to a sense of a lack of respect, sensitivity, and understanding.

Mary waited three months for her initial group therapy, three months for a community therapist, and another three to four months to see a psychiatrist. Her psychiatrist retired and at the point of the interview she was still waiting for a new one. She explained, “It’s a bit of a mess right now”. At the point of her interview Nicole was still on the waiting list for over a year.

Scott said waiting was not conducive to treatment. His psychiatrist was “so hard to make an appointment with - if you go to him seeking medication and he says – like he said to me last week, ‘I have to think about it for a little bit. Come back in two weeks’. Well, it’s not something that can wait”. The wait times affected the quality of his treatment. “Because it’s so hard to make appointments with him [psychiatrist] you can’t build that rapport. And it limits him and it limits the patient”. He said these barriers represented a lack of professionalism. “You have to call multiple times to follow up on
scheduling appointments” and if you are already feeling “ashamed” to see a counsellor “it’s asking a lot for them (youth) to follow up”.

Catherine was on wait lists for a counsellor and a psychiatrist because she was no longer in school and required adult services. “I haven’t seen my psychiatrist in half a year, and I haven’t seen a therapist since June or July. It’s been hard.” This transition from youth to adult services prompted Scott to say, “I’ll just forever be baffled by the way society looks at age”.

When Beth first sought treatment for her anxiety disorder she entered through the Emergency Department yet still waited due to a lack of a bed. “So it’s four beds. So all of those are taken up, and then there’s two extra beds – those were also taken up. So we ended up staying in the ER for a long time, so that was a lot of waiting”.

Beth said having entered the system through the ED was not ideal but it opened up referrals and counselling much quicker down than if they were to find treatment on their own. Two examples stood out where participants were able to bypass long wait times without entering through emergency pathways. Al utilized the community mental health in his local area and faced little to no wait-time because his mother knew an employee in community mental health and was able to bypass the wait-list. Similarly Elsie had access to multiple therapists over the years without major wait times because her mother worked for a mental health organization and was able to connect with therapists directly. Due to an overburdened system, personal or “inside” pathways must be taken to access timely care and treatments and raises issues of equity within the system.
Timing was also seen as critical when treating mental disorders and participants felt that you could not afford to wait. Mary said, “You might have lesser symptoms than when you tried to receive mental health care, because you might just end up taking it into your own hands and dealing with it that way, but then sometimes it might be too late”. Nicole said, “If you’re depressed or anything, things can go wrong so fast that I feel like we should be able to get help faster, right? So like somebody commits suicide, like I was on the waiting list for a year and things could have gone wrong fast, so I feel like they should try and get more counsellors, find a way to speed the process up”. Catherine explained, “I could have a breakdown for like three days, and then a week and a half goes by and I’m okay again. So by the time I’m seeing the counsellor, I’m saying, this happened a week and a half ago”.

The bureaucracy of mental health does not align with the needs of patients in a crisis situation. Scott said, “They told me, well they have a crisis team that meets during the days and stuff for youth but of course they don’t meet on Sundays… Because they only expect that kids will want to kill themselves on weekdays?”

6.3.3. Barriers in schools. “It would create more anxiety if I skipped for like three days and then I went back and I didn't know what was going on” – Elsie.

As discussed above, the education system played an important role throughout the narratives, both for how it facilitated treatment and for how schools created barriers in treating youth with anxiety symptoms. Having anxiety and other mental health challenges has caused extended absenteeism and dropouts with participants, and anxiety symptoms often manifested around school attendance and performance.
For Richard, school was where much of his anxiety manifested. He felt sick to his stomach when at school, and missed a lot of school time growing up. Al’s anxiety was also centered on school presentations, test-taking anxiety, and he missed time from class. Yet to access school mental health services the student must be in attendance. This has created problems for some participants. For example Scott dropped out of school, which created a barrier because he could not access those counselling services, which he felt would have helped. “I think the huge downhill slide over the years leading up to that with not feeling school was for me… and that’s very difficult when you’re counting the motivation to get up every day”.

Nicole did not think school’s philosophy on attendance was congruent with seeking mental health treatment. “If you have mental health problems…I don’t feel like it’s right if you miss that much school and they just kick you out”. Nicole continued. “I don’t really think schools really address mental health like the way they should. Like they just kind of like push it aside likes it’s nothing”.

Attending school was not easy for most participants. For example Elsie said, “I wish I went to school more because it would create more anxiety if I skipped”. School attendance represented a negative cycle; once you missed time you fell behind, your anxiety worsened, you lost access to counselling, and you missed more time, and so on. Elsie explained that you could ask for special help and guidance: “You can do that, but I just was already anxious enough to ask to do that. There was a learning center to do that in. I did some times, but I found it just made me anxious the whole thing about it”. Unlike some of the participants, Elsie did not connect with her school guidance counsellors. “I noticed at least here at [high school] there's like so many people that
they're mostly for courses, they're not actually there to help you with mental health stuff, it's just courses and school”. She felt that there were so many other kids looking for help that she didn’t fit in. She also explained that school was a second home so teachers should know what’s going on in your life. “They don't know, they don't know anybody's story, like somebody could be like getting abused or something at home and then they have to come to school because you have to”.

6.3.4. Medicating the problem. “You go into his office and he’s got lots of books and advertisements on ADHD meds” – Scott.

Medication has acted as a barrier when used as a primary line of treatment, or in place of other treatments that were not available due to wait times, resources, or accessibility. Further there was apprehension about medication. Many participants were reluctant to medicate and wanted more information before taking psychotropic prescriptions for anxiety. However this information was hard to find if participants did not have time or trust with their counsellors. If medication was offered too early in a therapeutic relationship it created a sense that they were being pushed upon you, and some recognized this. In the case of Richard, he began taking medication very young and did not remember a time prior to this.

Mary was reluctant at first. She said her first therapist was a “pill-pusher” and promoted medication from the start “before she even like assessed me or anything”. This did not mean medication was the wrong choice but it represented a lack of trust and quality time with her therapist. Later in her journey her psychiatrist prescribed her psychotropic medication. “I think it was Prozac. And that was just a shit show…”
everybody else seemed to think it was making my suicidal ideation a lot worse, so they just made me stop it completely”.

Scott recounted his first year with his psychiatrist: “I was kind of just perpetually stoned for the good portion of that winter. If it wasn’t weed, it was anti-anxiety medication… I couldn’t tell you when I started one and ended another because it’s always something, right? I had a Clonazepam script at one point, an Ativan script at another and other times I was buying Valium and Xanax on the streets”.

Medication was a first line treatment for Nicole because at the date of the interview she was on a wait list to see a psychiatrist. Her family physician prescribed her Ativan (benzodiazepine). Nicole was not happy with this form of treatment. “I find that sometimes over like a short period of time I feel okay, like I’m not like happy or good, but I’m okay. I can cope with things for a tiny short period of time and then everything goes downhill and nothing’s working. So, I haven’t noticed the pills working yet. I still feel the same way. I haven’t been crying. I’m just thinking the same way, I’m just lying there emotionless”.

6.3.5. Stuck in the margins. “It’s bureaucratic to the max, it’s following a mandate and not following any kind of human aspect.” – Scott.

Reaching out for treatment was not easy to do. Some questioned if they were sick enough to seek help and treatments during various stages of their journey. Others did not feel the types of emergency treatments available were appropriately aligned with what was required. Nicole, for example, had thoughts of harming herself but her physician explained to her “you think about it but don’t think you’d ever do it”. However, Nicole said it still “runs through my head all the time” that she “can’t do this anymore”. She felt
this response from a physician was not what she was looking for at that time and wanted better explanation or support. From a medical perspective Nicole had not yet met the requirements for emergency treatment.

Mary reiterated this idea, “A lot of the time I was scared to even reach out and get help because I’m like okay, I don’t think I’m sick enough”. She continued, “Like it sounds stupid, but you want to be sicker so you get the help that you need”. It was not until Mary had suicidal ideation that she was given access to services. Yet she was resistant to entering through emergency services. She told her therapist, “All they’re going to do is pump me full of more drugs, and keep me in a room”.

Scott did not think the medical system had the right approach to treating anxiety crises. “I don’t think to feel better I should have to feel worse… I don’t think I should have to go in and hate going in to an appointment and feel put down and feel put into place just to get my meds refilled for a couple of months”. Scott has entered through the ED but did not feel they were equipped to help him. “They pretty much ignored me. And that’s the thing that I struggle with, is that you have a kid who’s like me, who’s ruminating with these suicidal ideations and it’s like they’re just expecting you to wait it out… What did I get out of this? I’ve had to just convince these people multiple times that I didn’t feel suicidal anymore when I still did”. This highlighted a struggle between receiving that participants needed and saying what needed to be said to manage the social situation. Yet inpatient care had its issues as well for Scott who said, “I’m coming out and I’m having an anxiety attack, yelling – they’re more focused on telling me, ‘Okay, you can’t talk to us like that’ and all this and just kind of trying to approach an irrational
situation rationally… autonomy’s the word. Complete disconnect. There is a prison-like aspect to it”.

Participants who have been in the system for a number of years have expressed that their journeys with anxiety have left them in a void that symptoms must reach a crisis point before they feel able to seek help. In these situations self-harm, suicidal ideation and substance abuse were contributing factors. Nicole was doing everything she could to cope but it was not easy. “I’m just trying to just keep going. Get out of bed and just literally leave me alone – I can’t do this. In my mind I’m like, I have to go to school and deal with all this. It’s so hard to just have it all in your head and just try and focus on your life”.

Mary said, “It’s hard to have motivation to go and seek more help when you’re scared you’re going to get shipped away”. In this instance Mary was referring to the fact that there were no in-patient mental health services in her town and she would be sent the provincial capital to receive treatment. When asked where Mary would turn in a crisis instead she replied, “My bedroom…and hide away from the world”. She elaborated that no longer being in school she no longer has access to her guidance counsellor. As a substitute for school therapy her psychiatrist asked her, if? “I had a good imagination and I said, yeah. And then he asked me if I could ever think of pretending to be in the guidance rooms, and I was like, I’m not that creative”. Being forced to imagine a better alternative rather than being provided one is unacceptable for those who need treatment to deal with the symptoms of anxiety.
6.4. Chapter Summary

The thematic analysis grouped common themes as the barriers and facilitators youth faced when seeking treatment for anxiety in the mental health system. Their journeys were complex and barriers existed at personal and systemic levels. There were barriers when creating relationships and trust with therapists, compounded with wait times, and problems around how medication had been experienced, along with the health system potentially not being equipped for those with anxiety who “aren’t sick enough”. Yet there are still moments where participants would connect and find support from someone, or somewhere, in the system that helped get them on track for treatment. The hard work of some caregivers comes through in the complex web that youth must untangle when being treated. These discussion points will be considered further in the final chapter.
CHAPTER 7: DISCUSSION

7.1. Chapter Outline

This chapter provides a review of the research aims of this thesis, an overview of the research findings, considerations for these finding, and future directions moving forward.

7.2. Research Aims

The primary research objectives of this thesis were to explore how Atlantic Canadian youth with anxiety disorders have been treated in the mental health system from their perspective and how a social historical literature would inform our understanding of youth and anxiety treatment today. To answer the first question, narratives from youth who have experienced this phenomenon were collected and analyzed for barriers and facilitators of their experiences in the system. To answer the second question, social historical literature was analyzed to review the development of youth anxiety over time.

7.3. Overview of Main Research Findings

7.3.1. Youth perspectives. The interviews provided a snap shot into the lives of youth with anxiety disorders and each participant was at a different stage of their mental health journey when they participated in the study. Participants identified facilitators and barriers at personal and systematic levels regarding how they have been treated in the mental health system. As previous work has shown, the pathways in mental health are nonlinear and complex and often the factors that facilitate positive treatment for youth my also act as barriers in different circumstances (Boydell et al., 2006). The themes from
the narrative analysis represented the paradoxical struggles youth faced when being treated for anxiety in the mental health system.

For instance, it was clear that making a positive therapeutic connection was necessary for support and comprehensive treatment throughout journeys. Often no such connection was made or was difficult to find. When there was a disconnection with the service provider, participants frequently felt discouraged while being treated. This led to situations where participants would hold back, not trusting providers with their true feelings and also not trusting the treatment options provided. Some participants were not honest about their symptoms while others said what they needed to say in order get the prescription or referral they needed and saw the provider as a means to an end. In general participants expressed a desire “to be heard” and they wanted to talk with someone who “got” what they were going through. There was a sense that providers were overburdened and too busy to understand the youth perspectives. Overall this left a sense of being ignored in times when they needed the utmost support. Establishing effective communication therefore was a barrier in many treatments.

Participants experienced various states of transition that affected treatment options, such as long periods of waiting while transitioning in or out of school, moving locations, and when providers themselves moved or retired. Re-establishing a connection with new providers was not easy due to the time and energy it took to build personal trust and openness to tell their story and have it be heard. From a systematic level when service provider positions were left vacant or not accessible due to the long wait times it left participants alienated from their own mental health journey, not knowing the status of requests or referrals, and not knowing where or when they could receive help. One
participant was, at the point of the interview, still waiting to access therapy for over one year. There were examples of participants who did not face long wait times, however it was those who had entered through emergency services, or had “inside” pathways such as friends/family who work in the system, that helped book appointments. This raises questions of equity when navigating the system and accessing services.

Perhaps the most poignant theme of the analysis was the sense that participants where stuck in the margins amid the confusion of not knowing if they were sick enough to be treated by the medical system. They questioned if their symptoms would qualify them to enter through the ED, not knowing where else to turn while they waited. This is a troubling trend and signified a gap in anxiety treatment options and interventions when symptoms were not yet critical or acute. Other participants who did enter through in-patient pathways articulated that those services were not well suited for their needs dealing with anxiety and mood related issues. Again, one participant lied in this instance and said his symptoms were gone so he could be released from the hospital because his treatment needs were not being met.

Group therapy and medicalization were frequently offered while participants waited for one-on-one counselling. Participants who perceived these treatments as expedients did not receive them well. Participants could tell when treatments were not the right fit but were being provided instead as a placeholder. Often when pharmaceuticals were prescribed too soon in the therapeutic relationship, before a meaningful connection was made with the provider, the participant thought the medication was being “pushed” on them. These experiences may be in line with recent Canadian data that suggests psychotropic medication is being prescribed at a higher rate than psychotherapy and at a
higher rate than is recommended for youth (CIHI, 2015). It could point to the fact that there is a gap in other comprehensive treatment options for youth with anxiety.

Medication, when it was experienced as the right fit, was seen to stabilize participants and help them become functional in daily life, but when it was filling a gap in services it was experienced negatively.

Schools also played a central role in the narratives, again somewhat paradoxically given that they represented both the source of anxiety but were the most consistently available treatment option available. Many times anxiety symptoms would manifest at school yet anxiety would rise from missing too much school. Participants noted that school philosophies around attendance were not congruent with receiving mental health support. If you missed too much time you would be suspended, therefore somewhat ironically, you would be forced to miss more time and you would be cut off from counselling services. However, having had access to counselling services in school with someone who knew your story and with no wait times was crucial and often represented the best treatment option for many participants.

The consistent message delivered across the sample of narratives was that mental health interventions could not afford to wait. Finding someone who participants felt understood them was not easy but was the highest priority as they continued to seek treatments throughout their journeys. When a meaningful connection was found and maintained then productive and trusting treatment could begin. Timing of interventions was crucial though before critical situations occurred and emergency or acute care was needed. When participants had an anxious breakdown, felt suicidal ideation, or self-harmed, they did not feel they should be expected to wait and be stuck within
bureaucratic barriers, such as having to follow-up with service providers on the status of their referrals. As Scott noted, it was not easy to build up the courage to seek mental health treatment in the first place, it can be sometimes too much to pick up the phone to follow-up to advocate for access to services multiple times.

Yet advocate is what these participants did do, both by participating in this study to provide a voice in mental health research, and in their own mental health journeys when advocating better services and treatment options in the mental health system. In the current system youth perspectives and narratives have been marginalized throughout the treatment process. Participants searched for power in their relationships with providers and to have a choice in how they were treated. Their voices and concerns around their treatment too often though fell silent between what services they were seeking and what was actually made available to them.

7.3.2. Social historical literature. Although gaps were found in the social and historical literature reviews, seminal works of critical history informed the discussion around the conceptualization of youth and mental disorders through the rise of anxiety in the twentieth century. This unique blend of methodologies has produced insights regarding the marginalization of patient perspectives both past and present within various psychiatric discourses including the development of diagnostic criteria, the rise of medicalized treatment options, and navigating the system accessing services and treatments.

Historically, the psychiatric discourse has been presented as a monologue by those who possess power over those who received the psychiatric labels, which has created a silence or void within the diagnostic and treatment discourse of mental health
(Foucault, 1988). When applied to narratives today, there is an ongoing tension youth face when negotiating treatments for anxiety disorders, and experience a lack of power and marginalization throughout the many voids and gaps in the system.

Shifts in recent decades have aimed to improve patient autonomy, choice, and representation in mental health while resisting labels and power imbalances by the system (Reaume, 2002). These shifts regarding how patients are labeled have led to mobilization and representation in various social and political domains (Reaume, 2002). These trends have been documented largely with adult patients but youth perspectives should be incorporated moving forward. A shift in youth rhetoric could call to action youth patient needs, values, and autonomy within mental health practice, research and policy.

The social historical findings also explored the developments of anxiety diagnostic criteria and the rise of medicalization in the twentieth century (Healy, 2002; Horwitz, 2013). The end of the twentieth century marked a cultural shift in how youth mental disorders were treated with the acceptance of psychotropic medication for youth as a primary line of defense for mood and anxiety disorders (Healy, 2002). These economic, social, and political developments converged at the start of the twenty-first century with modern anxiety and youth becoming ubiquitous. Now anxiety as we know it has become the most common mental disorder among young people today (Merikangas et al., 2010).

As discussed in the literature review, CBT has been the most effective first-line treatment option for youth over the past 50 years (Higa-McMillan et al., 2016). Mood and anxiety psychotropic prescriptions have risen at a higher rate much higher than CBT and other psychological treatments (CIHI, 2015). CIHI stated that psychotropic medication
should not be a front line treatment; there has not been enough long-term empirical data on side effects and any dramatic increase in medication should be met with caution (2015). This rise in psychotropic treatment is the culmination of historical trends in the standardization of youth diagnosis and treatment within a medical system that lacks resources and comprehensive treatment options for youth. As discussed in the thematic analysis, medication has stabilized some participants in crisis situations yet the concern here is that medicating anxiety is offered in lieu of other more comprehensive psychological treatments and social supports that were not available in a timely manner. When youth are in transition, left on waiting lists, or left not knowing where to access treatments in the health system, medications fill a gap where more comprehensive psychotherapies and social supports are desired.

7.4. Considerations for Findings

This thesis proposes that youth perspectives have been marginalized and silenced in two key areas, in the review of mental health literature both past and present, and throughout the negotiation for treatments by youth within the mental health system today. Participants of this study expressed a desire to be heard and to have their perspectives influence the direction of future policy and research areas. The themes from this thesis highlight concerns around intervention and the importance of lived experience in mental health care research and policy development. Recent youth mental health strategies have stressed the importance of youth inclusion in service design (Burns & Birrell, 2014). Youth mental health patients should have power to contribute to decision-making. It has also been recommended by health researchers that a young person with anxiety, along with their guardians, should receive individualized interviewing to understand risks and
side effects of all treatments (Creswell et al., 2014). This thesis supports this position however having enough quality time with mental health providers is a luxury that some participants do not have. Youth perspectives and an understanding of how youth actually navigate the mental health system should be considered in mental health research, practice, and policy moving forward.

How then can we make the system more equitable and connect with providers before youth fall into the margins? Scott considered this question in his interview. He said, “How does one take the kind of intrinsic energy of people with similar issues wanting to confide in each other… and merge that with the pre-existing infrastructure and staff and resources in one of these hospital settings or with government funding?” Such a question cuts to the core of the issues explored in this thesis. Those patients within the mental health system have already reached out for help and wish to confide in someone and be treated. They have already taken the step to seek help, which itself would have required them to overcome barriers. Yet within the system limited resources and established infrastructure limit what can be done in many circumstances.

Mental health policy should focus on helping youth navigate these complex systems and provide treatment options before symptoms become critical. Youth journeys highlight the energy it takes to navigate the system through complex negotiations with providers and services. Acute or emergency options do not seem adequate nor do expedients provided in lieu of psychotherapies or social support. Evaluation and improvements to these areas could help reduce the strain on emergency and acute care systems and address the concerns of the rise of psychotropic medication prescribed to youth.
7.5. Future Directions

This thesis focused the thematic analysis around barriers/facilitators of treatment within the system yet there is more un-analyzed data within these narratives that could be further developed. For example, supportive social networks and the role of family and friends, and the role of sports, music, and other positive activities that acted therapeutically, were prominent throughout the narratives. How mental health is achieved outside of the formal mental health system and the role of larger social support systems could be an area of study in a larger social context.

There were also issues of self-harm and suicidal ideation raised by participants, and the centrality of anxiety along with comorbidities and addictions is raised by this thesis but was beyond the scope at this time. Merging this qualitative data with medical records could tie in diagnostic and prevalence statistics with the narrative analysis to explore youth specific nomenclature and if current diagnostic criteria for anxiety are appropriate for youth. As discussed in the literature review, it is often difficult to separate anxiety and depression treatment literature due to a lack of age specific data, high rates of comorbidity, and similarities in treatment options (Birmaher, Yelovich, & Renaud, 1998) along with potentially high phenotypical diversity within narrow categories for anxiety (Beesdo, et al, 2009). The participants did not reflect in great detail on youth nomenclature nor did many participants distinguish what type of anxiety they had been diagnosed with. Participants often had comorbidities and although they identified with anxiety at this stage of their journey at other times they identified with depression or other disorders. Merging youth journeys data with medical data could explore these research areas further.
Dyadic interviews could shed more light on the journeys taken by youth within the mental health system. There were times during the interviews in which younger participants had a hard time piecing together their timeline and recalling exact details of their journey. For example, not knowing the class or type of medication they were prescribed or they could not recall the type of the mental health professional they saw (e.g. psychiatrist, psychologist, or counsellor). The range of mental health literacy made documenting exact details difficult, and piecing together the timelines of the narrative summaries took considerable time. Parent interviews collected by the ACCESS-MH project often map out this information more clearly and can fill in some aspects of the timeline in more detail. The older youth participants had begun to develop more detailed mental health literacy and could articulate the type of treatments and services they received in more detail than the younger participants (generally speaking). Future research could focus the analysis of older youth who have had more time to reflect on their journeys or who have spent more time in the system. Overall this data reflects the rich and detailed narratives of young people currently navigating the system and has potential to uncover many insights into the youth mental health care moving forward.
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doi:10.1016/j.jad.2015.05.002


http://dx.doi.org/10.4135/9781452243696.n1


Tilleczek, K., & Bell, B. (June, 2014). Barriers and Facilitators in Child & Youth Mental Health in Atlantic Canada. Young Lives Research Lab, UPEI. For more project information visit http://access-mentalhealth.ca/


APPENDICES

Appendix 1: Consent Forms

ACCESS-MH Patient Journeys - Youth Consent Form
(for those 18+ years in NL/NS/PE and those 19+ years in NB)

Version Date: Jan 11, 2016

Title of Research Project:
Barriers and Facilitators in Access to Child/Youth Mental Health Services

Project Website: http://access-mentalhealth.ca/

Principal Investigator – UPEI
Dr. Kate Tilleczek (902) 620-5127 ktilleczek@upei.ca

Principal Investigators
Dr. Rick Audas, Memorial University of Newfoundland
Dr. Scott Ronis, University of New Brunswick
Dr. Michael Zhang, Saint Mary’s University

Post-Doctoral Fellow
Dr. Brandi Bell, UPEI 1-855-861-5127 (toll free) brbell@upei.ca

We would like to invite you to participate in a research project about how services are provided to children and youth identified with anxiety, depression, autism spectrum disorders, conduct disorder, and/or eating disorders.

Description of Research
We intend to document and analyze how treatment is received across government and non-government sectors including Health, Education, Social Development, Public Safety, and Youth and Family Services. We will collect a variety of information from 240 individuals (80 children/youth, 80 parents, and 80 service providers) from across the Atlantic Canadian provinces (PE, NB, NS, NL). To do so, we are using interviews augmented with a visual mapping process. Information collected will be shared and compared across provinces.

If you choose to participate in this research project it will take 90-120 minutes of your time. You will be asked to participate in an interview of 60-90 minutes to talk about your journey with mental health. Prior to the interview, you will be asked to find 3-5 visual images that you feel represent your journey in some way and to bring these to the interview (this is not required, but can be a helpful way to think and talk about your experiences). At the beginning of the interview, you will be asked to fill out a socio-demographic survey which will take about 15 minutes. The interview will be audio-recorded. During the interview you will be asked to create a ‘journey map.’ This will
involve placing items representing people, places, and things on a blank board to help show what your journey with mental health has been like. This project will continue for four years and some participants will be asked to participate in a follow-up interview similar to the first (approximately 60-90 minutes). You can indicate whether you can be contacted for this purpose on the attached Consent Form.

**Potential Harms**
We know of no harm that taking part in this study could cause. Researchers have been trained regarding the mental health conditions they are studying as well as techniques to encourage participation while limiting the risk of an emotional exit from interviews. Counseling services will be made available to participants who require them.

**Potential Benefits**
You will receive $30 as a thank you for your time. You may not benefit directly from this study. There is no guarantee that your participation will directly lead to changes in mental health services or changes in your experiences in the mental health care system. A summary of the results will be available for participants. If you are interested in receiving the summary, please provide your contact information on the attached Consent Form. We will also ask you about the best ways to provide the study results to you. We are committed to sharing our research findings with our participants and those who are in a position to make positive changes for young people.

**Confidentiality**
We will keep all information that we collect during this project confidential and anonymous. We will ensure that you will not be identified from any of your responses. We will destroy the audio-recording of your responses 15 years after the end of the study. All study material will be secured in a locked cabinet at UPEI. We will identify you only by a number or a code name in the final transcript.

**Exceptions to Confidentiality**
Due to legal and ethical requirements, the research team must break confidentiality if:

1. The interviewer becomes aware of child abuse or neglect of someone who is under the age of 19 in NB/NL, 18 in PEI, or 16 in NS;
2. The interviewer becomes aware of sexual abuse perpetrated by a health care professional toward an identified adult or child; or
3. The interviewer becomes aware that the participant is threatening harm to oneself or another identified person.

**Participation**
Whether or not you take part is completely up to you. If you do decide to be interviewed, you may stop participating in the project at any time and without any consequences.

**Sponsorship**
The funder of this research is the Canadian Institutes of Health Research (CIHR).

**Conflict of Interest**
The members of the research team have no conflicts of interest to declare.

**Consent**
By signing this form, I agree that:

1) *I have read and understood this consent form.*
2) The study has been explained to me. All my questions were answered.
3) The possible harms and discomforts of this study have been explained to me.
4) I understand that I have the right to refuse to take part in this study. I also have the right to withdraw from this study at any time. e.g., before or even after the recordings are made.
5) I can ask any questions about the study at any time now and in the future.
6) I have been told that all research information will be kept confidential, except where required by law (e.g., suspected child abuse, court subpoena).
7) I understand that no information that would identify me will be released or printed.
8) I understand that no information about me (including recordings) will be given to anyone or be published without first asking my permission.
9) I understand that I can keep a copy of the signed and dated Consent Form.

The Research Ethics Boards of UPEI, UNB, SMU, and MUN have approved this research project. If you have any difficulties with, or wish to voice concern about, any aspect of your participation in this study, or the ethical conduct of this study, you may contact the relevant Research Ethics Board (REB) associated with the province you are located. Contact information is noted below:

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I agree, or give consent, to allow the use of anonymous quotations from my interview in research reports (understanding that I will not be identified in any way)

______________________________
Name
______________________________
Signature and Date

For facilitator only: I was present when __________________________ read this Consent Form and agreed/consented, to participate in this research study.

_____________________________________
Printed Name of person who obtained consent Signature & Date

I understand that a short summary of the research results will be available to participants at some point in the future.
I would like to receive this summary: ___ Yes ___ No
Please indicate how you would like to receive the summary:
Mail to home _____ Email to you _____
Other ____________________________________________
Please provide a mailing or email address:
Name:  __________________________________________
Organization (if applicable): _______________________
Street Address: _________________________________
City: __________________________ Province: _________ Postal Code: ______
Email: ___________________________________________
ACCESS-MH Patient Journeys -
Parent (for Child/Youth <18yrs in NL/PE/NS and <19yrs in NB) Consent Form

Version Date: Jan 11, 2016
Title of Research Project:
Barriers and Facilitators in Access to Child/Youth Mental Health Services

Project Website: http://access-mentalhealth.ca/

Principal Investigator – UPEI
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This project will continue for four years and some participants will be asked to participate in a follow-up interview similar to the first (approximately 60-90 minutes). You can indicate whether your child can be contacted for this purpose on the attached Consent Form.
Potential Harms
We know of no harm that taking part in this study could cause your child. Researchers have been trained regarding the mental health conditions they are studying as well as techniques to encourage participation while limiting the risk of an emotional exit from interviews. Counseling services will be made available to participants who require them and extra care will be taken to explain to your child that participation is voluntary and that they may choose to stop participating at any time.

Potential Benefits
Your child will receive $30 as a thank you for their time. You and your child may not benefit directly from this study. There is no guarantee that your child’s participation will directly lead to changes in mental health services or changes in your or your child’s experiences in the mental health care system.
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Name

______________________________
Signature and Date

Name of Child

For facilitator only: I was present when ___________________________ read this Consent Form and agreed/consented, to allow their child to participate in this research study.

______________________________
Printed Name of person who obtained consent

Signature & Date

I understand that a short summary of the research results will be available to participants at some point in the future.

I would like to receive this summary: ___ Yes ___ No

Please indicate how you would like to receive the summary:
Mail to home _____ Email to you _____
Other ____________________________

Please provide a mailing or email address:

Name: ____________________________

Organization (if applicable): ____________________________

Street Address: ____________________________

City: __________________ Province: __________ Postal Code: __________

Email: ____________________________

ACCESS-MH Patient Journeys - Child/Youth Assent Form
(for <18yrs in NL/PE/NS and <19yrs in NB)

Version Date: Jan 11, 2016

Title of Research Project:
Barriers and Facilitators in Access to Child/Youth Mental Health Services

Project Website: http://access-mentalhealth.ca/
**Principal Investigator – UPEI**
Dr. Kate Tilleczek  (902) 620-5127  ktilleczek@upei.ca

**Principal Investigators**
Dr. Rick Audas, Memorial University of Newfoundland
Dr. Scott Ronis, University of New Brunswick
Dr. Michael Zhang, Saint Mary’s University

**Post-Doctoral Fellow**
Dr. Brandi Bell, UPEI  1-855-861-5127 (toll free)  brbell@upei.ca

We would like to invite you to participate in a research project about how services are provided to children and youth identified with anxiety, depression, autism spectrum disorders, conduct disorder, and/or eating disorders.

**Description of Research**
We intend to document and analyze how treatment is received across government and non-government sectors including Health, Education, Social Development, Public Safety, and Youth and Family Services. We will collect a variety of information from 240 individuals (80 children/youth, 80 parents, and 80 service providers) from across the Atlantic Canadian provinces (PE, NB, NS, NL). To do so, we are using interviews augmented with a visual mapping process. Information collected will be shared and compared across provinces.

If you choose to participate in this research project it will take 90-120 minutes of your time. You will be asked to participate in an interview of 60-90 minutes to talk about your journey with mental health. Prior to the interview, you will be asked to find 3-5 visual images that you feel represent your journey in some way and to bring these to the interview (this is not required, but can be a helpful way to think and talk about your experiences). At the beginning of the interview, you will be asked to fill out a socio-demographic survey which will take about 15 minutes. The interview will be audio-recorded. During the interview you will be asked to create a ‘journey map.’ This will involve placing items representing people, places, and things on a blank board to help show what your journey with mental health has been like.

This project will continue for four years and some participants will be asked to participate in a follow-up interview similar to the first (approximately 60-90 minutes). You can indicate whether you can be contacted for this purpose on the attached Assent Form.

**Potential Harms**
We know of no harm that taking part in this study could cause. Researchers have been trained regarding the mental health conditions they are studying as well as techniques to encourage participation while limiting the risk of an emotional exit from interviews. Counseling services will be made available to participants who require them.

**Potential Benefits**
You will receive $30 as a thank you for your time. You may not benefit directly from this study. There is no guarantee that your participation will directly lead to changes in mental health services or changes in your experiences in the mental health care system.
A summary of the results will be available for participants. If you are interested in receiving the summary, please provide your contact information on the attached Assent Form. We will also ask you about the best ways to provide the study results to you. We are committed to sharing our research findings with our participants and those who are in a position to make positive changes for young people.

**Confidentiality**
We will keep all information that we collect during this project confidential and anonymous. We will ensure that you will not be identified from any of your responses. We will destroy the audio-recording of your responses 15 years after the end of the study. All study material will be secured in a locked cabinet at UPEI. We will identify you only by a number or a code name in the final transcript.

**Exceptions to Confidentiality**
Due to legal and ethical requirements, the research team must break confidentiality if:
1) The interviewer becomes aware of child abuse or neglect of someone who is under the age of 19 in NB/NL, 18 in PEI, or 16 in NS;
2) The interviewer becomes aware of sexual abuse perpetrated by a health care professional toward an identified adult or child; or
3) The interviewer becomes aware that the participant is threatening harm to oneself or another identified person.

**Participation**
Whether or not you take part is completely up to you and your parent. If you do decide to be interviewed, you may stop participating in the project at any time and without any consequences.

**Sponsorship**
The funder of this research is the Canadian Institutes of Health Research (CIHR).

**Conflict of Interest**
The members of the research team have no conflicts of interest to declare.

**Assent**
By signing this form, I agree that:
1) I have read and understood this assent form.
2) The study has been explained to me. All my questions were answered.
3) The possible harms and discomforts of this study have been explained to me.
4) I understand that I have the right to refuse to take part in this study. I also have the right to withdraw from this study at any time. e.g., before or even after the recordings are made.
5) I can ask any questions about the study at any time now and in the future.
6) I have been told that all research information will be kept confidential, except where required by law (e.g. suspected child abuse, court subpoena).
7) I understand that no information that would identify me will be released or printed.
8) I understand that no information about me (including recordings) will be given to anyone or be published without first asking my permission.
9) I understand that I can keep a copy of the signed and dated Assent Form.
The Research Ethics Boards of UPEI, UNB, SMU, and MUN have approved this research project. If you have any difficulties with, or wish to voice concern about, any aspect of your participation in this study, or the ethical conduct of this study, you may contact the relevant Research Ethics Board (REB) associated with the province you are located. Contact information is noted below:

<table>
<thead>
<tr>
<th>Province</th>
<th>University REB</th>
<th>Contact Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>PEI</td>
<td>UPEI</td>
<td>(902) 620-5104, <a href="mailto:reb@upei.ca">reb@upei.ca</a></td>
</tr>
<tr>
<td>NB</td>
<td>UNB</td>
<td>(506) 453-5189, <a href="mailto:ethics@unb.ca">ethics@unb.ca</a></td>
</tr>
<tr>
<td>NS</td>
<td>SMU</td>
<td>(902) 420-5728, <a href="mailto:ethics@smu.ca">ethics@smu.ca</a></td>
</tr>
<tr>
<td>NL</td>
<td>Health Research Ethics Authority (MUN)</td>
<td>(709) 777-6974, <a href="mailto:info@hrea.ca">info@hrea.ca</a></td>
</tr>
</tbody>
</table>

### Assent

<table>
<thead>
<tr>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>I agree, or give assent, to participate in an interview</td>
<td></td>
</tr>
<tr>
<td>I agree, or give assent, to be contacted to participate in a second interview in about 2 years’ time</td>
<td></td>
</tr>
<tr>
<td>If yes, please provide contact details (email or phone):</td>
<td></td>
</tr>
<tr>
<td>I agree, or give assent, to being audio-recorded as part of this study</td>
<td></td>
</tr>
<tr>
<td>I agree, or give assent, to have my selected images photographed as part of this study</td>
<td></td>
</tr>
<tr>
<td>I agree, or give assent, to have my ‘journey map’ photographed as part of this study</td>
<td></td>
</tr>
<tr>
<td>In addition, I give permission for the photographs and interview data to be used on the project website, <a href="http://access-mentalhealth.ca/">http://access-mentalhealth.ca/</a> (understanding that I will not be identified in any way)</td>
<td></td>
</tr>
<tr>
<td>In addition, I give permission for the photographs and audio recordings to be used for additional research projects on the same topic</td>
<td></td>
</tr>
<tr>
<td>I agree, or give assent, for data collected from this study to be used in future publications such as dissertations, journal articles, and books. This includes use in graduate student dissertations and theses by individuals who serve as research assistants on the project and who are also graduate students at UPEI</td>
<td></td>
</tr>
<tr>
<td>I agree, or give assent, to allow the use of anonymous quotations from my interview in research reports (understanding that I will not be identified in any way)</td>
<td></td>
</tr>
</tbody>
</table>

______________________________  ___________________________
Name                                      Signature and Date

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For facilitator only: I was present when ____________________________ read this Assent Form and agreed/assented, to participate in this research study.

____________________________________

Printed Name of person who obtained assent Signature & Date

I understand that a short summary of the research results will be available to participants at some point in the future. I would like to receive this summary: ___ Yes ___ No

Please indicate how you would like to receive the summary:
Mail to home _____ Email to you _____
Other _______________________________________

Please provide a mailing or email address:
Name: ______________________________________
Organization (if applicable): ____________________________
Street Address: ______________________________________
City: __________________________ Province: _________ Postal Code: ___________
Email: _____________________________________________
Appendix 2: Interview Protocol

Child/Youth Patient Journeys Interview – Time 1

Note: Use developmentally appropriate language and a conversational approach; focus on narrative.

Questions and Probes:

A) Early signs (retrospective)

- Could you describe what was happening in your life when you first felt you would need support for your mental health? (family, school, friends, community, spiritual, other)
- What happened next? (probe with each of family, school, friends, community, spiritual, other)
- Were you pleased about this action or response? Why/why not?
- Start a journey map, what would be main elements of life journey at this time?
- What worked/did not work well for you? (at all levels - ACCESS and CARE)
- What would you have liked to have seen happen? (at all levels)
  - What would you do differently?

B) Entering the system (or not)

- After this initial phase, what happened when you were looking for support for your mental health? (family, school, friends, community, spiritual, other)
- What happened next? How much time did you wait? What did you do? What did other people (parents, friends, teachers, etc.) do?
- Were you pleased about this action or response? Why/why not?
- Return to the journey map, what would be the main elements of your life journey now?
- What worked/did not work well for you? (All levels, ACCESS and CARE)
- What would you have liked to have seen happen?
- What part did school, teachers, mental health, allied professionals, community supports, others play in this journey? How and what happened?

C) Exits and Returns

- Were there any times in which you left the system? Why? What happened?
- Did you return? Why, how, what happened?

D) Recommendations and Directions (prospective)

- If you could speak to family doctors (therapists, teachers, parents, other kids, others) what would you like them to know about your journey?
- If you could make three recommendations for fixing the youth mental health system, what would they be?
- If you had a chance to map a system of youth mental health care in your province, what would it look like? Where would the young people and families begin and end in a perfect journey? Where are they mainly beginning and ending at present? (ACCESS and CARE)
Appendix 3: Survey

ACCESS-MH Patient Journeys - Child/Youth Face Sheet

Please note: If any of these questions make you uncomfortable, you are free not to answer them.

☺☺☺☺☺☺☺☺☺☺☺☺☺☺

Part 1 – ABOUT YOU
What is the name of the city or town where you live? What is your age?
How do you identify your gender? Were you born in Canada?
yes no
If no, in which country were you born?
In what year did you first come to Canada?

What language(s) do you most often speak at home? (check all that apply)
   English
   French
   Other(s):

People in Canada come from many racial or cultural groups. You may belong to one or more groups on the following list.
Are you ….
   Aboriginal (e.g. North American Indian, Métis, Inuit) Arab
   Black Chinese
   Japanese Filipino
   South Asian (e.g. East Indian, Sri Lankan, etc.) White
   Southeast Asian (e.g. Vietnamese, Cambodian, etc.) Korean
   West Asian (e.g. Iranian, Afghan, etc.) Latin American
or another group; Please specify:
   Declined

With whom do you currently live in your MAIN home? Please indicate the number of each.
   mother female guardian foster mother step-mother
   father male guardian foster father step-father
   sister half-sister foster sister sister (blended family)
   brother half-brother foster brother brother (blended family)
   other (please specify):

Do you have another home you live in? yes no
If yes, who lives with you in that home? Please indicate the number of each.
- mother
- female guardian
- foster mother
- step-mother
- father
- male guardian
- foster father
- step-father
- sister
- half-sister
- foster sister
- sister (blended family)
- brother
- half-brother
- foster brother
- brother (blended family)
- other (please specify):

Compared to other young people, do you feel that your family:
- does not have enough money
- has enough money
- has lots of money
- declined

Part 2 – ABOUT YOUR EDUCATION AND WORK
Are you in school now? yes no If yes, what grade?
what school?
what are your favourite classes?
what classes do you find most difficult? If no, what is the name of the last school you attended?
What is the highest Grade you completed?
Do you have a job? yes no If yes, how many hours do you work each week?

Part 3 – ABOUT MENTAL HEALTH
Do you know if you have received a formal diagnosis from a health professional (e.g., psychiatrist, psychologist) for a mental health condition? Yes No
If ‘yes’, what diagnosis(-es) did you receive and when did you receive them? (check as many as apply)

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Date Received (month/year)</th>
</tr>
</thead>
<tbody>
<tr>
<td>To what extent does this mental health condition create problems for you in everyday life?</td>
<td></td>
</tr>
<tr>
<td>Not at All</td>
<td>Little</td>
</tr>
</tbody>
</table>

Anxiety
Depression
Autism spectrum disorder
Conduct disorder
Eating disorder
Other (please specify):
If ‘no’, do you currently SELF-IDENTIFY as having any of the following mental health conditions? And since when do you feel you’ve had the condition? (check as many as apply)

Condition   Since (month/year)   To what extent does this mental health condition create problems for you in everyday life?  
                  Not at All               Little               Some-what               Much               A Great Deal
Anxiety
Depression
Autism spectrum disorder
Conduct disorder
Eating disorder
Other (please specify):

THANK YOU FOR COMPLETING THIS FORM
Appendix 4: REB Letter of Approval

April 30 2014

Dr K Tilleczek
Faculty of Education

Re: REB Ref # 6005704

“Barriers and Facilitators in Access to Child/Youth Mental Health Services”

The above mentioned research proposal has now been reviewed under the expedited review track by the UPEI Research Ethics Board. I am pleased to inform you that it has received ethics approval. Please be advised that the Research Ethics Board currently operates according to the Tri-Council Policy Statement 2: Ethical Conduct for Research Involving Humans and applicable laws and regulations.

The approval for the study as presented is valid for one year. It is your responsibility to ensure that the Ethics Renewal form is forwarded to Research Services prior to the renewal date. The information provided in this form must be current to the time of submission and submitted to Research Services not less than 30 days of the anniversary of your approval date. The Ethics Renewal form can be downloaded from the Research Services website (http://www.itepi.ca/research/reb_forms).

Any proposed changes to the study must also be submitted on the same form to the UPEI Research Ethics Board for approval.

| The Research Ethics Board advises that IF YOU DO NOT return the completed Ethics Renewal form prior to the date of renewal: |
| - Your ethics approval will lapse |
| - You will be required to stop research activity immediately |
| - You will not be permitted to restart the study until you reapply for and receive approval to undertake the study again. |

Lapse in ethics approval may result in interruption or termination of funding.

Notwithstanding the approval of the REB, the primary responsibility for the ethical conduct of the investigation remains with you.

Sincerely,

James E. Moran, Ph.D.
Chair, UPEI Research Ethics Board