MOTHERS’ CARE-SEEKING JOURNEYS FOR
DAUGHTERS WITH DEPRESSION

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ABSTRACT

Atlantic Canadian mothers’ experiences in seeking and accessing mental health care and support for their adolescent daughters’ depression were explored in this thesis. The care-seeking journeys were depicted through the narratives of seven mothers whose eight daughters accessed the provincial mental health systems and obtained a diagnosis of depression. Qualitative semi-structured interviews and patient journey mapping methods guided data collection to assist in understanding mothers’ experiences in the mental health system, education system, and family life. The interview transcripts and journey maps were analyzed using narrative and thematic analysis and by drawing on critical and feminist theories. The three overarching themes in mothers’ journeys were; a) marginalization and loss of control, b) becoming empowered, and c) hope for the future.

Recommendations for improving mothers’ care-seeking experiences in Atlantic Canada were reported, including evidence to enhance continuity of care, increase collaborative team-based supports, and strategize quality mental health education. This research can help to increase awareness and understanding among health care professionals and educators regarding the challenges that mothers face while seeking care for their daughter’s depression, highlighting the need to provide more consistent and collaborative support and conform to a streamlined system to assist in the journeys of Atlantic Canadian mothers and youth.

Keywords: mothering, depression, mental health, care-seeking, qualitative, narrative research, patient journeys, Atlantic Canada
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Chapter 1: Introduction

I found it a frustrating experience because I didn’t really know what to do. She was getting worse. I know that they were not really keen to admit her—their doctor was trying to delay admission I think, because she felt that my daughter wanted to be admitted and that wasn’t very good. You don’t want them to want to be admitted. You want them to want to get better at home. (Beth)

Mothers of adolescent girls with depression navigate various obstacles as they interact with others and attempt to seek mental health care for their daughters. This thesis explores the care-seeking journeys of seven mothers whose eight daughters have accessed their provincial mental health system in Atlantic Canada and obtained a diagnosis of depression. Three themes that were identified in mothers’ narratives were 1) marginalization and loss of control, 2) becoming empowered, and 3) hope for the future with examples in the mental health system, education system, and family life. Mothers experienced marginalization and loss of control in their interactions with others while also fighting to becoming empowered throughout the depression care-seeking journeys. They maintained hope for the future and made recommendations for improvements to the systems that they felt would facilitate depression care-seeking journeys.

1.1. Purpose

The purpose of this narrative study is to understand Atlantic Canadian mothers’ experiences in seeking and accessing mental health care for their adolescent daughters’ depression. The focus is on the power dynamics that mothers face in the mental health system, education system, and family life. Participants’ suggestions on improvements to the system that would facilitate their journeys are also explored. The ultimate goal is to
provide evidence for improving support and care for mothers of young people with depression and adhering to a streamlined youth mental health system to ease the journeys of families.

1.2. Background

Depression, medically termed major depressive disorder or clinical depression, is characterized by feelings of sadness, hopelessness, decreased energy and interest in activities, appetite or weight changes, and thoughts of death and suicide or suicidal attempts (National Institute of Mental Health, 2016). Depression is estimated to be the largest contributor to the burden of disease in the population, leading to early death and disability at a higher rate than other illnesses (World Health Organization, 2009). When comparing all age groups, the prevalence of mood and anxiety disorders is highest in the 15 to 24 year old group (Statistics Canada, 2012). Furthermore, Statistics Canada (2012) reported that one in five teenagers experienced suicidal ideation in the past year, which is typically associated with depression.

When youth are suffering with depression, it is often their parents that are closely involved in recognizing changes and providing support for them (Howe, Coates, & Batchelor; 2014). Mothers’ roles, in particular, are emphasized in the child’s health care and mothers are held to a higher degree of responsibility for managing their child’s health than fathers (Howe et al., 2014; Jackson & Mannix, 2004; Phares, 1992; Phares, Fields, Kamboukos, & Lopez, 2005). The emphasis on the mother’s role can be understood in light of cultural expectations that mothers be highly involved in their child’s lives and should take responsibility for their child’s happiness and wellbeing (Clarke, 2012; Wall, 2010). Due to the gendered expectations of parenting roles, mothers frequently interact
with health care professionals and other service providers and to an even greater extent when their child is experiencing mental health problems (Clarke, 2012; Francis, 2012a; Jackson & Mannix, 2004).

The mental health system in Canada has been shown to be problematic for mothers and youth, as it does not offer coordinated and efficient services for the younger population (Boydell, Pong, Volpe, Tilleczek, Wilson, & Lemieux, 2006; Kirby & Keon, 2006; Kirby, 2008). Mothers often attempt to navigate services among separate systems, and experience isolation, difficulty accessing information and little to no support or respite (Kirby & Keon, 2006) when they are seeking care for their child.

This thesis project is a smaller part of the Atlantic Canada Children’s Effective Service Strategies in Mental Health (ACCESS-MH) project, a 5-year CIHR-funded project that examines the child and youth mental health system in Atlantic Canada. Below is a brief summary of the ACCESS-MH project:

Our team of researchers across Atlantic Canada is deepening understanding of child/youth mental health in the region. The Atlantic Canada Children’s Effective Service Strategies in Mental Health project (ACCESS-MH; http://access-mentalhealth.ca/) is a 5-year initiative funded by the Canadian Institutes of Health Research (CIHR). It employs the newest knowledge on youth journeys and arts-based methods and melds it with the analysis of provincial and national statistical data (e.g., provincial administrative data and statistics, Statistics Canada, Health Canada, CIHI, NLSCY)…The combination of quantitative and qualitative methods provides an opportunity to examine mental health conditions and the mental health system from a variety of perspectives. Our journeys approach is
especially suited to understanding the complex contexts of young lives.

(Tilleczek, Bell, Munro, & Gallant, in press).

This thesis connects to the larger ACCESS-MH project in that it involves a portion of the parent sample from the qualitative patient journeys that participated in the larger project and contributes to the goals of this CIHR-funded initiative.

1.3. Context

Depression can significantly affect a young person’s quality of life due to the difficult and sometimes unbearable symptoms that influence daily activities such as eating, sleeping, going to school, and socializing (American Psychological Association [APA], 2010; Farmer, 2002; McCann, Lubman, & Clark, 2012). The causes of depression are generally understood to be a combination of interconnected factors including biological, psychological, social and environmental, which differ from person to person (Akiskal & McKinney, 1973; APA, 2010; Harris, 2003). Youth with depression are also likely to experience co-morbidities with other diagnoses including anxiety (Adams, Balbuena, Meng, & Asmundson, 2016), substance abuse disorder (Curry & Hersh, 2016), and eating disorder (Puccio, Fuller-Tyszkiewicz, Ong, & Krug, 2016).

Mood disorders including depression are highest among youth aged 15 to 24 with a prevalence of 8.2%, and depression reportedly affects females at higher rates across the lifetime than males (Statistics Canada, 2012). The largest difference for depression rates between genders is seen in young people, with females in the 15 to 24 age group who met criteria for depression at 9% and males in the same age group at 5.3% (Statistics Canada, 2012). Females are also three to four times more likely to attempt suicide (Langlois & Morrison, 2002; Mustard, Bielecky, & Etches, 2010), and are 1.5 times more frequently
hospitalized for suicidal attempts, than males (Canadian Institute for Health Information, 2011). In Canada, suicide is the second leading cause of death for young people aged 10 to 24, and depression is a common factor in 60% of suicides (Canadian Mental Health Association, 2016; Cavanaugh, Carson, & Sharpe, 2003; Lesage, Boyer, & Grunberg, 1994).

There is a lack of current data on Atlantic Canadian youth depression and self-harming rates, as well as their behaviour in care-seeking and impact of care. We do know that Canadian youth aged 15 to 24 with mental health conditions reportedly seek professional care more frequently than those without mental health conditions (Findlay & Sunderland, 2014; Findlay, 2017). One study found that half of Canadian youth with a mental heath condition reported seeking care from a professional in the past year (Findlay & Sunderland, 2014). Another study found that less than one-third of youth experiencing suicidal ideation reported seeking professional support (Fuller-Thomson, Hamelin, & Granger, 2013). Thus the number of youth that are seeking professional treatment for depression, the results of their attempts to seek care, and the adequacy of the mental health care still remain unclear.

There is also a large gap in the research in terms of mothers’ experiences with their daughter’s depression and mental health care, especially within Atlantic Canada. As mothers are most often closely involved in the mental health care experience (Phares, 1992; Phares et al., 2005), and as depression reportedly continues to affect girls at higher rates than boys (Statistics Canada, 2012), it is important to listen to the individual and collective stories of mothers regarding the depression care-seeking journey. This will
assist in finding solutions and making improvements to the current Atlantic Canadian mental health system.

1.4. Research Questions

What are the care-seeking experiences of mothers of adolescent girls with depression in Atlantic Canada? The guiding research questions are: What power dynamics do mothers experience in the mental health system, education system, and family life while seeking care for their daughters? What types of supports are needed for mothers of daughters with depression to facilitate the care-seeking journey?

1.5. Scope

The scope of this study is limited to Atlantic Canadian mothers’ experiences seeking care for an adolescent daughter between the ages of 13 and 19 with a diagnosis of depression. The components of the mothers’ interviews that described the care-seeking experience for some of the daughters’ other diagnoses, such as eating disorder or autism spectrum disorder (ASD), could not be included in this study. Mothers living in rural areas of Atlantic Canada were not included in this thesis. Certain aspects of the mothers’ interviews that I felt did not exemplify power dynamics in social institutions while seeking care could not be included, such as mothers’ views on the impacts of technology on their daughters’ mental health.

1.6. Chapter Summary

This chapter introduced the topic of mothers’ narratives and experiences in care-seeking in Atlantic Canada, with connection to the literature on depression and youth mental health. It highlighted the increased prevalence of depression in young girls compared to boys and the need to incorporate mothers’ voiced journeys in research. The
The research purpose, background, and context were outlined, including an explanation of the larger ACCESS-MH project and the significance of the study. The chapter concluded by stating the research question and the two guiding questions as well as defining the scope of the study.

The thesis is divided into five chapters in addition to the references and appendices sections. The second chapter contains a review of the literature. Chapter 3 details the methods and methodology employed in this study, and Chapter 4 contains the findings. Chapter 5 is a discussion of how the findings relate to the literature, and the thesis ends with recommendations, future directions, and conclusions.
Chapter 2: Literature Review

The purpose of this literature review is to explore mothers’ experiences seeking care for a child with depression. The search terms used to scan the databases PsycINFO, PubMed, CINAHL, ERIC, and CBCA included variations of the terms “mother experience,” “parent experience,” “youth mental health,” “adolescent” or “teenage depression,” “Canada,” “Atlantic Canada,” and “qualitative.” Twenty-one English-language peer-reviewed journal articles were included in this chapter, with only six qualitative studies from Canada. No qualitative abstracts or theses/dissertations were found that were relevant to the topic. One published study (Stapley, Midgley, & Target, 2016) was found that focused on parents’ experiences with their adolescent child’s depression, and no studies were found that focused specifically on mothers’ experiences seeking help for a child with depression.

The literature review begins with a discussion of the qualitative literature pertaining to parents’ experiences of care when they have a child or youth with one or more mental health challenges. This section includes parents’ experiences with their child’s depression and/or related mental health issues that affect their everyday life. The literature that describes specifically mothers’ experiences with their child’s mental health care is then explored. The chapter ends with identification of the gaps in the literature. It is important to note that the terms youth, adolescent, and child are used interchangeably in this chapter, as it is not always clear what age group is being studied.

2.1. Qualitative Literature on Parents’ Experiences

Studies examining the parents’ experiences of care-seeking for young people with depression often include parents’ accounts of when they recognized that their children
were first having mental health problems (Harden, 2005; Jackson & Mannix, 2004; Stapley et al., 2016). For parents of youth with depression, the onset of depression is often difficult for parents to detect but becomes more identifiable as symptoms slowly start to effect more areas of the child’s functioning and family life (Highet, Thompson, & McNair, 2005; Stapley et al., 2016). Since depression is considered an internalizing disorder, the young person who is affected may not appear to be functioning any differently to those around him or her (Logan & King, 2002). The youth’s depression may not cause family disruption in the same way that other more externalizing disorders could, which can prevent adults in the youth’s life from seeing the changes as signifying of a major issue initially (Stapley et al., 2016). Parents reported that they could better identify behavioural changes in hindsight, but that they were initially unsure whether the changes in the youth were due to hormones during puberty or physiological imbalances that affected their mood (Stapley et al., 2016).

Parents who had experience with mental illness or who were educated on the early signs and symptoms of depression were often in a better position to identify the mental health challenge in their child and seek professional help (Boydell et al., 2006). Aside from previous knowledge of mental illness, parental attitudes also strongly affected whether they recommended that the youth seek professional help or whether they facilitated that connection (Logan & King, 2002; Radovic, Reynolds, McCauley, Sucato, Stein, e al., 2015). Even when parents recognized that the youth might be experiencing depression, studies show that the youth and parents do not typically access services until symptoms become uncontrollable and extremely burdensome in many areas of the youth’s and family’s life (Highet et al, 2005; Stapley et al, 2016).
Other personal and systemic factors that prevent youth and their parents from seeking care for the youth’s mental health problem include stigma, wait times, and lack of human resources (Boydell et al, 2006). The fact that there are not enough service providers and the public knowledge of long wait lists for mental health services can prevent parents from seeking care for their child until issues become debilitating. Aside from this, parents may expect to experience blame and judgement from other people, including health professionals, when their child is having mental health challenges, and these expectations often become a reality when they enter the system or try to share details about their child’s problems with others (Johansson, Anderzen-Carlsson, Ahlin, & Andershed; 2012).

As parents often experience judgement from one or more of their child’s health care providers, they also encounter it through their interactions with friends and family—those that would normally serve as a support system for them in times of need (Blum, 2007; Byrne, Morgan, Fitzpatrick, Boylan, Crowley, et al., 2008). As the symptoms of depression are not always visible, there tends to be general misconceptions around the roles of parenting and genetics in its development (Francis, 2012a). This can lead some people to extend most of the blame to parenting practices, when it is really understood as a combination of environmental and genetic factors influencing each other (Lockwood, Su, & Youssef, 2015).

Whereas causes of physical challenges are generally easier to understand than the causes for mental health challenges, the contributing factors to depression remain unclear to many people. Due to this lack of public knowledge about mental health, parents report that their friends and family members often don’t understand what they are experiencing
with their child (Svensson, Nilsson, Levi, & Suarez; 2013). This can induce feelings of isolation in not having anyone to turn to for support and guidance at a time when much of their time and energy is being focused on their child’s problems (Stapley et al., 2016). When a youth and his or her parents seek care for mental health, the services they access beyond the primary care provider often depend on the ways in which the youth’s mental health issue is treated by the provider and whether or not it is understood as a serious issue (Harden, 2005). Mothers have reported that their accounts to their doctor of their child’s issues were not taken seriously even though the mother could recognize that the child was in need of professional help (Clarke, 2012; Francis, 2012b). In this way, parents often feel “deskilled” in their role as a parent when they enter the system (Harden, 2005, p. 211; Coates, 2016). Harden’s term “deskilling” refers to “the ways in which parents felt that their parenting skills were challenged by the illness and by the medical profession” (p. 211).

When a youth enters the mental health system and starts receiving care, parents may feel excluded from the youth’s treatment and decisions around care due to lack of knowledge about mental illnesses, and feel as though they don’t know how to support their child, leading to feelings of helplessness (Coates, 2016; Harden, 2005; Stapley et al, 2016). The literature on parents’ experiences in the mental health system illustrates how parents, and especially mothers, often feel undermined and confused when their child seeks professional treatment for mental health challenges, which is connected to these feelings of helplessness (Blum, 2007; Clarke, 2012; Harden, 2005; Hight et al., 2005).

From the parental perspective, involvement and integration of the whole family into the youth’s mental health treatment is considered a marker of the quality of care
(Coates, 2016). Parents also judge the quality of mental health services by the provider’s availability, the information they supply about mental health and services, their professionalism, their collaboration with other professionals, and their empathy and commitment to help their child (Widmark, Sandahl, Piuva, & Bergman; 2013).

Family focused treatment can be beneficial because the family dynamic often shifts as one or more children deal with mental health issues, which can also affect the spousal relationship and the care that the other siblings receive (Svensson et al., 2013). These relationships can become disrupted due to the increased focus on the child with mental health issues (Svensson et al., 2013). Changes in routines and family activities can also affect the parents’ identities, wellbeing, and overall health and cause them to feel as though their other roles are being neglected (Francis, 2012b; McDonald, O’Brien, & Jackson, 2007). Due to this disruption in the family life, family-focused therapy along with meeting client’s specific needs are important factors to parents who have children accessing youth mental health services (Coates, 2016).

As children with mental health issues develop and age, parents tend to give more responsibility to their child in managing their mental health and caring for themselves through re-examination of their own responsibilities as a parent (Francis, 2012a). Parents re-examine their parenting identity by questioning psychiatric treatment and practice after doing their own research (Harden, 2005). By attempting to accept and integrate their child’s illness into their lives (Harden, 2005), parents may feel more equipped to cope with the diagnosis of depression as well as their changed parenting roles as a result of the mental health challenges.

2.2. Qualitative Literature on Mothers’ Experiences
Mothers are likely to experience blame and judgement when they have a child with depression due to their generally higher levels of involvement in their children’s lives and healthcare, but also due to cultural beliefs that mothers are responsible for their families and moulding children into productive members of society (Blum, 2007; Clarke, 2012; Francis, 2012a; Wall, 2010). Mothers seeking support for their child can experience judgement from various people including family, spouse, friends, health providers, and themselves (Jackson & Mannix, 2004).

This stigma and the suffering that mothers experience with their child can be understood through the theories of intensive parenting/mothering and medicalization of childhood problems (Clarke, 2012; Francis, 2012a), where children are diagnosed and treated for more challenges and mothers are implicated in the development of these challenges (Blum, 2007; Jackson & Mannix, 2004). Intensive parenting and medicalization are influenced by cultural beliefs about gendered parenting roles and responsibilities that place the mother at the forefront of care, as well as beliefs about whether mental illness is an actual illness (Francis, 2012a; Wall, 2010). These beliefs put an immense amount of pressure on the mother to keep her child healthy and happy, and if her child deviates from this norm she will most often be implicitly or outwardly blamed (Smith & Estefan, 2014).

When mothers enter the mental health system with their child with initial concerns about their child’s mental health, the severity of the issues are often minimized by health care professionals through denial of mental illness or attributing changed behaviour to adolescent changes (Clarke, 2012; Harden, 2005; Highet et al, 2005). The severity of the young person’s mental health is often not recognized by service providers
until they are close to or in crisis (Clarke, 2012; Harden, 2005; Hight et al., 2005). Mothers are then questioned about the child’s development in relation to the depression, which implies to mothers that the early childhood environment they helped create for their child influenced the development of mental illness (Clarke, 2012; Stapley et al., 2016; Wall, 2010).

Intensive parenting discourses imply that parents, and mothers in particular, are responsible for creating the perfect mentally stimulating environment for their child, assuming that mothers can control the child’s future outcomes and achievements based on their early years (Wall, 2010). The detrimental effects of this discourse can become apparent to mothers when their child is having mental health problems or other challenges where they may deviate from the expected norm, and this is when mothers may internalize a feeling of responsibility for causing the problems and begin to self-blame (Svensson et al., 2013; McDonald et al., 2007; Smith & Estefan, 2014).

When the child or youth requires care and assistance from the mental health and education system, mothers tend to become advocates for themselves and their child (Boydell et al., 2006), and defend against the impact of mother blaming (Blum, 2007). The term “mother blaming” refers to “a sexist bias toward studying mothers’ contributions to child and adolescent maladjustment and at the same time ignoring similar contributions by fathers”” (Phares, 1992). Mothers often feel they need to fight for appropriate care for their child in the medical and education systems in order for their child to receive mental health services and support, but even when they receive care it is often discontinuous and fractured (Blum, 2007; Clarke, 2013). Mothers’ fighting and advocating roles can sometimes lead to feelings of frustration and helplessness when they
are not listened to or taken seriously (Jackson & Mannix, 2004; Stapley et al., 2016).

Some mothers of adolescents who deliberately self-harm report feeling embarrassed that their child was so unhappy, and they connected their child’s actions to their own parental identities (McDonald et al., 2007; Smith & Estefan, 2014). Mothers of adolescents with other mental health problems, such as substance abuse and eating disorder, also felt that their child’s health and wellbeing was strongly linked their own wellbeing and identity as parents (Smith & Estefan, 2014; Hoskins & Lam, 2001). This substantial influence on the mothers’ sense of self shows the effects of cultural beliefs about mothers’ roles and the internalizing impact that it can have on mothers of children with mental health issues.

2.3. Chapter Summary

Mothers’ stories are beginning to be heard through qualitative exploratory research methods, but mothers’ experiences with mental health care when they have a daughter with depression are still missing from the literature. Using various combinations of the search terms “mother experiences,” “parent experience,” “adolescent” or “teenage depression,” “youth mental health,” “Canada,” “Atlantic Canada,” and “qualitative,” only six qualitative peer-reviewed studies from Canada were located on parents’ experiences with seeking help for a child with mental health challenges and no studies were found that focused specifically on mothers’ experiences seeking help for a child with depression. To that end, there is a need for mothers’ narratives to be heard in order to create more awareness about the issues that are affecting them and their daughters on their journeys to mental health.
This literature review shows that mothers of youth with mental health challenges often have difficulty recognizing the onset of depression and seeking and accessing care from the mental health and education systems. They also experience changes and setbacks in the family life. However, it also shows that mothers can be strong-willed and determined to help their child get the appropriate treatment, and that they go to great lengths to ensure the health of their child. My research questions relate to these findings but specifically examine the experiences and journeys of mothers in the Atlantic Canadian context to understand the differences and similarities to the literature.

Following this chapter, the answers to the research questions and a description of the ways in which the answers were produced will be detailed. The main research question is: What are the care-seeking experiences of mothers of adolescent girls with depression in Atlantic Canada? The guiding research questions are: What power dynamics do mothers experience in the mental health system, education system, and family life while seeking care for their daughters? What types of supports are needed for mothers of daughters with depression to facilitate the care-seeking journey? The next chapter explores the methods that were chosen to answer these questions.
Chapter 3: Methodology & Methods

This chapter begins with an overview of qualitative inquiry and identifies the ontological and epistemological beliefs guiding this research. The theoretical framework and methodology are then explained, followed by details about the researcher’s position. The methods and elements of methodological and interpretive rigour are then outlined. The chapter ends with a discussion of ethical rigour and a chapter summary.

3.1. Qualitative Research

A qualitative paradigm is best suited to understanding the journeys of mothers and daughters in that it is an inductive approach based on the belief that reality is socially constructed and subjective (Broom & Willis, 2007). This inductive approach consists of gathering data and then analyzing themes and patterns throughout the data collection and analysis processes, which can assist in exploring care-seeking journeys. This is in comparison to a deductive approach where the researcher would start with a hypothesis before data collection and analysis. The qualitative approach leads to uncovering and clarifying meanings and takes into account the contextual nature of reality (Denzin & Lincoln, 2011) that is present within mothers’ stories. As each person’s social context and life conditions vary, they influence their interpretation of reality making it important to attend to contextual factors. This includes acknowledgement of the researcher’s own context and role in the study including the researcher’s own self-reflection during the research process.

The focus on interpretation of participants’ experiences, stories, and meanings is a primary characteristic of qualitative research (Denzin & Lincoln, 2011). It is important to note that the participants’ experiences presented in this study are not generalizable to all
mothers of daughters with depression. Rather, they represent the rich and contextualized stories of the seven mothers who participated in the study.

Ontological and epistemological beliefs help guide the qualitative research process and are congruent with the methodology and methods. Broom and Willis (2007) explain that ontology signifies the nature of reality or the ways in which reality is known, whereas epistemology defines the nature of knowledge or the ways that individuals come to know and understand the world. The ontological and epistemological beliefs are interconnected with the guiding theory or interpretive framework of the study.

3.1.1. Ontology. The ontological belief that defines this research includes the assumption that reality comes into being based on social relationships and power (Creswell, 2013). Mothers of daughters with depression are often marginalized and oppressed in different ways. This ontological belief was implicated throughout the research project as mothers explained their experiences interacting with people in various systems when seeking care for their daughters. Mothers’ narratives illustrate turning points where they resist oppression and fight to become empowered, such as in Zoe’s and Claire’s stories. They also demonstrate instances of loss of power and control as a result of social influences, as exemplified in Alice’s story.

3.1.2. Epistemology. The epistemological position guiding this thesis project involves knowing and understanding the world through the study of social structures of power, control, freedom, and/or marginalization (Creswell, 2013). The participants’ realities are understood and known through their attempts to fight against marginalization by social institutions in order to regain power and control that is threatened. Through

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1 All names are pseudonyms
their narratives we can come to understand their struggles and victories in the specific contexts in which they occur. Thus individuals are always impacted by the social and political context, and the injustices present in those contexts inform our ways of knowing the world.

3.2. Theoretical Framing

Critical and feminist theories guide this research design and approach to analysis (Carroll, 2004; Smith & David, 1975). The primary area of focus is the power struggles that are experienced through participants’ interactions with key social institutions in the care-seeking journey, such as health, education, and family, and the people operating within those institutions. Carroll (2004) explains how the critical theorist acknowledges major injustices in the world and how those injustices impact our actions. However, the social world and the products of it are not understood to be inevitable and natural, but rather they are a result of historical actions and can be changed or reshaped in the future (Carroll, 2004; Creswell, 2013). Becoming intimately aware of the detrimental effects of these inequities that are evident within narratives can bring about change in future actions that reduce domination and disempowerment.

The participants’ experiences and stories in this study are understood in relation to these historical representations of gender roles that still greatly influence women’s experiences (Smith & David, 1974; Tilleczek, 2014). Feminist theory can help us to understand women’s experiences in social institutions where they have felt disempowered, silenced, and/or controlled, such as within the mental health and education systems as well as in the family life as mothers and carers (Smith & David, 1975). It is important to listen to the stories of women regarding their experiences within
these social institutions, and their stories “must be understood in the context of the radical deprivation women have suffered of the means to speak of themselves and their condition.” (Smith & David, 1975; p. 4). Thus the lack of research that values women’s, and particularly mothers’, experiences within these social institutions can be understood as a reflection of historical attempts to control and silence them. In this way, the injustices that occur are not voiced, and challenges that women face cannot be acknowledged or understood.

The critical and feminist theoretical frameworks in this thesis project invite mothers’ narratives to illustrate the ways in which they are vulnerable, but also how they wrestle with social expectations that disempower them, and actively resist marginalization. The stories were re-organized into a chronological framework (Ollerenshaw & Creswell, 2002) to ease understanding and assist in identifying key elements of the stories that were related to the research questions guided by the chosen theories. The participants’ narratives along with the researcher’s co-construction of their stories can lead to social action and new understandings through examining mothers’ experiences using these theoretical frameworks.

3.3. Methodology

Stemming from the ontological and epistemological assumptions of a critical theory approach, narrative methods were selected. Narratives were incorporated into the study as both a method of data collection and analysis and were analyzed using narrative and thematic analysis (Chase, 2005; Clandenin & Connolly, 2000). Participants’ experiences and stories were examined and re-organized chronologically with attention to various narrative features such as turning points and contextual orientations.
(Czarniawska, 2004; Reissman, 2008). These helped convey power dynamics in their interactions. The collaborative construction of the narrative between participant and researcher is an important feature as the story is told through their conversation in the interview and also re-told through the researcher’s summary and analysis of it in identifying themes and patterns (Reissman, 2008). The particular type of narrative used is personal experience as described by Denzin (1989), in which illustration and examination of the stories of a small group of people with a few key similar experiences is undertaken. Participants’ reflections are apparent, and psychological and social processes are highlighted that may be both unique to them and more general across the sample.

This approach invites the participants’ stories to be heard in detail and the researcher is positioned as a co-constructor of these stories. Individuals engaging in narrative research often pay attention to detail, describe actions and behaviours, and follow a certain timeline (Czarniawska, 2004; Reissman, 2008). Participants reflect on their experiences throughout the timeline of interest and their stories are context-dependent (Sools, 2006). The context is a key feature that will be examined in relation to the participants’ stories and leads to better understanding of the meaning behind them.

Narrative research is powerful in creating a dialogue between the participants and the researcher and through this process highlights one or several important issues that the group of people experience (Creswell, 2013). The chronological aspect of this research, as part of the design of ACCESS-MH and this thesis project, attends to the participants’ narratives of past, present, and future and in this way creates transparency and openness about the research process. Through identification and examination of participants’ stories during a certain time frame, the reader becomes engaged as the story foreshadows
and leads up to the realization or turning point. The contextual information and collaboration between researcher and research participants enhances the quality and credibility of this research. Narrative research can shed light on the participants' views through their interactions with others and allows their stories to be of potential benefit to the participant in addition to readers and those engaged in the research outcomes.

The narrative approach outlined by Denzin (1989) is the most appropriate to use to answer my questions while also coinciding with the aims of the qualitative data collected through the larger ACCESS-MH project. My epistemological position closely connects with this approach because it allows for a critical co-construction between the researcher and the participant of the participant’s realities and life stories to illustrate mothers’ experiences with seeking care for their daughter.

The interview protocol questions, as well as the ways that mothers discussed their involvement in their child’s mental health journey through their interviews, assisted in the decision to use a narrative approach. Carter and Little (2007) explain how methodology interacts with methods and study design but not always in a linear fashion, which is applicable to this research design and the decision-making process in that methodology and study design for this thesis were influenced by the methods used in the ACCESS-MH study.

This choice of methodology and methods influenced how I formulate my purpose statement and research questions in that I framed them in a way that allowed me to chronologically describe the mothers’ experiences. In doing so, it invited participants’ identifications of the major challenges they faced through their interactions with various people and social institutions to be heard. One of the key aspects to the purpose statement
and questions will be to understand experiences and stories, which is a main focus of narrative research. The intent is to understand the positive and negative components of mothers’ depression care-seeking journeys with their daughters in order to provide a complete story that invites their voices to be expressed and privileged through the research.

3.4. Recruitment

Recruitment efforts differed slightly across provinces, as they were planned in the larger ACCESS-MH study and were organized by the principal investigators of the research team in each province. The recruitment strategy was purposive in that individuals who met the criteria for the study were selected to participate. The mental health disorders that were of interest for ACCESS-MH are anxiety, depression, eating disorder (ED), conduct disorder (CD), and autism spectrum disorder (ASD). Inclusion criteria for ACCESS-MH included Atlantic Canadian children or youth between ages 10 and 18 with any of the identified disorders; parents of children or youth ages 5 to 18 with any of the identified disorders; and service providers working in child and youth mental health.

There was a higher level of organization within the overarching ACCESS-MH project to involve the appropriate participants. Recruitment occurred through outreach to various stakeholders within the provinces who could inform potential participants about the project, and recruitment posters (Appendix A) were placed in public healthcare, community, and online settings. Participants could contact the research team through phone or email if they were interested in participating in the study. Research team members then set up interview times and locations with individuals who met the criteria,
and further information about the study was provided when they met for the interview. Participants were recruited through the use of snowball sampling techniques and they voluntarily took part in the study as part of a self-selection process.

3.5. Sample

The sample of participants in this thesis project included seven mothers who discussed eight adolescent daughters between the ages of 13 and 19 with a depression diagnosis. These participants were chosen for this study based on their child’s gender (female) and mental health diagnosis (depression). All mothers who took part in an ACCESS-MH patient journeys interview who had a female daughter with a depression diagnosis at the time that this thesis project began were incorporated into the study. One participant had two daughters with mental health diagnoses but the remaining participants only discussed one daughter.

3.6. Data Collection

The participants took part in a semi-structured interview (Appendix B & C) after providing informed consent (Appendix D). Participants also completed a demographic face sheet (Appendix E) that provided information on age, living situation, relationship status, household income, employment, and details on their daughter’s diagnoses. This demographic information is presented in section 4.1 of the findings chapter. Participants were asked to give 90-120 minutes of their time to participate in the interview and journey mapping process.

Interview lengths of the seven participants ranged from 42 minutes to 1 hour and 48 minutes. Participants were asked to share aspects of their journey that created barriers or facilitators to receiving care and support. The patient journey map was integrated into
the interview process, and both the interview and journey mapping process were audio-recorded. The journey map is described in further detail in section 3.9 of this chapter.

The journey map was photographed once completed. Participants were given a certificate of volunteer participation following their interview (Appendix F). An external transcription company transcribed the audio recordings verbatim to be used in data analysis. A graduate student, a research associate, and a post-doctoral fellow at the University of Prince Edward Island as well as a graduate student at Memorial University of Newfoundland conducted the interviews that were used in this thesis project.

It is important to note that I did not complete the seven interviews in this thesis, as this was not part of my role as a graduate student. As the ACCESS-MH study had already begun before I became a graduate student, many interviews, including those used in this thesis project, had already been completed. One of my main roles as a graduate student was to assist with the remainder of the patient journeys interviews needed for the ACCESS-MH study; thus, I conducted approximately thirty interviews with a mixture of parents, youth, and service providers. I was able to choose which patient journeys data to use from the ACCESS-MH study for my thesis project. As I was most interested in mothers’ experiences and journeys seeking care and noticed a large gap in the research in terms of their voices, I chose to use the data from these seven mothers.

3.7. Researcher Position

In qualitative research, it is important that the researcher locate him or herself in relation to the study so that the reader can better understand the researcher’s social position and epistemological assumptions connecting to the chosen methodology. As a white female living in Prince Edward Island, who is a daughter from a middle-class
family, I have designed my study in a way that is connected to my worldview and social location. My beliefs and paradigms have influenced my choice to use narrative inquiry, as I believe that it is important for people’s voices to be heard to create change and to help others. I felt it was important to tell mothers’ stories in as much detail as possible and to honor their journeys through the system. As their stories were told and re-told through my interaction with the data produced from the interviews, the findings represent my interpretation of them that interacts with my personal perspective as related to my social position.

My social location also influenced an intrinsic interest in critical issues such as the power dynamics between people and social institutions. Through many encounters with these issues while conducting interviews with mothers, youth, and service providers for the ACCESS-MH project, I found myself especially drawn to the mothers’ stories in terms of their emotionally charged narratives and detailed responses to questions. I am personally connected to several mothers whose child experiences depression, who have had challenges with social systems and have felt the need to fight against blame and disempowerment by institutions and individuals. In listening to their stories informally through conversation, and through my awareness about the unique context of Atlantic Canada where stigma in particular places extra burden on mothers of young people struggling with mental health issues, it has further sparked my interest and highlighted the necessity to research mothers’ care-seeking experiences for their daughter’s depression.

3.8. Geographical Context
The geographical context of this thesis is the Atlantic provinces of Canada. The healthcare system in Canada is publicly funded and operates on a single-payer insurance plan, where each province shares funds but each has responsibility for allocating those funds within the province. Each province also provides free public health services, including child and youth mental health care, within regional hospitals and clinics. Three Atlantic provinces are represented in this thesis.

3.9. Materials

The interview materials were uniquely and specifically designed for the ACCESS-MH study by Tilleczek & Bell (2014). They included face sheets, consent forms, an interview protocol, and a journey mapping kit. The semi-structured interview protocol was divided into subsections of early signs of the mental health challenges; attempting to seek care; entering, exiting, and returning to the mental health care system; and recommendations for improvements to the system. Four participants used the patient journey map to assist in their storytelling by providing a visual representation of their experiences (Alice, Zoe, Karen, and Macy). I created the other three participants’ journey maps (Beth, Tanya, and Claire) in reference to their narrative summaries to provide a visual representation of their experiences. Patient journey mapping involves placing felt items that represent key individuals, places, and objects on a blank board to assist in visualizing the participant’s journey.

3.9.1. Visual methods. Visual methods of research can be incorporated to better understand participants’ social positions and their lived realities within these conditions (Hodgetts, Radley, Chamberlain, & Hodgetts; 2007; Tilleczek et al., in press). They can reveal tacit knowledge that helps convey underlying assumptions and meanings in stories,
along with providing a second medium for participants’ to tell these stories (Harrison, 2002). Visual methods are often able to assist in communicating unique underlying details and perspectives that other methods are not able to fully capture.

Research by Hodgetts et al. (2007) incorporates visual methods and interviews to explore the culture of homelessness and to demonstrate the material, spatial and relational considerations that impact the health of homeless individuals. Their use of photography methods allows for improved integration of participants’ social context and environments into the analysis of the participants’ experiences. Visual methods can be viewed as forms of communication that are bounded by culture and context, and can be interpreted as narratives or in collaboration with spoken or written stories (Harrison, 2002; Guillemin, 2004). In this way, visual and arts-based methods can reveal information about differences in the participants’ worldview that make them unique or similar to others, and can also highlight their personal position within the environment (Tilleczek, 2011; Tilleczek & Loebach, 2015; Tilleczek et al., in press).

In addition to enabling a more holistic understanding of inequities and health disparities among populations, visual methods can also be used as a way to meet the needs of patients and provide evidence for improving health service delivery (Tilleczek et al., in press). McCarthy, O’Raghallaigh, Woodworth, Lim, Kenny, & Adam (2016) use a visual method called patient journey mapping where health providers created diagrams mapping out patient pathways through the system including information such as their health providers’ names, where the patient was accessing health care, and the physical and emotional effects of the health care experience each week (McCarthy et al., 2016). This was used to explore the quality of health services and to examine the ways in which
medical protocols could be changed or developed to better meet patients’ health needs (McCarthy et al., 2016).

Visual methods can be multi-disciplinary in that they can be used in different types of health care settings to collaborate and improve continuity of care (McCarthy et al., 2016). Patients can be intimately involved in the research process when using visual methods, encouraging their voices and experiences to be used to create change (Tilleczek et al., in press). For these reasons, patient journey mapping was incorporated into the ACCESS-MH study and this thesis project.

3.10. Data Analysis

The transcripts were analyzed through the use of narrative and thematic analysis (Reissman, 2008). I read each transcript multiple times to increase familiarization with the data. I recorded memos in the margins of the transcripts for reference when coding, or when patterns and themes in the data were organized into categories. Individual participant narrative summaries were developed from the memos and themes were identified and presented separately. First-order coding involved development of visual theme webs that illustrated participants’ experiences in the mental health system, education system, and family relationships through the care-seeking journeys. Second-order coding included exploration of patterns within and across narratives, theme webs, and journey maps. The codes were then organized into a quotation table for each participant in preparation for mapping out the information into thematic categories, which showed a broader conceptualization of mothers’ experiences.

The analysis fits with the methodological approach in that I analyzed the narratives leading to the creation of narrative summaries for each participant. I used the
narratives to develop the first-order and second-order themes that answered the research questions. The journey maps that were created by the participants and those that I created were analyzed using narrative analysis through reference to the corresponding narratives.

3.10. Analytical decision-making process. An audit trail of the decision-making that occurred while conducting narrative and thematic analysis is detailed to ensure rigour and transparency of the analytical process.

3.10.1. Narrative analysis. Narrative analysis began by reading through each transcript once and then writing memos that were relevant to the research questions in the margins. These were created using the comments function on Microsoft Word. Memos consisted of short phrases or words that captured the main ideas expressed in a sentence or paragraph. Participants’ turning points or epiphanies were also identified in the memos as well as their recommendations for improvements to the system. These memos were used to create narrative summaries for each participant.

After interviews were completed, I created journey maps for the three participants who had chosen not to complete one during their interview. The three journey maps that I created reflect a co-construction of meaning based on my interpretation of the mothers’ experiences that they shared during their interviews. Participants chose not to complete a journey map for a number of reasons including time constraints, unfamiliarity with the mapping materials, or discomfort with the creative process. I created their journey maps in reference to the narrative summaries in order to provide a visual reference for their journeys to assist in analysis. Explanations of the journey maps were written under the photos as transcripts were read and interpreted, and were then refined in reference to the narrative summaries.
3.10.1.2. **Thematic analysis.** Thematic analysis (Reissman, 2008) began following narrative analysis. Patterns in the memos and narratives were identified and these initial codes were listed in a separate document. They were then organized into four theme webs as shown in section 4.3, first sketched on paper and then transferred to Microsoft Word. Information in the theme webs represents first-order themes that were later re-grouped into second-order themes.

A table of quotations from each participant’s transcript was then created with an assigned code for each quotation. These codes were analyzed in combination with the narrative summaries, theme webs, and journey maps to produce three second-order themes of marginalization and loss of control, becoming empowered, and hope for the future. The two themes marginalization and loss of control and becoming empowered had separate subsections adapted from the theme webs that pertained to their experiences in the mental health system, education system, and family life. The theme of hope for the future included subsections representing participants’ main recommendations on how to improve the system and the care-seeking experience.

A subtheme entitled blaming the mother was changed to blame as it became evident through closer examination of the transcripts that in some narratives, both the mother and the father were blamed while at other times it was only the mother that was blamed. A subtheme entitled conflicting motherhood roles was removed after further analysis revealed that quotations in this subtheme were more closely aligned with the subtheme advocating and educating about mental health in the education system.

The subtheme entitled disempowered mothering was changed from the original title of helpless parenting. After revisions it became clear that the term helpless could be
considered derogatory and may contribute to the phenomenon of mother blaming. This is important to note for future studies as well, as the present literature describes parents’ feelings of disempowerment in the parenting role by using the term helpless. The term parenting was changed to mothering so as to make the theme more specific to the unique experiences of disempowerment that mothers expressed. The remainder of the themes and subthemes remained intact throughout the analysis, which compiled concepts and patterns from narrative summaries, journey maps, quotation tables, and theme webs.

3.11. Methodological & Interpretive Rigour

Some of the techniques I have used to ensure methodological and interpretive rigour in the research process closely align with the criteria outlined by Whittemore, Chase, & Mandle (2001) that are adapted from the work of other research scholars in the field (Lincoln & Guba, 1985; Sandelowski, 1986). They exemplify primary and secondary criteria that closely connect with the paradigm and objectives of this thesis project. Primary criteria that apply to all qualitative research include “credibility, authenticity, criticality, and integrity,” whereas secondary criteria, which are more flexible depending on approach, include “explicitness, vividness, creativity, thoroughness, congruence, and sensitivity” (Whittemore et al., 2001, p. 529). All primary criteria will be met as well as the secondary criteria of congruency and explicitness. Other common rigorous techniques introduced by Fossey, Harvey, McDermott, & Davidson (2002) and Patton (2002) were also incorporated into the research process.

3.11.1. Credibility & authenticity. Credibility and authenticity of the research are closely connected in that credibility refers to trustworthy and accurate interpretations of participants’ narratives in the analysis, and authenticity refers to the accurate portrayal
of participants’ lived experiences through the use of their quotations (Fossey et al., 2002; Whittemore et al., 2001). These two criteria were met by using a multitude of quotations from participants’ interviews and rich description to reflect participants’ meanings, while also incorporating my own experience and self-reflection as a researcher to convey integrity and transparency. Explicit descriptions of the research and decision-making process also assist in displaying transparency and credibility (Fossey et al., 2002), which were outlined in section 3.10.1 of this chapter. Triangulation of methods (Briller, Meert, Schim, Thurston, & Kabel, 2008) is used through incorporation of both semi-structured interview data and the visual method of journey mapping. This assisted in the interpretation process and showed participants’ story explanations in diverse ways.

3.11.2. Criticality & integrity. The criticality criterion of Whittemore et al. (2001) was met through exploration of a wide variety of literature as well as incorporation of reflexivity throughout the research process. Integrity of the research is closely connected to criticality and is illustrated through repetitive reviewing of transcripts, coding, and themes and comparing them to the existing literature.

3.11.3. Transferability, dependability, & confirmability. This research meets criteria for transferability, dependability, and confirmability. Transferability refers to the applicability of the research to other contexts or circumstances (Patton, 2002). The nature of qualitative research is that it is context-specific and that interpretations are developed based on the sample in the study, which may or may not apply to other individuals (Denzin & Lincoln, 2011). By providing detailed information about context and demographics of participants in the research report, it allows the reader to interpret whether the findings would be transferable to another context.
Dependability refers to research consistency, or whether the study would have similar results if repeated again (Shenton, 2004). This criterion was met by providing an audit trail of the decision-making process and clear documentation of the steps taken at each phase of the research process. Confirmability relates to the quality of the results and the accurate reflection of participants’ narratives rather than purely the researcher’s voice. This criterion was met through triangulation of methods, reflexivity of the researcher, thick description of quotations, and a detailed review of the relevant literature as presented in Chapter 2 and incorporated into the discussion section.

3.11.4. Congruency. The congruency of this research will be demonstrated through connection of the epistemology, methodology, and methods in their goals and outcomes. These three components together provided a framework for planning and conducting the research and analyzing the data (Carter & Little, 2007). There is also congruency between the research questions, method, and findings in that they are focused on examining and understanding the same phenomenon. The overall aims are consistent throughout the research and each step provides an additional component to understanding the findings.

3.12. Ethical Rigour

The larger ACCESS-MH project has adhered to ethical guidelines in each Atlantic Canadian province, and this thesis project was ethically approved within the ACCESS-MH approval. Ethical considerations at each stage of the research are detailed in this section.

3.12.1. Ethics approval. The ACCESS-MH project has received ethical approval from the ethics review boards in each of the four Atlantic Canadian provinces. In PEI,
ethics approval has been received from the University of Prince Edward Island Research Ethics Board, the Health PEI Research Ethics Board, and the English Language School Board of PEI. Ethics approval has been received from the University of New Brunswick Research Ethics Board and Horizon Health Network for the province of New Brunswick, the Saint Mary’s University Research Ethics Board for the Province of Nova Scotia, and the Health Research Ethics Authority at Memorial University in Newfoundland.

3.12.2. Potential harm or risk to participants. There was a low risk involved in participating in this study. The only risk involved for participants was retelling stories from potentially difficult and emotional situations to answer the interview questions. Participants were informed of this risk before their interview began and were given the option of skipping any questions they didn’t feel comfortable answering. They were also told that they could end the interview at any point without consequences.

Interviewers were properly trained in using the interview protocol and dealing with emotional topics. Interviewers handled discomfort or distress of participants by providing lots of time for the participant to respond or take a break, sensitively listening to the participant, moving to another question, or stopping the interview. Interviewers were also trained in debriefing after the interview to minimize the possibility of an emotional exit. Debriefing involved ending the interview with a discussion on recommendations for change as well as guiding the interview towards more positive and hopeful ideas for the future (Appendix G). Researchers also provided a mental health resource card specific to the participant’s province (Appendices H, I, & J).

3.12.3. Informed consent. Informed consent was obtained through a written and signed form that was used as part of the ACCESS-MH procedure (Tilleczek & Bell,
Consent was obtained to conduct the interview, audio-record, use images of the journey map, and use the data in reports in the ACCESS-MH study. Informed consent also involved obtaining the participant’s permission for their interview data to be used for theses projects at the universities associated with the ACCESS-MH study including the University of Prince Edward Island, Memorial University of Newfoundland, and University of New Brunswick.

3.12.4. Anonymity & confidentiality. The information that was collected during this study remained confidential and anonymous, so participants cannot be identified from any of their responses. No identifying details of the participant were included in any reports associated with this study and were not available to anyone outside of the study. All mothers, daughters, and other people mentioned were given pseudonyms. Any institutions and organizations were removed from the transcripts before analysis began. This protected participant anonymity and confidentiality during data collection, analysis, and dissemination of findings.

3.12.5. Data storage. The data from the study is stored securely in a locked cabinet at UPEI. Individuals working on the ACCESS-MH project will have confidential access. The data will be kept for 15 years after the study’s completion and will then be destroyed.

3.13. Chapter Summary

This chapter outlined the research design, methodology, and theoretical framework. The research methods were discussed, including recruitment, sampling, data collection, and analysis. The analysis section contained a description of the decision-making processes for both narrative and thematic analysis. The researcher’s position and
role in the research process was also presented. A discussion on methodological and interpretive rigour followed, describing the strategies used to enhance the quality and trustworthiness of the research. The ethical rigour section included information on ethics approval, the consent process, anonymity and confidentiality of participants, and data storage.
Chapter 4: Findings

4.1. Participant Demographics

The seven participants completed a demographic face sheet that provided information on their age, living situation, relationship status, household income, employment, and daughters’ diagnoses. All seven participants were between the ages of 31 and 50, primarily English-speaking, and Caucasian. Five participants were born in Canada. One participant was born in Spain and one was born in the United Kingdom. They had been living in Canada for 40 and 50 years, respectively, at the time of their interviews.

Five of the participants had paid employment outside of the home. Participants’ household incomes ranged from $30,000 to $100,000 or more. Four participants had a household income of $30,000 to less than $40,000 per year, which was considered low socioeconomic status. Low socioeconomic status was determined by examining the household income in reference to the number of people living in the household. One participant was in the $80,000 to less than $90,000 range and two participants were in the $100,000 or more bracket, which were considered high socioeconomic status. The demographic information of participants is detailed in Table 1 as follows.
Table 1

*Mother Demographic Information*

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age Range</th>
<th>Marital Status</th>
<th>Number of Children</th>
<th>Paid Employment (Y/N)</th>
<th>Socioeconomic Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alice</td>
<td>31-40</td>
<td>Divorced</td>
<td>2</td>
<td>Y</td>
<td>Low</td>
</tr>
<tr>
<td>Zoe</td>
<td>41-50</td>
<td>Divorced</td>
<td>3</td>
<td>N</td>
<td>High</td>
</tr>
<tr>
<td>Karen</td>
<td>41-50</td>
<td>Separated</td>
<td>2</td>
<td>Y</td>
<td>Low</td>
</tr>
<tr>
<td>Beth</td>
<td>41-50</td>
<td>Married</td>
<td>2</td>
<td>Y</td>
<td>High</td>
</tr>
<tr>
<td>Tanya</td>
<td>41-50</td>
<td>Married</td>
<td>2</td>
<td>N</td>
<td>High</td>
</tr>
<tr>
<td>Macy</td>
<td>31-40</td>
<td>Separated</td>
<td>4</td>
<td>N</td>
<td>Low</td>
</tr>
<tr>
<td>Claire</td>
<td>41-50</td>
<td>Married</td>
<td>2</td>
<td>Y</td>
<td>Low</td>
</tr>
</tbody>
</table>

Three of the mothers were married, two were separated and two were divorced. All mothers lived with their children full-time, but four were single parents. All eight of the participants’ daughters had a formal diagnosis of depression; however, all daughters had at least one other comorbidity. The other diagnoses were anxiety (n=7), eating disorder (n=3), obsessive-compulsive disorder (OCD; n=1), conduct disorder (n=1), and autism spectrum disorder (n=1). Table 2 details the demographic information of participants’ daughters.
Table 2

_Daughter Demographic Information_

<table>
<thead>
<tr>
<th>Mother</th>
<th>Daughter Pseudonym</th>
<th>Age</th>
<th>Diagnoses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alice</td>
<td>Chelsea</td>
<td>16</td>
<td>Depression, anxiety, ED</td>
</tr>
<tr>
<td>Alice</td>
<td>Emma</td>
<td>13</td>
<td>Depression, anxiety</td>
</tr>
<tr>
<td>Zoe</td>
<td>Hannah</td>
<td>16</td>
<td>Depression, anxiety, ASD</td>
</tr>
<tr>
<td>Karen</td>
<td>Taylor</td>
<td>18</td>
<td>Depression, anxiety, OCD</td>
</tr>
<tr>
<td>Beth</td>
<td>Candace</td>
<td>15</td>
<td>Depression, ED</td>
</tr>
<tr>
<td>Tanya</td>
<td>Shawna</td>
<td>19</td>
<td>Depression, anxiety, ED</td>
</tr>
<tr>
<td>Macy</td>
<td>Charlotte</td>
<td>15</td>
<td>Depression, anxiety, CD</td>
</tr>
<tr>
<td>Claire</td>
<td>Laura</td>
<td>16</td>
<td>Depression, anxiety</td>
</tr>
</tbody>
</table>

4.2. Narrative Summaries

Each of the seven mothers’ narrative summaries is presented here.

4.2.1. Alice, Chelsea, & Emma. Alice was the mother of two daughters, Chelsea and Emma, who both experienced depression. Alice first found out about her older daughter Chelsea’s depression when Chelsea was self-harming and attempted a drug overdose at age 15 followed by admittance to the hospital. Alice’s younger daughter, Emma, had called 9-1-1 the night that Chelsea had attempted the overdose while Alice was at a work meeting. Alice attributed this traumatic event and the changed family dynamics following it to triggering Emma’s mental health challenges. During Chelsea’s stay in the hospital’s psychiatric unit, she was put on three separate
medications without consulting Alice. A hospital nurse told Chelsea that her parents’ separation and lack of discipline were the cause for her mental health challenges:

The head nurse in the [psychiatric unit of hospital], you know, her and my daughter had many, many fights because she kept saying, like, you know, “You wouldn’t be like this if your parents gave you rules.”

This experience led to anger and frustration for both Alice and Chelsea.

Near the end of Chelsea’s hospital stay, a team of health care providers and educators working at her school met with Alice to discuss a transition plan for Chelsea, but no concrete plan was ever developed. Alice felt that this was partly because Chelsea had not been provided with any clear diagnosis. Alice explained, “There was just so many voices at the table and so many different opinions… And, without a clear diagnosis of actually what she was struggling with, you couldn’t come up with a specific plan.”

Thus Alice felt that a diagnosis would have been beneficial in leading to more appropriate and specialized treatment and supports for Chelsea.

Alice and Chelsea were connected to community mental health for counselling and Chelsea was seeing a psychiatrist, but the unreliability of care created barriers to improvement. For instance, the appointments would often be cancelled due to the psychiatrists’ high demand in the community and hospital and Chelsea waited eight months to be rescheduled for a new appointment. Chelsea had to switch counsellors three times which negatively impacted her progress and left Alice feeling confused due to conflicting information and advice from different service providers. Her psychiatrist moved out of the province during Chelsea’s care and her family doctor now manages her
prescriptions. Alice feels she must monitor Chelsea’s medication effects but finds that the family doctor is reluctant to change the dosage, which is another source of frustration.

Even though Chelsea’s care was inconsistent in that she switched service providers multiple times and received inadequate transition care from the hospital, Alice feels that Chelsea is doing better now that she has a more appropriate medication dosage and is receiving counselling from a community mental health therapist. Alice received advice from a mental health professional to take Chelsea to a hospital in another province if she is in need of inpatient mental health care. “I have been told that [hospital in neighbouring province] has actually built a specific unit for youth who are struggling with mental health issues. And that it’s set up in a supportive way.” She recognizes this as a sign that the provincial system is failing and that “the system sees how broken it is.” The ability to manipulate the mental health system when it is not meeting her daughters’ needs is considered a source of empowerment for Alice in spite of her disappointment with the provincial system’s current functioning.

Alice’s younger daughter Emma started self-harming while Chelsea was receiving care. Alice felt she was able to pick up on the warning signs earlier with Emma and through the school guidance counsellor’s recommendation tried to book an appointment for her to see a psychiatrist, but found out it would be a nine-month wait. A therapist in community mental health knew about the severity of Emma’s mental health issues and helped her fast-track through the system by writing a letter that Alice and Emma were to take to the doctor at the walk-in clinic explaining the urgency of service need. The doctor wrote a prescription to be filled immediately and sent referrals to community mental health and to their family doctor. Emma now receives counselling therapy through
community mental health and is taking medication but Alice feels she is not on the correct dosage. Alice notes that finding the correct dosage is a process that takes time and trials.

The school environment continues to be challenging for both of Alice’s daughters, as Alice explains the lack of youth mental health educational information for teachers and other school staff. Alice tries to educate them but feels she is not being heard. She experiences blame and judgement from other people because both of her daughters have mental health issues. Alice recognizes that she is trying her best to provide appropriate care for her daughters in every way possible. Alice’s journey map is shown in Figure 1 below.

*Figure 1. Alice’s journey map.*

This figure illustrates Alice’s first daughter Chelsea’s challenges with depression and the steps that Alice took to seek care for Chelsea. The blade and the exclamation symbol above the ‘my child’ piece depict Chelsea’s self-harm and attempted drug overdose. The school bus piece symbolizes Chelsea’s challenges with going to school. Chelsea was admitted to the hospital and had an overall negative experience, shown with the crossed out circle piece above the hospital. The question mark symbolizes Alice’s
unanswered questions about Chelsea’s diagnosis and frustration in the system. Chelsea was referred to community mental health after she was discharged, shown with the walk-in clinic piece. The man with the plus sign indicates that the psychiatrist that Chelsea was referred to was helpful, but he left the province during Chelsea’s care and she had to wait for services as shown by the clock pieces. The ‘me’ piece next to the school building symbolizes Alice’s many interactions with educators about her daughters’ depression challenges.

4.2.2. Zoe & Hannah. Zoe started noticing mental health issues in her youngest daughter, Hannah, when she was just four years old. Hannah’s behaviours were rigid and she would become very angry if routine was disrupted. Hannah was diagnosed with autism spectrum disorder (ASD) and experienced problems with communication and memory as she grew and developed. She started receiving services for ASD at age 5 and Zoe began paying for Hannah to see a private counsellor to help her cope with her parents’ divorce. As Hannah transitioned into her teen years, she withdrew from counselling, school, and extra-curricular activities that she had previously enjoyed. Zoe consulted counsellors, doctors, the principal and guidance counsellor at the school on what she should do to help her daughter but they each gave different suggestions. She continued to encourage Hannah to go to school, but one day Hannah became so distressed that Zoe took her to the emergency room at the hospital.

Zoe’s experience at the hospital was frustrating in that she felt Hannah’s problems were not taken seriously and that the responsibility to manage her daughter’s mental health challenges was forced back on Zoe:
I'm just a parent who's trying to get help for their daughter. And I thought, at that point when she [hospital nurse] started, to me, seeming accusatory, as if in well, “you need to take this and you need to be in control and you, you, you”… And I'm thinking wait a second. I'm not a doctor! I don’t know what to do!

The nurse gave Zoe the contact card for a psychiatrist in the province and Zoe tried to make an appointment for Hannah, for which she had to wait several months. Hannah’s father spoke to the staff at the psychiatrist’s office and initially denied that she needed psychiatric care even though he hadn’t seen her since she was very young, which further delayed her treatment. In the meantime, Zoe began paying a tutor to homeschool Hannah because she could not go to school due to her depression. When the psychiatric appointment arrived, the psychiatrist prescribed medication to Hannah but moved out of the province during treatment, so the family doctor took over medication management.

Hannah attempted to go back to school for her Grade 9 year when she became better adjusted to her medication but again stopped going after only a few weeks. Zoe advocated for Hannah to move to an alternative education program that was part of the public school system. “And I made then the suggestion of [alternative education program]. They agreed, with the thought that she would return back to the classroom if she could, but she didn't. She didn't end up returning back to the classroom.” This program was very helpful for Hannah, and Zoe felt that the staff members at the alternative education program were very understanding and supportive. Hannah returned to homeschooling after finishing a year with the alternative education program.
Zoe and Hannah do not find counselling effective for Hannah because it is too inconsistent and cannot be scheduled often enough to provide her with support when she really needs it:

The consistency of the availability for someone is not there. That once a week is not enough for kids like Hannah… I’d like a support group for my daughter. I would like a support group for my family. There’s no group therapy, there’s no parent therapy for parents who are dealing with this.

Zoe finds that Hannah is developing her own coping skills as she gets older and Zoe now better understands the seasonal and cyclical manifestations of depression in her daughter’s life. Zoe still struggles with finding appropriate supports for her daughter and herself and feels that luck, rather than clearly defined resources or available health professionals, was the main reason they ended up finding the services that they did to help Hannah. Zoe’s story is illustrated in Figure 2.

*Figure 2. Zoe’s journey map.*

The left side of the map depicts Zoe with her three daughters. The angry face with the exclamation symbol illustrates Hannah’s early challenges with mental health. The arrows point to the service providers that Hannah saw for her ASD diagnosis, including a
public health nurse and a speech language pathologist. Tutoring and homeschooling were expensive, shown with the tutor and the money pieces. The clock depicts the waiting period for Hannah to receive services for her depression that started severely impacting her life and schooling in seventh grade. The school bus and sad faces indicate Zoe and Hannah’s challenges with the school system.

The arrow then points to the negative experience at the hospital, but led to Hannah’s referral to the psychiatrist. The psychiatrist is shown with a clock, which indicates the wait time to see him, but there are also positive signs and medication symbolizing his assistance in trying to find the right medications for Hannah. The arrow pointing to a building with positives beside it signifies the helpfulness of the alternative education program. Hannah finished the program and started homeschooling again, shown by the teacher piece with the money beside it indicating the expenses for paid tutors.

4.2.3. Karen & Taylor. The realization for Karen that her daughter, Taylor, was having difficulties with mental health came when Karen found out that Taylor was self-harming at 12 years old. Karen thought her daughter was suicidal and called community mental health, only to find that there was a very long wait list to see a provider. Karen explained the urgency of the situation to the providers at community mental health and to the family doctor and they assisted in fast-tracking Taylor into the system. The family doctor did this by contacting community mental health explaining Taylor’s need for help, and they were able to decrease her wait time for services. She waited 3 months to see a counsellor at community mental health, but she was not suited to Taylor’s challenges and said she could not do anything further to help Taylor. Karen
then advocated for Taylor to have a different counsellor who helped her start to open up about her challenges. Taylor’s mental health didn’t seem to improve at home, as she was becoming either extremely aggressive or very withdrawn and depressed.

As Karen and Taylor waited for the appointment with a psychiatrist through community mental health, Karen wanted to find out what she could do to help her daughter so started attending counselling sessions on her own. The counsellor said to encourage her daughter to keep herself clean after self-harming and to provide antiseptics for her. This was difficult for Karen to do because she felt it wasn’t assisting in her daughter’s treatment and recovery. Taylor’s therapist recommended that Karen see a psychologist, but she was placed on the wait list and had not been contacted for an appointment in five years.

After a year on the psychiatrist’s wait list, Taylor saw the psychiatrist who wanted to prescribe medication to her at age 13. Karen agreed that her daughter would benefit from medication but Taylor refused to take it because she didn’t like the way it made her feel. Taylor was admitted to the hospital for a few days to stabilize her on the medication, but once she was discharged she stopped taking them again. Karen felt that Taylor’s mental health issues were not addressed while she was in the hospital and that the health providers could not fully understand what was going on with her daughter.

After Taylor left the hospital, she saw the psychiatrist and school guidance counsellor but her mental health continued to worsen and she stopped going to school. One day, Taylor expressed suicidal thoughts to Karen after having an anxiety attack. Karen explained:
So then she came out and she told me pretty much that she’d had enough of dealing with all this and she just wanted to end it - she was done. She said “I can't deal with this anymore; I can't deal with how I feel anymore”... So I recognised of course this is a suicidal thought.

Karen and her ex-husband took Taylor to the hospital. Taylor was admitted to the psychiatric unit of the hospital and the psychiatrist wanted her to start taking a different medication. After a few days in the hospital, the psychiatrist wanted to discharge Taylor but Karen refused to take her home this time until the doctors found out what was wrong and provided appropriate care. Karen explained, “Well, first, well I flatly refused – ‘I'm not taking my daughter out of hospital. You guys need to figure out what's going on.’” After Karen spoke out, Taylor remained in the hospital for two months. Once Taylor received the proper diagnoses of depression, anxiety, and OCD, she was put on different medications which helped her start to feel better and improve.

Taylor transitioned back to school but both Karen and her daughter found that some of the school staff did not understand how to support Taylor with her mental health challenges. The principal did not believe that Taylor had these diagnoses and Karen had to explain the severity and effects of the mental health problems several times before he took it seriously. However, Taylor was still not able to find adequate support at school and experienced overstimulation in the school environment.

She completed an alternative education program for two years and eventually transitioned back to public school for her last year of high school. Taylor’s psychiatrist left the provincial mental health system during her care and she now sees her family doctor to refill her prescriptions. Karen perceives the system as “overworked” and the
hospital treatment similar to a “revolving door”, where the youth are discharged as quickly as possible to make room for new youth coming in. She feels that youth mental health problems are not taken seriously due to a lack of education around symptoms and signs that may appear differently in young people than in adults. Figure 3 displays Karen’s journey map.

Figure 3. Karen’s journey map.

The journey starts with the ‘me’ and ‘my child’ pieces, illustrating Taylor’s frustration, sadness, and self-harming behaviour. The arrow then points to the family doctor who fast-tracked Taylor into counselling at community mental health, represented by the ‘walk-in clinic’ piece and the clock piece. The woman and the medication piece represent the psychiatrist who prescribed medication to Taylor. Taylor wasn’t adhering to the medication schedule and was admitted to the hospital, shown with the hospital building piece and the frustrated face above it, but didn’t receive appropriate treatment.

The alternative education program is shown with the purple school building piece. Taylor again went to community mental health for counselling after leaving the hospital a few days after admittance. She then became suicidal, as shown with the ‘my child’ piece and the pills, crisis bubble, and sad face. Taylor was admitted to the hospital again and
remained there for two months, represented by the hospital chart. The arrow then points to the hospital psychologist who diagnosed Taylor with OCD in addition to depression and anxiety, and connected her to the appropriate supports. Taylor then returned to public school, as shown by the purple school building piece on the right side of the map.

4.2.4. Beth & Candace. Beth’s daughter Candace was 15-years-old at the time of her interview and was still in the midst of her journey with depression and mental health care. Beth first found out her daughter was having mental health issues when she was contacted by the school guidance counsellor who told her that Candace was not eating enough and losing a lot of weight. Beth regretted that she hadn’t noticed Candace’s weight changes and took her to see the family doctor. The family doctor connected Candace to services at the hospital but she had to wait a month to see the health providers there. The services at the hospital were helpful once they were accessed, but Beth also wanted her daughter to see a psychologist to start therapy and address the main causes of the mental health issues.

Meanwhile, Candace did not want to go to school and found the school environment to be overwhelming. Beth explained, “And I think, certainly in my daughter’s case, I think maybe for other kids as well, it's sort of the number of bodies and there's just a kind of overstimulation thing.” Beth wanted to remove her daughter from the school system and start homeschooling but the guidance counsellor encouraged her to stay, ensuring that the school could adapt to Candace’s needs:

So she [guidance counsellor] said, “well she can come here [to the office] and work kind of quietly”… except that when my daughter did that, she has an office
and then there's a little kind of room, but it was full of people. So it was full of all
the other kids who needed space or were working on the computer.
Thus with the number of other youth at the school who were experiencing challenges,
Candace couldn’t get the support that she needed through the guidance counsellor and her
mental health continued deteriorating.

Beth found it very difficult to access information on how to help her daughter and
the services that were available. Through her own research and through connecting with a
counsellor, she found out about a day treatment program, a parent support group, and a
workshop on family therapy that she and her husband took part in and found to be
effective. Beth described the helpfulness of the support group:

And [counsellor for parent support group] who runs those is excellent… She kind
of understands family dynamics… and she's able to offer suggestions about how
to deal with certain kinds of situations... You feel very isolated as a parent dealing
with this kind of stuff and so it was very helpful both to talk to her and also to talk
to the other people in that group.
Beth found it helpful to connect with other parents whose daughters were going through
similar problems, and she received advice from one of these parents on a private
psychologist for Candace that might suit her needs. Beth contacted the private
psychologist’s office and Candace was put on a wait list, but it took several months for
her appointment date to arrive.

As Candace transitioned into high school and still wasn’t receiving adequate
support services, her depression lead to suicidality and she was admitted to the hospital
psychiatric unit for almost one month. Beth’s story does not go into detail about this
initial hospital stay. When her daughter was discharged, Beth was told to supervise her
daughter’s meals and to come back to the emergency department if any issues arose. Beth
described this:

Well, what my job as a parent was to supervise like the three meals and the three
snacks, and then you supervise for 30 minutes to an hour after every one to make
sure that they're not going off and vomiting… And if that didn’t pan out, like if
things weren’t working out, then over the holidays we could always come back
and go to Emerg. So we ended up going back to Emerg sort of every day.

Beth was frustrated with going back to the hospital every few days over the Christmas
holiday, as Candace’s other supports were not available during this time and Candace
was not eating.

The doctors at the hospital didn’t think that Candace should be admitted as they
determined that her symptoms put her on the borderline of needing hospital care. Her
assessments showed that she wasn’t suicidal or extremely depressed. Beth felt that the
doctors thought Candace wanted to be admitted as an escape from reality:

I think really they felt that the long-term outcome would be better if she didn’t
have an admission at this point. That they're concerned that she's going to be
become dependent and want to keep shunting back into hospital whenever things
get a bit tough, because the psych ward is a place where you don't have the
pressures that you have in your normal life….It is kind of a bubble.

Despite this perception, Beth became frustrated and anxious in knowing that her daughter
was in critical condition, and could see that she desperately needed help.
As Beth and Candace continued to return to the emergency department almost every day over the holidays, Candace was eventually admitted to the hospital a few days prior to Beth’s interview. Beth felt that the communication between Candace’s service providers in the hospital was good, but that their communication with her could be improved. The social worker at the hospital offered family counselling for Beth and her husband, but they found it wasn’t helpful for them due to compatibility issues and switched to a family counsellor instead. Beth also expressed, “I just feel like this situation is getting more and more complicated and I mean I was out of my depth at the beginning and I'm way more out of my depth now.” She felt that as Candace’s mental health issues became more serious, she required more specific guidance on how to support her.

Beth explained that the most useful thing for her would be to have a counsellor that knew Candace’s particular situation and could assist Beth with how to help her daughter in different areas, as well as to help her better understand her daughter’s issues. Beth is currently wrestling with thoughts about her daughter’s responsibility to manage her illness and her own responsibilities as a parent, but feels that it is ultimately up to her daughter to make any significant changes to lead herself on a better path. Candace’s depression and eating disorder were not visible to Beth one year ago and she remembers her daughter as healthy and happy but now feels that the symptoms are taking over her life. Beth’s journey map is shown in Figure 4 below.
Figure 4. Beth’s journey map (created by Sarah).

The left side of the map illustrates how Beth found out about Candace’s mental health issues through her school guidance counsellor, shown by the ‘my child’ piece, the distressed face, and the school with the guidance counsellor between Candace (‘my child’ piece) and Beth (‘me’ piece). Beth took Candace to the family doctor who referred her to hospital outpatient services, which was a 3-month wait. This is shown by the doctor piece pointing to the hospital with the clock piece. The hospital services were helpful, depicted by the plus sign, and Candace then returned to school but still felt overwhelmed and distressed.

Beth and her husband attended a parent support group, which they found helpful, as shown above the hospital piece. They found out about a psychologist from the support group and Candace was put on the waitlist for an appointment. However, she became suicidal and was admitted to the hospital psychiatric unit, shown by the arrows pointing to the second hospital piece. As Candace was discharged and was still struggling with her depression and eating, Beth and Candace came back to the hospital emergency department each day for several days until Candace was admitted again. This is
illustrated by the arrows going from the hospital to the ‘my child’ and ‘me’ piece with the crisis marker and the frustrated face. The arrow finally points to the family counsellor who helped and supported Beth.

4.2.5. Tanya & Shawna. Tanya noticed early signs of mental health issues in her daughter, Shawna, when she was 14-years-old. Shawna was over-exercising and under-eating while also being affected by mood issues. Tanya and her husband, Greg, discussed their concern with Shawna:

How we worded it was, “We're concerned about your health; we've been noticing these behaviours and they're very concerning to us and we're going to bring you in to see the doctor about it.” And she was extremely relieved. She just said, “I was hoping that someone would notice.”

Shawna was willing to get treatment because she knew she was having issues but hadn’t wanted to bring it up to her parents.

Tanya and Shawna then went to the family doctor who referred Shawna to the paediatrician at the hospital. During the wait period to see the paediatrician, Tanya and Greg paid for private counselling for their daughter and for themselves because Shawna was also experiencing anxiety and depression. The counsellor was not experienced in dealing with eating disorders and placed responsibility for the development of Shawna’s mental health problems on Tanya and Greg. Tanya explained:

So we had a very poor entry-level experience with dealing with her issues.

Basically her [private psychologist’s] approach was to tell us that our behaviour, my husband's and mine, had created this problem for our child and that the best way to deal with it was not to label it.
They recognized that the counsellor was neither supportive nor assisting in Shawna’s treatment process and made no further appointments with her.

Once Shawna was assessed by the hospital paediatrician, she started receiving outpatient services regularly to help with her mental health issues. Tanya and Greg had meetings with a social worker to provide them with information and support while their daughter was receiving outpatient hospital care, and they also attended a parent support group. Tanya said, “And once we got into the [hospital], frankly it just felt like oh, thank goodness we’ve found the place we need to be, because there was a wonderful multidisciplinary approach that was taken right from the first visit.” Thus Tanya felt that Shawna had consistent and high quality support at the hospital, and was able to receive all the services she needed in one building which made the process very coordinated and efficient.

Shawna had difficulties at school before and after her care, and Tanya thought that the school environment might have contributed to some of Shawna’s mental health challenges. Tanya expressed, “We really were going through a tremendous struggle, teasing out what parts of this problem were our daughter and what parts of this problem were the school that she was in.” From Tanya’s perspective, many of the students were not well disciplined and there were major issues with bullying, especially for girls.

Tanya and Greg complained to the school about the “bullying culture” and saw that a few changes were made. Tanya discussed her disapproval with some components of gym class, such as the public weighing component. She said, “So once I heard that and then heard that she had even watched one episode of The Biggest Loser [in gym class], my husband and I immediately went into the school and spoke to the principal and the
Phys. Ed. Teacher.” Tanya stated that there should be more coordination between the health and education systems so that the schools are educating the students about mental health in positive and effective ways.

Shawna received both individual and group counselling, which she found to be very helpful in her care, according to Tanya. As she entered high school, she found the school environment became more positive and Shawna was able to speak out to her peers about mental health, which empowered her and assisted in her treatment. Tanya expected her daughter’s journey to be linear but instead saw lots of variation in her progress:

It's an amazing process though because from a parent's perspective you think that it'll be linear and you'll see this progress and then they're sick and then they're going to get better. But in this case you think they're better and then they dip and come back, so there's a lot of up and downs with it.

She is unsure if her daughter will ever fully recover and acknowledges that Shawna may always need extra support and guidance throughout her life due to the non-linear nature of her mental illnesses. Figure 5 illustrates Tanya’s journey through the system.

Figure 5. Tanya’s journey map (created by Sarah).
The journey begins by showing that Tanya and Greg approached Shawna when they noticed changes, as shown by the ‘me’ piece standing beside the man with the ‘my child’ piece and the distressed face. Above them is the school piece with a crossed out circle and a dissatisfied face, depicting Shawna’s challenges in the school environment and Tanya and Greg’s disappointment in the school administration. The arrow points to the family doctor where Shawna received a referral to the hospital paediatrician. As she waited to be assessed, shown by the clock piece, Tanya and Greg paid for a private counsellor for Shawna and themselves.

Once Shawna’s appointment with the paediatrician arrived, she started receiving outpatient services from the multidisciplinary hospital treatment team. This is shown by the hospital piece with the three service providers around it and the plus signs, indicating the beneficial treatment Shawna experienced. The arrow then points to the school piece with a plus sign, signifying the improvements in Shawna’s school experience as she transitioned to high school. She sees a psychologist for counselling with whom she was able to develop and maintain a relationship over a long period of time, represented by the psychologist piece at the end of the map.

4.2.6. Macy & Charlotte. Macy’s daughter Charlotte started experiencing mental health challenges when she was 5 years old. She was extremely hyperactive and Macy noticed that her behaviour and development differed from other children. Macy did some research and found out that Charlotte may have ADHD so she self-referred when Charlotte was 6 years old. They waited two years for the assessment, which concluded that she didn’t fully meet the criteria for an ADHD diagnosis. Macy explained, “So, at the end of that [ADHD diagnostic services] experience she came out with, ‘She's borderline
but you have your hands full, good luck.’ And then within a few months everything deteriorated.”

In the following three months, Charlotte’s behaviour became more disruptive and Macy felt that it was getting out of control, so she contacted mental health services again. She was told that Charlotte’s file had just been closed so they would have to wait another three months for an assessment. Macy became frustrated because she hadn’t known that the file would be closed that quickly, and contacted the patient advocate for the hospital, who was a health care worker who acted on the patients’ behalf and helped them avoid the wait list for the psychiatrist as they re-entered the system.

After the second assessment, Charlotte was diagnosed with Oppositional Defiant Disorder (ODD) and ADHD. The doctor was shocked that she had not been diagnosed after her initial assessment two years ago. He prescribed ADHD medications and Charlotte took them for over two years, but found they were not helping her symptoms. Charlotte eventually started seeing a paediatrician who specialized in behavioural issues after Macy asked for a referral from their family doctor, and the paediatrician prescribed a mixture of different medications. Macy said, “He was willing to play a little more, and push the traditional “here's your med max dose, sorry can't help you.” And that's when we got the Risperidone mixed with an ADHD med.” This mixture of medications did temporarily improve Charlotte’s symptoms.

Charlotte started experiencing more intense mental health problems again after a physical abuse incident with her grandfather, which happened shortly after Macy and her husband separated. To help with her symptoms, the paediatrician prescribed Charlotte with the maximum recommended dosage of medication but she still was not feeling any
better. Macy decided that she should try to seek help for Charlotte from the hospital psychiatric department because the paediatrician could not do anything more. They started the referral process through the family doctor, who helped them avoid the wait list to re-enter the system by referring Charlotte for a medication consultation rather than continuous care:

And that's when I was told to go through my family doctor again for the one time med consult. So, we could get in faster rather than waiting for the - 'cause a med consult they can see you in say two months… And that would get us in.

Meanwhile, Charlotte was seeing a private psychologist as she waited for psychiatric services, and the private psychologist thought she might have autism.

When Charlotte went for her consultation with the psychiatrist, her ADHD diagnosis was re-confirmed but in addition she now had diagnoses of depression, anxiety, and post-traumatic stress disorder (PTSD) from the abusive incident. She was switched to a third psychiatrist for care, who referred her to a day treatment program. The doctor at the day treatment program also suspected Charlotte might have autism but she did not receive an assessment or diagnosis, as there was a two-year wait list.

Charlotte’s day treatment abruptly ended while the treatment centre switched locations and underwent renovations. She was then referred to an inpatient program where she could come home only on the weekends, and was eventually weaned out of the inpatient program. Charlotte had a social worker to help with the transition, but Macy found that the social worker wasn’t always available when needed, contributing to a difficult transition.
Charlotte continues to struggle with depression and self-harming, and has shared her thoughts of suicide with Macy. However, Charlotte no longer wants to receive mental health services because they have not proven helpful or supportive for her, and has started experimenting with other drugs. Charlotte has become violent in the home, and social services have been involved in concern for the safety of Macy’s other children. Macy is trying to keep the family life balanced in order to protect and support all her children. She feels that Charlotte is falling through the cracks in the mental health system because she is not receiving the support that she needs. Macy’s journey map is shown in Figure 6 below.

*Figure 6. Macy’s journey map.*

The journey map begins with the ‘my child’ piece pointing to the doctor, signifying Charlotte’s early assessments for ADHD that did not lead to a diagnosis. It then shows the ‘me’ piece pointing to the hospital central referral, illustrating Macy’s contact with the hospital to seek a proper diagnosis for Charlotte. There was a long wait for services, indicated by the hourglass piece and the crisis marker. It then points to the
family doctor who referred Charlotte to the intensive behavioural treatment program. The family doctor piece is next, and it then points to the mental health paediatrician who prescribed a mixture of medication for Charlotte. The money piece next to the medication indicates the expense of trying out so many different medications.

The arrow then points to the ‘my child’ piece and shows that Charlotte went through puberty and trauma, causing more problems with depression. The arrows point to a police officer, signifying the police involvement in her daughter’s mental health issues and Macy’s concern that her other children would be taken from her care due to Charlotte’s aggression. It then leads to the hospital piece with a plus sign next to it, illustrating how the hospital connected Macy and her family to support workers that came into her home. The journey map ends with a clock piece and a question mark, showing the wait time for services that caused Charlotte’s dissatisfaction with the system and her removing herself from care. It also illustrates that Macy is unsure what will happen next, hopeful that Charlotte will eventually receive services for her depression.

### 4.2.7. Claire & Laura

Claire found that her daughter Laura began having mental health challenges when she was a teenager, as she expressed to her parents that she self-identified with having anxiety. Claire and her husband, Joe, tried to help her through it themselves. They felt that she was coping well but then the school guidance counsellor contacted Claire and informed her that Laura had been self-harming. The family doctor gave them a few psychologists’ names where they could self-refer, and each had a wait list so Claire put Laura on the shortest waiting list of four months. In the meantime, Laura went to a private psychologist for talk therapy, but found that it wasn’t effective for her.
When Laura’s appointment with the psychologist arrived later that year, her assessment concluded she scored higher in depression than anxiety but was diagnosed with both. Claire felt that Laura’s mental health issues were associated with the school environment, and as she started counselling in the summer her issues improved. She stopped seeing the psychologist before she started back to school in September, but that was when her symptoms came back.

They went back to the family doctor who referred Laura to a paediatrician, which was a 6-8 week wait. During this time, the guidance counsellor contacted Claire: “We got a call from the school, from the guidance counsellor, who had still been meeting fairly regularly with our daughter, and telling us that she was feeling suicidal, and was expressing that she didn’t feel safe at school.” Claire and Joe picked Laura up from school and later took her to the hospital emergency department, where she was admitted.

Laura remained in the emergency department for almost a week waiting for a paediatric bed to become available. During this time, various psychiatrists assessed her and thought she was too young for medication but recommended that she see a psychologist. Claire and Joe thought she needed more intensive care. Claire felt that Laura didn’t receive very much assistance while in the hospital, and she was discharged after a few days. Laura was referred to a community mental health counsellor who would support her along with the continued appointments with her school guidance counsellor.

Claire was aware that there were many other students, especially girls, in Laura’s class who were dealing with similar mental health issues:

My daughter’s not alone in suffering from anxiety and depression. Roughly eleven girls in her class, nine of them have looked for help for mental health
stuff… And I think there is a couple of the boys as well, so I shouldn’t say it’s just
the female gender, but definitely the girls seem to be having the rougher go of it.
Claire had met several times with other parents and the school board to talk about the
students’ mental health. The other parents were thankful that she brought up the issue and
were able to find support from one another.

Claire recommended that the teachers at the school receive mental health first aid
training, but was told by the school board told that it wouldn’t be happening and wasn’t a
priority. The teachers at the school were removing the students with anxiety and
depression from the class, but Claire felt that it was in ineffective way to deal with the
students’ mental health. Claire took the initiative to do presentations in various schools to
educate parents about navigating the mental health system and the mental health
programs that are available for students at the school.

Claire felt that there was no communication between Laura’s service providers,
such as her school guidance counsellor and community counsellor, and expressed that
improved coordination would improve Laura’s treatment progress. She also would have
preferred that the mental health system communicate and touch base about services and
appointments, as Laura was never scheduled for an appointment with the paediatrician
even though she was told she was on the wait list.

Claire feels that there is a lack of information and research about mental health
services to access and ways to manage kids’ exposure to technology. She explained:

As a parent, when the kids were younger, we just turned the Internet off, right?
And then, you have some time when it’s on. But now, I have a 16-year-old in the
house who’s doing homework or she needs to be connected to the Internet. I’ve
got a younger one who probably could use a break, but if I turn the Internet off, the older kid is going to be like, “How am I going to get my homework done?”

Claire spoke about the potentially harmful impacts of technology on youth’s mental health due to their constant exposure. Claire also stated that there should be more focus on earlier intervention and awareness among parents about mental health, early signs, and available services. Claire’s journey map is displayed in Figure 7.

*Figure 7. Claire’s journey map (created by Sarah).*

The ‘me’, ‘my child’ and the man pieces are shown at the beginning of the map, indicating that Laura was initially open with Claire and Joe about her challenges and that they tried to help her through them. The arrow points to the school, with the guidance counsellor and the ‘my child’ piece with a knife beside it, showing that Claire was contacted by the guidance counsellor about Laura’s self-harm and suicidal thoughts at school. The next step was the family general practitioner, who provided some contacts of psychologists for Laura for self-referral. During Laura’s 4-month wait period, Claire
paid for a private counsellor who Laura did not find helpful. This is shown by the psychologist and next to the money sign, and the crossed-out circle. The psychologist that Laura waited for was helpful but her appointments ended before she went back to school. She started self-harming when she returned to school after the summer break, shown by the school piece with the blade next the ‘my child’ piece. Claire took Laura back to the family doctor who referred her to a paediatrician, as shown by the arrows pointing to the GP then pointing to the paediatrician and clock. During the wait to see the paediatrician, whom Laura was never contacted for an appointment, she was admitted to the hospital where she was assessed. The hospital piece, the distressed face, and the chart depict this part of the journey. Once Laura was discharged, she was referred to a counsellor at community mental health and continued to see her guidance counsellor at school, who were both good supports for her and are shown on the far right side of the journey map.

4.2.8. Section Summary. This section of the chapter told mothers’ narratives through chronological summaries that highlighted the main points of interest to the research questions. Their narratives and maps display fragmented, non-linear journeys seeking care and illustrate interactions and power struggles with people in the mental health system, education system, and family life. The next section includes theme webs that were part of the analytical process to assist in organizing codes and categorizing major themes in the narratives.

4.3. Theme Webs

Four visual webs are presented with initial thoughts and observations from memos of the seven participants’ transcripts and their summaries. These patterns and
initial themes are relative to the research questions and were regrouped into second-order themes for clarity and a further detailed analysis in section 4.4 of this chapter. The visual theme webs are displayed in Figures 8 to 11.
4.3.1. Barriers in the mental health system.

Figure 8. Barriers in the mental health system. The red bubbles indicate the main barriers or challenges that were identified in mothers’ journeys.
4.3.2. Facilitators in the mental health system.

*Figure 9.* Facilitators in the mental health system. The blue bubbles indicate the main facilitators that were identified in mothers’ journeys.
4.3.3. Experiences with the education system.

Figure 10. Experiences with the education system. The blue bubbles represent facilitators in the care-seeking journey, whereas the red bubbles represent barriers.
4.3.4. Mother/daughter and family relationships.

*Figure 11.* Mother/daughter & family relationships. The blue bubbles represent facilitators in the care-seeking journey, whereas the red bubbles represent barriers.
4.4. Overall Analysis

Three overarching themes of marginalization and loss of control, becoming empowered, and hope for the future are presented here. They were developed from the combined analysis of the narratives, journey maps, and theme webs. These themes are not linear chronological themes in that marginalization and loss of control did not necessarily come before empowerment nor did they become removed from mothers’ situations as they fought to become empowered. Rather, most participants experienced loss of control in certain areas along their journey while simultaneously becoming and remaining empowered in others. Subthemes for the first two overarching themes include examination of the mothers’ experiences with the mental health system, education system, and family life. Subthemes for the last overarching theme include the three composite recommendations on improvements to the system from the participants’ perspectives. Each of these subthemes has unique examples.

Examples of marginalization and loss of control in the mental health system included a) Daughter’s condition & mother’s accounts not taken seriously, b) Blame, c) Lack of guidance and information, and d) ‘Falling through the cracks’. Examples of marginalization and loss of control in the education system included a) Ignored and b) Lack of understanding about mental health needs. Marginalization and loss of control were exemplified in the family life through the examples of a) Disempowered mothering, b) Lack of support, and c) Internalizing blame & feelings of guilt.

Becoming empowered in the mental health system involved a) Questioning professional treatment, b) Advocating & fighting for appropriate care, and c) Actively resisting blame. Examples of becoming empowered in the education system were a)
Advocating & educating about mental health, b) Finding alternatives, and c) Collaboration & flexibility. Mothers’ experiences of becoming empowered in the family life were demonstrated through the examples of a) Turning point: re-examining maternal role, b) Understanding daughters’ mental health needs, and c) Communication.

The third theme of hope for the future consisted of participants’ recommendations for improvements to the system. These were grouped thematically into three subthemes of a) Consistency, b) Collaboration, and c) Education. Each theme, subtheme, and example is explored in detail with exemplifying quotations from participants.

4.4.1. Marginalization and loss of control. Mothers all experienced marginalization and loss of control along their depression care-seeking journeys within the mental health system, education system, and family life. Each subtheme consists of specific examples and quotations from participants.

4.4.1.1. Mental health system. Marginalization in the mental health system was a pertinent theme in the mothers’ narratives. They felt a loss of control when their daughters’ depression and their concerns as mothers were not taken seriously. Participants felt that they were blamed for their daughter’s depression in their interactions with health care professionals, which lead to a feeling of marginalization and victimization. The lack of available information and guidance for them to help their daughter also contributed to loss of control along the depression care-seeking journey.

4.4.1.1.1. Daughter’s condition and mothers’ accounts not taken seriously. When mothers and their daughters attempted to seek help from the mental health system, health care professionals often dismissed mothers’ concerns about their daughters and did not
acknowledge the severity of the daughters’ conditions. This was especially evident when participants and their daughters went to the hospital emergency department and their daughters were not treated or admitted for care. Macy felt that her daughter Charlotte was not properly cared for at the emergency room when Charlotte was struggling with depression and self-harm:

But bringing her in here into Emerg, they just diffuse the situation for the moment and send you home. I think you'd have to be dead for them to admit your child… She's cutting but she's not suicidal. She's out of control, she's crying to the point of throwing up. But now she's exhausted and pretty much passed out, so now she's okay so you can go home.

Macy’s concerns for Charlotte, as well as Charlotte’s emotional and physical states, were not addressed in the hospital, and they were referred from one hospital specialist to another to make a decision on whether or not Charlotte should be admitted. Macy and Charlotte were sent home from the emergency department without receiving care or support, leaving them feeling as though Charlotte’s mental health state was not considered a priority.

Beth had a similar experience in the mental health system when she and her daughter Candace went to the emergency department in a mental health crisis and Candace was not treated:

So I felt like we were kind of being shunted from one department to another and everybody was saying “oh she's kind of okay,” but at the same time I have this ill child who's lost a lot of weight and hasn’t eaten for days and is obviously in a bad
place, and I don't know what the hell to do with her. And I kind of felt like they were testing us a little, I mean, really, I think probably they were testing her.

Beth had a difficult experience in the hospital in that she knew that Candace was in need of professional help for her depression, but could not access it when she was most in need. A sense of lost control is evident within Beth’s narrative in her desperation for her daughter to receive some form of treatment from the system. Beth’s quotation also exemplifies the power dynamics that mothers felt between themselves and the mental health system when they were not taken seriously, in which case participants felt like they and their daughters were being “tested” by health care professionals rather than helped.

A major concern of mothers is that their daughters’ mental health problems are not clearly understood or differentiated from hormonal or behavioral issues. Karen expressed this concern:

> And I felt like that's how the system feels. That they're kids just looking for attention, or they're kids that are just being teenagers, or they're just being kids - they're just acting out – “it's hormones,” I got that a lot… And so I felt like they really don't recognise mental health in teenagers.

Karen’s quotation suggests that she felt her concerns and her daughter’s problems were not addressed, and that people misattributed Taylor’s challenges to hormones, behavioral problems, or the desire for attention. This quotation came after Karen explained that she had had a chat with an orderly at the hospital who told her that he sees young people coming in to the hospital all the time looking for attention. Karen thought that this also
reflected the beliefs of other health care workers and attributed this belief as one of the reasons why Taylor’s depression was not being properly treated.

4.4.1.2. Blame. Mothers experienced blame on several occasions from service providers in the mental health system. For example, Tanya and her husband Greg began seeing a private psychologist as their daughter Shawna was waiting for mental health services, and experienced explicit blame and judgment for Shawna’s challenges:

[Psychologist] was also – my husband and I have had this conversation many times – I would say very hurtful from a parental perspective in that a burden of guilt was placed on us, right off the bat. “This is something you did to your child; you've given your child this problem.” And from a parental perspective, that’s devastating.

Tanya’s quotation exemplifies the theme of marginalization of mothers whose daughters have depression. Mothers felt that their parenting was targeted for causing depression in their daughters, which was neither supportive nor helpful for them in the care-seeking journey.

Alice experienced blame and marginalization from one of her daughter Chelsea’s providers while Chelsea was in the hospital. Alice explained what she had heard:

And, you know, “Oh, she’s just a teenager that has parents that parent from two separate homes, because her mom and dad are divorced. And she has no boundaries and no rules,” and we don’t discipline her so “it’s all a parenting issue.”
Alice’s quotation shows the hurtfulness and unhelpfulness of these comments, and how they were not in any way health promoting for Chelsea while she was in hospital to receive care.

Interestingly in the aforementioned situation, both parents were blamed for Chelsea’s challenges while in another instance Alice’s parenting in particular was viewed as the cause of both of her daughters’ depression:

And, I mean, I shared with the doctors, because they say, “Well, can you pinpoint anything that happened in your daughter’s life that would have created this?”… You know, like, they had a lot of things happen in their lives in a very short period of time, in those very fundamental years of their lives. And then I’m, kind of, looked at, like, oh, so it’s your fault they’re like this…So then you’re blamed for what’s happening with your children.

When health providers question parents in this way, it can be hurtful as it may imply that one or both parent(s) caused the depression. This can sometimes lead to either a conscious or unconscious blaming of mothers by mental health professionals, as well as a feeling in mothers that the information they provide to health care professionals is then being used against them in a non-supportive way, as exemplified through Alice’s quotation.

4.4.1.1.3. Lack of guidance and information. The theme of lack of availability of information was apparent in all seven of the mothers’ narratives. Zoe attempted to find information from several different sources concerning what she could do to help her daughter and what services she could access. She found this process extremely challenging: “I'm making calls and I'm trying to find out all that I can, but there's no real
answers. There's just telephone calls and lots of questions.” The lack of readily available information for mothers on where they could turn to for support and guidance was a major burden for many of the participants.

Another example of the stress associated with lack of guidance and information in the depression care-seeking journey was in Beth’s narrative, when she explained how she was given very little information or guidance when her daughter was struggling with her depression. When she took her daughter to the hospital emergency department, the health providers did not provide her with the information she felt she needed to handle her daughter’s condition without continuously returning to the hospital. Beth explained:

I did feel slightly pushed around by the system as well. I think that to leave me dangling with no real direction as to what I was supposed to do, except "Oh you can keep coming back [to emergency department]," is not very helpful.

In Beth’s narrative, she expressed that she had expected to receive more guidance from health providers but that the only option she was given was to continue returning to the hospital if Candace’s condition worsened. This created further distress and disruption for Beth and Candace, as Beth would have liked to be provided with resources and information on how to help her daughter at home. In this way, she felt that the information available online and provided to her through health providers was not adequate to help her cope with Candace’s issues and assist Candace in her journey to mental health.

4.4.1.1.4. ‘Falling through the cracks’. A sense that their daughter was “falling through the cracks” in the system was experienced by several of the mothers. For example, Macy felt that the system was not working for her daughter and that she was
going through the motions without receiving any real treatment. She explained, “You know, if you have these standard cases that come in and make a diagnosis, they got medicated and left, that's great 'cause the system worked. But in my case I feel like she's falling through the cracks.” Macy felt that there were no services available that were properly helping Charlotte with her mental health conditions or offering Macy any support as a mother of four children. She experienced conflicting information from the system about what steps should be taken regarding Charlotte’s mental health:

Charlotte’s case was way too complicated for any of their support workers so was best left in the [hospital]'s hands. So, here they are saying these kids shouldn’t be in my care but at the same time they're saying they don’t have the services to help her. So it was “we're going to take her but we're not.”

In this quotation, it is evident that Macy felt a sense of lost control in helping with Charlotte’s depression. There were no links to appropriate services or clear plans of action to help Macy with Charlotte’s condition.

In some cases, mothers felt that they themselves were falling through the cracks in the system along with their daughters. Karen explained how she felt she had been forgotten about when she was not contacted for an appointment for her own mental health while coping with her daughter’s journey:

[Taylor’s counsellor] said, “You have a lot on your plate, you need to start seeing somebody for yourself” because I started having anxiety attacks too, right? So I said “Yeah, you’re right.” So when I was leaving that day from seeing her about Taylor, I went to the receptionist and said that I would like to - I had to see somebody. Yeah, that was five years ago and I've yet to get a phone call.
Karen’s quotation illustrates her concern she was not contacted even though she was on the wait list. It exemplifies the issues that mothers and daughters experienced while waiting for services where they had seemingly been forgotten about or their concerns had been neglected, creating a barrier in the care-seeking journey.

**4.4.1.2 Education system.** Mothers often felt that their daughters’ educators did not understand youth mental health needs or how to support their daughters. Marginalization and loss of control in the education system were also part of the depression care-seeking journeys when mothers’ concerns and recommendations were ignored.

**4.4.1.2.1 Ignored.** Mothers’ interactions and experiences with the education system often resulted in their concerns or suggestions being ignored. Claire and other parents at her daughter’s school had a meeting with the school board where their suggestion for focused mental health education for teachers was dismissed:

Some of our recommendations were, we really wanted to see all the teachers have access to mental health first aid, which is, like, a two-day course. And we were told, frankly, by the person from the school board that that wouldn’t be happening. They just said they have too many other priorities for them, that they didn’t see how they could do that.

In this instance, Claire and other parents had expressed their concern for the mental health of many of their children attending the school and felt that the mental health first aid would be a positive step to helping the children and preventing future mental health crises in students. Power dynamics between Claire and the school board are evident in
that the education system is exercising their power over the mothers and not attempting to make compromises.

Karen also felt a loss of power when she tried to educate the principal at Taylor’s school about Taylor’s depression and was continuously met with resistance. Her attempts to educate about her daughter’s mental health needs were ignored and she started becoming quite frustrated:

And then I kind of lost it with him [principal], and I said to him, “I've been in here six, seven times talking to you, telling you what's going on.” I said, “and you still don't believe me that she has mental health issues.”

As most of the mothers’ daughters had challenges with the school environment and missed many school days, mothers would try to help educators understand what their daughters were experiencing but were often misunderstood or ignored. In Karen’s example, the principal did not believe that Taylor had depression and did not understand the connection between her behaviour and her mental health even after Karen attempted to educate several times.

4.4.1.2.2. Lack of understanding about mental health needs. Mothers experienced loss of control with their daughter’s school when educators did not understand how to properly help their daughters with their depression. Alice expressed her concern that there were not clear guidelines for how to support students with mental health challenges:

So they [school staff] try to help to the best of their abilities but there’s such a ... this lack of understanding, and education and knowledge. And it’s so complex from one person to the next on how it affects people… So there’s no one formula
of this is what you do if somebody was having a panic attack. And I think just for people to understand that is really difficult.

The individual differences in mental health symptoms make it challenging to develop clear guidelines and know how to support the students who are struggling, as Alice explains. However, mothers also found that the lack of collaboration between the health and education systems was a major barrier preventing their daughter from getting the appropriate supports at school.

Other participants attempted to assist educators in learning about their daughter’s mental health needs and in doing so recognized the lack of education about supporting youth mental health among some of the educators. This occurred when Claire met with the school board to discuss changes that could be made to improve understanding about ways to support students with depression and other mental health challenges. Claire explained:

And they [school board] pulled out some programs that, you know, nice, big, thick catalogue binders of, “Well, we have this program, and we have that program.” And I said, “Well, are any of your teachers actually trained or using this, at this time?” “No,” was the answer, right? So, you know, the research has been done, but maybe it’s difficult for teachers to implement it as well.

In this quotation, differences in perception are apparent in that Claire felt that there was lack of understanding among educators about how to support students with mental health challenges, whereas the school board felt otherwise based on the fact that there were several mental health programs implemented at the school. Mothers mentioned that some educators understood their daughter’s mental health needs due to previous or personal
experience with depression and that guidance counselors in the school were generally very knowledgeable about how to help.

Educators and guidance counselors often left responsibilities with students to access mental health care in the school. However, several mothers expressed that they didn’t think their daughters would feel comfortable seeking out care or assistance for depression at school even though that option was available. Educator knowledge on identifying potential mental health concerns in students, guiding them to appropriate resources, and making appropriate accommodations were viewed as important pieces of the care-seeking journey and aspects that mothers felt could be improved upon in the education system.

4.4.1.3 Family life. Mothers felt power struggles in the family life through challenges with parenting their daughter with depression and their other children, the lack of support from family members, and internalizing the blame that they experienced from those with whom they shared their concerns about their daughter.

4.4.1.3.1. Disempowered mothering. Mothers felt a loss of control and disempowerment in the family life through their challenges in parenting and dealing with their daughters’ changes and behaviours. They often expressed that they felt they were doing everything they could to try to help their daughter with no results, or were unsure if what they were doing was helping at all. Zoe expressed her feelings of disempowerment as a mother when she tried to persuade Hannah to go to school:

And that was it. She was done. There was no more school for Hannah. She wouldn't go… So what did we do? Oh, my god. I cajoled, I bribed, I promised, I begged, I cried, I screamed. I did all of the things that I thought I could do to get
her to continue to go to school to a point that she was so worked up one day that she snapped. Snapped. Just hysterical.

Mothers often attributed the feeling of disempowerment in mothering their daughter with depression as partly due to not having enough support or guidance from professionals as well as from their social networks such as immediate and extended family members. Zoe’s quotation illustrates that she did not know what steps to take when Hannah stopped going to school even though Zoe contacted several people asking them what to do, but they each offered conflicting advice.

Another way that mothers expressed disempowerment in mothering was when they tried everything that health care professionals suggested to help their daughter with no improvements. Mothers felt powerless in their abilities to help their daughters get better and that any information they did have was not helpful. Extreme cases resulted in mothers fearing for their daughters’ lives due to self-harm or lack of nutrient intake. Beth felt disempowered as a mother in the process of Candace’s mental health deterioration that was not being properly treated:

I guess I just felt like it's the holidays, you know, here I am trying to cope with this thing and I don't know what to do and she hasn’t eaten anything for a day and a half, or whatever. I'm supposed to be doing these meals and snacks, only it's not happening. I'm doing everything I can do.

Beth and Candace had been sent home from the hospital emergency department several times over the holidays when Candace’s other supports were not available. Beth was given instructions on how to help Candace but could not get her to eat or drink, which resulted in power struggles between Beth, Candace, and the health care workers at the
hospital. Responsibilities to micromanage Candace’s eating and mental health were given to Beth, which she ultimately found too difficult to handle in Candace’s quickly declining state. These situations exemplify the disempowerment that mothers experienced in the journey.

4.4.1.3.2. Lack of support. The theme of lack of family support was influential in mothers’ and daughters’ depression care-seeking journeys. Most mothers expressed that they felt they didn’t have the support of their families while seeking care for their daughter’s depression. For example, Alice recounted a conversation with her daughters’ grandmother who didn’t support them in seeking professional care and treatment for depression:

And even still the other day, you know, like, “Why is she still on that medication?” You know, “It’s been over a year. She doesn’t need to be on that.”

I’m like, “She needs to be on that for the rest of her life and that’s what it’s going to be.” You know, she’s like, “Well, I don’t think that’s right.”

Alice had challenges with educating her family, and found that through their lack of understanding about mental illness they were not able to support her or her daughters in their care-seeking journey.

Another example of lack of support in the family life that influenced feelings of powerlessness and loss of control was Zoe’s explanation on how she wasn’t able to take time to research information about depression because she didn’t have adequate supports in other areas of the family life. Zoe explained: “The reading material for me was limited, trying to figure it out, trying to raise the other two kids, trying to keep a household going with not a whole lot of help from anyone.” Her quotation exemplifies
this theme of lack of support and assistance in that she was caring for her daughter with depression in addition to her other children and managing household tasks as a single mother with no support.

Examples of this theme were especially apparent in single mothers’ narratives. In several cases, fathers were not involved in the daughter’s life or in the care-seeking journeys, and in some instances fathers were negative influences when mothers and daughters attempted to seek care. As discussed in Zoe’s narrative summary, her ex-husband had tried to prevent their daughter Hannah from receiving psychiatric care. Zoe explained this situation:

[Child psychiatrist] tried to speak to my ex-husband, who denied any problems with Hannah whatsoever. Which, when he denied any problems with Hannah, before he even spoke to Hannah, [psychiatrist] ended our sessions. Because the second parent had decided that there's nothing wrong with her, and so therefore he can't continue any work with her.

This lead to feelings of frustration and disempowerment for Zoe because she had worked very hard to try to seek psychiatric care for Hannah. Zoe knew how much Hannah needed this care as she had full custody of her children and witnessed Hannah’s struggles on a daily basis, whereas Hannah’s father had not seen Hannah since she was young. Instances such as these created additional barriers in mothers’ and daughters’ journeys to mental health.

4.4.1.3.3. Internalizing blame and feelings of guilt. Contributing to mothers’ marginalization and loss of control in the family life was the theme of internalizing blame, which often leads to feelings of guilt. Mothers’ narratives illustrated this theme
when they placed responsibility on themselves for their daughter’s depression, as
exemplified in Alice’s narrative:

And Emma was just crying for attention, because all of our attention for a period
of time was going on our oldest daughter… And you didn’t know when you were
in it that you were impacting her as well. And, you know, like, “Oh, no, you can’t
say that to your sister.” So, like, we were forcing her to, kind of, change her
normal, natural behaviours.

The tendency for mothers to find fault within themselves or explain how their own
actions may have impacted their daughter’s depression was evident in several of the
narratives. Alice explained Emma’s depression and changed behaviour as results of her
own neglect and parenting styles while focusing on Chelsea’s depression, and in this way
disregarded other possible reasons for Emma’s depression onset.

Feelings of guilt for potentially contributing to their daughters’ depression
were part of mothers’ experiences in the depression care-seeking journey. Zoe explained
the challenges she faced as a mother in getting psychiatric care for Hannah due to
feelings of responsibility and guilt that she may have caused the problems that Hannah
was experiencing:

At the time, I didn't think it required like psychiatric kind of… I don't know
whether it felt to me like it just wasn't there yet, or it felt to me like “oh my god, I
can't imagine sending my daughter.” There was still a little bit of a stigma there
for myself, right? Because mental health at that time was still not talked about and
what would my family think, what would my friends think, what would my
community think, you know?
The stigma and judgment that Zoe expected to experience from family, friends, and the community when she accessed mental health care for Hannah was a factor that influenced their care-seeking journey. Mothers’ narratives reflected instances where they feared being demonized and looked down upon as parents due to their daughters’ depression. Their quotations exemplified some of the ways in which their expectations became reality, leading some mothers to internalize the blame and feel guilty and ashamed.

Mothers experienced marginalization from being blamed, ignored, and invalidated in the mental health system and education system, resulting in feelings of guilt which affected the family life. They felt a loss of control and powerlessness in instances such as when they could not easily access information to help their daughter, and when others did not understand their daughter’s depression and care needs. An absence of control was also felt when mothers were trying to care for their daughter and take care of the family with little to no support, making the depression care-seeking journey even more challenging.

Conversely, mothers’ narratives also reflected the theme of becoming empowered and fighting to gain back control that was threatened in situations illustrated through the first overarching theme. Assertion and vocalization became apparent throughout mothers narratives as they fought against marginalization and blame along the depression care-seeking journeys.

**4.4.2. Becoming empowered.** Subthemes and examples of mothers’ experiences of becoming empowered are presented here. Quotations illustrate the ways in which mothers fought to become empowered in the mental health system, education system, and family life and regain a certain level of control in different situations along the journey.
4.4.2.1. Mental health system. Participants experienced empowerment in the mental health system by questioning professional treatment and opinions, advocating for their daughter and fighting for appropriate care, and actively resisting the blame that they received from professionals working in the mental health system.

4.4.2.1.1. Questioning professional treatment. Mothers questioned professional treatment in the mental health system and offered suggestions or asked for explanations about decision-making and treatment. Macy’s experience with the system reinforced a need to speak out and maintain a strong presence in Charlotte’s treatment plan rather than allow mental health professionals to fully control the direction of her care. Macy describes:

I've been pushing kind of back against the system, not rudely but just trying to speak up more… I started to kind of ask a lot of questions. Why is it this? Why is it not this? Can you be certain? Can you do a referral anyway?

Through Macy’s questioning of mental health professionals and asking for clarification she was able to increase her knowledge about Charlotte’s treatment plan, vocalize her concerns, and suggest other options if she felt they were appropriate. This enabled a sense of control in the care-seeking journey.

Similarly, Claire questioned Laura’s psychiatrist’s suggestion for her depression treatment and identified her concerns:

His initial recommendation was, “Why not try medication?” My thought was, as a parent, I was like I’d rather try a longer therapy without medication, just to see if we can get her through, you know, cognitive behavioural therapy. If she can
change the way she thinks about these things rather than... I'm very leery of the developing brain and anti-anxiety medication or antidepressants.

Claire was able to voice her own opinions about what might be beneficial treatment for Laura as she gained a sense of power. Through her own research, she became cautious of medication side effects and brought forward her concern to professionals. The mothers’ empowerment in this sense redirected their daughters’ care journeys in a positive way.

4.4.2.1.2. Advocating and fighting for appropriate care. Another way that mothers regained some control and became empowered was through advocating for their daughter. All mothers were strong advocates in that they invested an immense amount of time and efforts into helping their daughters get well. For example, Karen advocated to the hospital psychiatrist for proper care for Taylor when she was almost discharged:

I said, “I want you to help her, and by being in the hospital for four days on two different times, you're not doing anything. What are you doing? Nothing.” And I said, “that doesn't make sense; you need to find out why she's doing what she's doing and feeling what she's feeling. You guys aren’t getting it; four days ago she wanted to kill herself.”

Mothers challenged mental health professionals and demanded that their daughters receive care after experiencing lack of treatment in the hospital. Through Karen’s advocating efforts, Taylor’s hospital stay was extended and she received a proper assessment and appropriate treatment.

Alice’s quotation also exemplifies mothers’ advocating roles in their daughters’ depression care. Alice managed Emma’s depression medication symptoms
and connected her to the family doctor when needed since Emma’s psychiatrist left the province:

So when it comes to her medication, she has to stay on the doses that she’s at right now. And when the prescription runs out I’m going to have to fight tooth and nail to get somebody to see her to assess what she needs for medication, if she needs any at all.

Alice felt she needed to fight for Emma’s assessment because the family doctor was uncomfortable managing medications that were prescribed by the psychiatrist who had left. Several participants spoke about their need to “fight tooth and nail” to find appropriate mental health care for their daughter. In this way, mothers took on the advocating role and through it became empowered, while at the same time some mothers expressed that taking on that role was the only way their daughter would ever receive appropriate care. As Zoe pointed out, “I can see how easily you would fall into becoming one of those adults with addictions if you didn't have someone to protect you while you weave your way through it.” In this way, they saw it as a necessary role in the depression care-seeking journey.

4.4.2.1.3. Actively resisting blame. Mothers actively resisted blame once they began to recognize blame as a pattern within the system, and realize that it wasn’t their ‘fault’ that their daughter had depression. Macy resisted blame when she was told that she would have to take parenting classes before Charlotte received depression care:

Never mind that when I first went through this self-referral they thought, “you need parenting classes.” I ran a daycare of four kids; I've done this before. I don’t
need to know how to do a time out and I don’t need to how to do a rewards chart—this is a little bit beyond a rewards chart.

By requiring Macy to take parenting classes before referring Charlotte to treatment, Macy felt that her parenting was blamed by the mental health system for causing or contributing to Charlotte’s depression. She resisted this blame and attempt at disempowerment on her own terms by explaining the reasons why there was nothing wrong with her parenting and why it should not influence Charlotte’s timing of treatment.

Alice similarly felt blamed by health care professionals when they asked about her family history and whether anything in her daughters’ childhood could have caused their mental health challenges. When Alice explained her history and how she was a young single mother, she felt she was being blamed for causing her daughters’ depression. She recognized the power dynamics in this interaction and viewed the treatment as unfair: “We all have family histories and we all come from brokenness. But that doesn’t mean that I’ve created it, you know.” In certain interactions with health care professionals, mothers recognized that they were being unfairly blamed or judged regarding their daughter’s depression and internally resisted these accusations.

4.4.2.2. Education system. Mothers became empowered in their interactions with educators through advocating and educating about mental health, finding alternative options to the regular school system, and collaboratively working with school staff when they were flexible to find solutions to their daughters’ issues in the school environment.

4.4.2.2.1. Advocating and educating about mental health. A major contributor to mothers’ sense of regaining control and becoming empowered was through her advocating and educating efforts within the education system. Mothers educated
principals and teachers about their daughter’s needs, even if they were not always heard or taken seriously, and advocated for better support and accommodations for students with mental health challenges. Karen persistently educated the principal about mental health and felt powerful in eventually influencing his changed perception:

I said, “If you had a student that came in here in a wheelchair, you would bend over backwards to make revisions to your programmes… so that person is comfortable with their disability.” I said, “Why can't you recognise that mental health issues are also the same debilitating things?” And he was like “Well, I’d never really thought of it that way.”

Mothers often spoke about interactions with principals, whom they educated about what supports their daughter needed in the school setting and felt a sense of empowerment.

Participants dealt with tensions between themselves and the school system and though initially feeling powerless to speak up about concerns or issues, they eventually felt they needed to take an advocating role in the education system in addition to maintaining a similar role in the mental health system. Claire was vocal with Laura’s educators about what needed to happen to help Laura with her depression. She explained: “So I think because of that, I’ve been more out there and talk to people and been ready to pick up the phone and, you know, say to the school, “Hey, we need to meet and talk about this.”” Claire connected with other parents of students at Laura’s school and contacted the school board continuously about information she had found or changes she thought should be made in the school.

4.4.2.2.2. Finding alternatives. Mothers often found alternatives to public school education for their daughters when the education system became too difficult or the
school staff could not accommodate participants’ daughters’ needs. For example, Tanya spoke about alternative approaches for Shawna’s education when Shawna found the school environment unsupportive in helping her overcome her mental health challenges:

We weren't able to get her out of that school, so our approach to her was, quite frankly, you don't have to go to school if you don't want to. We'll get the work sent home, we'll home school you—whatever it takes, because the atmosphere is that toxic.

Tanya discussed the high prevalence of bullying and aggression at Shawna’s school, which Tanya felt contributed to Shawna’s depression and self-esteem issues. After Tanya’s attempts to educate and improve the school environment as well as move Shawna to a different school were unsuccessful, she decided that other measures would need to be taken to help Shawna’s depression improve. Mothers took control of their daughter’s education and sought out information on other options they could avail of instead.

Three of the mothers spoke about an Alternative Education program that was available for students who were struggling with the public school environment or workload. Alternative Education is a program that offers “low student-teacher ratios, youth worker support, increased opportunities for individualized adaptations and modifications, and more flexible scheduling, all aimed toward the goal of high school graduation in a well managed setting” (Clark, n.d., p.1). Karen arranged for Taylor to attend Alternative Education when she heard that it was helpful for students struggling with missed class time and other issues related to mental health. “She had a really, really hard time in school. So I took her out of mainstream school, I took her and I put her into a
special education programme.” Taylor had a very positive experience in Alternative Education and Karen found they were flexible and open about Taylor’s mental health needs.

4.4.2.2.3. Collaboration and flexibility. A facilitator in the education system for the depression care seeking journeys of mothers and daughters was collaboration and flexibility of the daughter’s school. Mothers were able to attain a sense of balance and control when educators were being open and adaptable to their daughter’s needs. Beth found that Candace’s guidance counselor was willing to be flexible and collaborate to assist in Candace’s wellbeing:

So she said, you know, “we'd like to keep her in here, what about things like dropping a course, or you know, adjusting things in the school system” so that she'd be able to carry on there. Rather than saying, “this isn’t working, I'm taking her out.” So she was helpful in providing a variety of options.

Flexibility in the school was a major facilitator in mothers’ and daughters’ experiences seeking care and support. Although in Beth’s case flexibility was found through the public school system guidance counsellor, often mothers found that the staff members in Alternative Education were especially helpful in collaborating and understanding when daughters had to miss school due to their depression symptoms. Zoe had a positive experience when her daughter left public school and began attending Alternative Education:

So at this point, the school has been really great in that they're going to offer her… because her marks are so good, and that she doesn't have any aggression
and she's a really good kid, otherwise, they see that she wants to be there and realize that she just can't. And they're going to work with us.

Mothers had positive experiences with the education system when their daughters’ educators were able to understand their mental health needs and work with their daughters to help them succeed.

4.4.2.3. Family life. Empowerment in the family life was experienced when mothers re-examined their role in their daughters’ depression care, gained better understandings about their daughters’ mental health needs, and had open communication with their daughters and the rest of their family.

4.4.2.3.1. Turning Point: re-examining maternal role. Mothers became empowered in the family life by re-examining their roles and responsibilities in their daughter’s depression journey. Separating the self from the daughter’s depression was a major turning point in several of the mothers’ narratives. Beth explains this process of re-examining the maternal role and separating herself from Candace’s challenges:

It's a journey that they take deliberately… That's what's very difficult to understand as a parent, is that they don't feel that they’re choosing but actually they are choosing. So it's like she's getting on a train and waving goodbye and going inside somewhere and it's… her own personal journey that she's taking.

Mothers’ sense of empowerment and freedom was exemplified through this process where they were able to detach and understand the depression as part of their daughters’ life journeys rather than becoming consumed by it in their own lives.

Similarly, Claire explains the need for parents to step back and separate their own ego from their child’s mental health problems in order for their child to receive proper
care. In her narrative, Claire describes how the depression care-seeking process should not reflect poorly on the child’s parents, and how efforts to reduce the stigma of seeking mental health care would facilitate youth and parents’ care-seeking journeys. She explains:

Ultimately, our kids are their own human beings. They’re their own people and… they’re going to have positive, negative experiences that we shouldn’t be attaching our ego to it so much that we prevent them getting help.

When Claire attempted to remove herself from Laura’s mental health challenges and resist internalizing feelings of guilt or shame, she was able to better support Laura in her journey towards improved mental health. This theme was exemplified in several of the mothers’ narratives and illustrated a renewed sense of empowerment in mothers to continue their journeys with their daughter but from a different standpoint than they had previously.

4.4.2.3.2. Understanding daughters’ mental health needs. Mothers attained a sense of control when they learned through experience what types of supports their daughter needed to help with depression. Zoe was able to recognize the cyclical nature of Hannah’s depression when she started noticing a pattern in Hannah’s symptoms throughout the years:

She was at probably the worst I’ve ever seen her, like she was in such a depressed state at this point. Not realising, for me, that the seasons had something also to do with that. So it was dark, it was dreary. I know that now because it's a cycle now, right? I've seen the cycle. We've been in it enough and long enough to know that I see the cycle.
In this quotation, Zoe’s ability to recognize the seasonal link to Hannah’s depression through experience enabled her to feel empowered, as she was able to prepare and organize accommodations with the school to help Hannah through her most challenging times. Over time, mothers learned the ways in which their daughter’s depression manifested in the family life and developed their own mechanisms to best help their daughters.

Mothers also increased their understanding about the nature of mental illness in general and eventually accepted the diagnosis as a part of the family life. Tanya spoke about the non-linear path of Shawna’s mental health journey and the ways in which she was able to help Shawna with her challenges:

I think she'll always have little struggles, but I think she's in a place now where she has all the equipment she needs to overcome those struggles. So it's a matter of just saying, “remember what you know and think about where you were and how far you've come.”

Through the mental health journey, Tanya gained an understanding that Shawna would likely always deal with mental health challenges but felt confident in their journey forward based on this increased understanding of Shawna’s needs. At certain points, mothers acknowledged their increased understanding of the depression symptoms that their daughters experienced and felt they were able to face future challenges with their daughter based on attaining a stronger grasp of what types of supports most benefitted their daughters.

4.4.2.3.3. Communication. Mothers’ communication with their families and with their daughters helped them become empowered and maintain confidence that future
challenges could be overcome. Increased communication and openness with daughters occurred through several of the mothers’ depression care-seeking journeys, as exemplified by Alice:

And I mean, going through this experience has... it’s really opened up our relationship... And, I mean, we had a good relationship before but now it’s, kind of, gone to another level where she, you know, she can talk to me. And I’ve talked to her about my experiences and everything too, where I hadn’t before.

The mother–daughter relationship became stronger in some mothers’ experiences through more open communication, which occurred for Alice when Chelsea had to be supervised 24 hours a day by Alice when she was discharged from the hospital. Communication and stronger relationships were connected in many of the narratives, signifying a new step in the journey where mothers felt they had the power to face future challenges with their daughters.

Communication and openness with other members of the family also signified a positive component of the journey where mothers conveyed empowerment and confidence in approaching issues that occurred. For example, Macy discussed an increase in communication and understanding in the family regarding Charlotte’s depression symptoms:

And they [support workers] come into your home and work with— not just the child but the family so we can understand how to respond to her, the siblings understand she's not doing this to be mean. So they can be more sensitive to her...

Macy’s support workers facilitated more open communication in the family, and Macy viewed this as a factor that would assist in creating a supportive environment to help
improve Charlotte’s mental health. In essence, communication, stronger relationships, and increased understanding were interconnected in mothers’ narratives and led to empowerment and a sense of control in the care-seeking journeys.

Mothers experienced tensions in control and power dynamics within the mental health system, education system, and the family life through their experiences seeking care for their daughters. These power struggles impacted mothers’ and daughters’ care-seeking journeys and their actions. They also emphasized the importance of mothers’ steps toward empowerment through actions of advocating, educating, and understanding. As mothers became empowered, they reflected on the injustices that occurred in their experiences and were able to make recommendations on possible improvements to the system that could facilitate depression care-seeking journeys.

4.4.3. Hope for the future. Recommendations from mothers on ways to facilitate depression care-seeking journeys are explored in this section through themes and exemplifying quotations. Their recommendations fit into three main categories of consistency, collaboration, and education, which are each explained.

4.4.3.1. Consistency. A major recommendation for improving the system was improved consistency and continuity of care. Tanya explained that this consistency could be attained through creation of more clinic-based mental health centers:

All of her needs were being met in the one place at the one time and for us that was just amazing, because we know how difficult it can be to get a specialist appointment. And for us that was the quality of life issue that mattered a great deal. We were not constantly running back and forth to appointment; we had one steady, stable appointment… So the more we can advocate for a healthcare
system that is clinic-based, is convenient for the users of the system where we're not managing multiple appointments, which is something the [hospital outpatient program] does. And that alone is a huge service.

Tanya and Shawna had a positive experience with the hospital outpatient program because Shawna was able to see multiple specialists in one day to address each of her health needs that were connected to her mental health. Tanya found this extremely helpful because it ensured that all of Shawna’s needs were being addressed and treated in one place.

Macy also recommended improved consistency in the mental health system based on her and Charlotte’s experience of being forced to re-start the referral process and have to start treatment with new doctors several times who would have to be informed of Charlotte’s history. Macy explains her idea of integration and consistency: “So, when I say integration it means - it would be nice if when you come into the referral you didn’t get dropped along the way. Like there should be some continuity of care.”

Major issues in continuity of care included not having consistent providers, waiting long periods of time to receive care, or not being contacted for appointments when attempting to reach out for care.

Similarly, Karen brought up the recommendation for improved treatment while in the hospital and appropriate follow-up care once discharged, rather than discharging without providing any significant mental health care. She explained:

They're trying to get them out, like they're just trying to get that bed free because they have somebody else that needs to come in. And that's not right, like they need to be looked after - it's not a revolving door. It shouldn't be a revolving door.
Thus a major recommendation gleaned from the narratives was the need for consistent and continuous care while attempting to access or receive treatment.

4.4.3.2. Collaboration. Team-based care was a major recommendation coming from mothers’ narratives in terms of facilitating the care-seeking journey. Alice was thankful for the collaboration between health providers, educators, and parents that occurred before Chelsea was discharged from the hospital, but found that there was no concrete transition plan developed from the meetings. She recommended improved organization and collaborative efforts in order to provide better care to youth and assist parents in knowing how to support their child:

So just having those roundtable discussions is great. But figuring out a way to facilitate it so... the parents are feeling supported and are feeling empowered with a plan when they leave that table at the end of the day.

As collaboration in general was viewed as a major facilitator in the journey when it occurred, mothers felt it could be improved and that communication among providers and between providers and parents would assist in the journey towards improved health for their daughters.

Most mothers spoke about the need for collaboration between systems and departments, such as between justice and health or education and health, to improve care outcomes. Tanya explained how the education system and the health system should be more collaborative in order to assist in maintaining good health for children and youth:

So yes, from the education side of the institutional access to care, I think there really needs to be a better dialogue between the health system and the education system at a systemic level, at an institutional level, to make sure that the care that
children are receiving in school, because they are being cared for there as well as being educated, goes with the care that they need for good health.

It was important to mothers that their daughters’ educators understood their mental health care needs. Open communication and collaboration between health and education systems would likely reduce the need for mothers to feel they had to educate and advocate for their daughters in the school system and could facilitate the depression care-seeking journeys.

4.4.3.3. Education. Almost all mothers spoke about the need for increased education as a way to improve care-seeking journeys. Increased knowledge of youth mental health was needed at the parental level, education system level, and health system level. Alice made a recommendation for improved youth mental health literacy and understanding among educators:

And if we could educate teachers ... You know, like, could we take one of those [professional development days] a year and just put it around mental health. And let them ask questions and gain knowledge and, you know, fill their toolbox up with things that they can utilize to help the kids in their classrooms, you know. Mothers felt it was important that educators be aware of the prevalence of mental health challenges in children and youth and be knowledgeable in how to approach and support their students’ mental health challenges while creating positive and health-promoting school environments.

Participants also recommended increased public education and more readily available resources for parents of young children, which would in turn help to reduce stigmatization of mental illness. Claire spoke about the need for parents to have the
resources early to help their child if they ever experienced mental health challenges. In this sense, she recommended a more preventative approach to child and youth mental health care:

I think parents definitely need… some information about navigating their way through the mental healthcare system when the kids are even younger. You shouldn’t have left elementary school without being somewhat aware, as a parent, of what to look for and what levels of service are available, what things you can self-refer to…

This theme of accessible information and education for parents was discussed in several of the narratives and was a major recommendation that mothers felt would greatly assist in the care-seeking journey.

4.5. Summary of Findings

The depression care-seeking journeys are depicted through the narratives of seven mothers whose eight daughters have accessed the provincial mental health system and obtained a diagnosis of depression. Narrative summaries, journey maps, theme webs, and an overall analysis were presented in this chapter and illustrated three overarching themes in mothers’ narratives. These themes were marginalization and loss of control, becoming empowered, and hope for the future. Mothers experienced marginalization and a sense of lost control in their interactions with people in the mental health system, education system, and family life, while also fighting to becoming empowered in other areas of the care-seeking journeys. These mothers maintained hope for the future and made recommendations for improvements to the systems that would facilitate depression care-seeking journeys of others.
Chapter 5: Discussion and Conclusion

This chapter includes a discussion of the findings in relation to the research questions and the theoretical framework. This is followed by a comparison of the differences and similarities in the narratives and themes compared to other research studies. Recommendations from participants and implications for practice are then explored, followed by future directions of the study. An explanation of the expected contributions and dissemination strategy is discussed and suggestions for future research are also incorporated. The chapter and thesis finishes with final concluding statements.

5.1. Theoretical Discussion of Findings

Critical and feminist theories (Carroll, 2004; Smith & David, 1975) guided this research design and analysis, where the main areas of interest in mothers’ narratives and journey maps were mothers’ experiences of power and control in the social institutions of mental health, education, and family life. These were evidenced by the themes of marginalization and loss of control and becoming empowered, with several specific examples and quotations for each.

Mothers often recognized the injustices that were present in these three social institutions, and this thesis reflects the parts of their journeys involving marginalization and empowerment shown through the quotations in each subtheme. Thus the parts that illustrated mothers’ steps towards empowerment and their need to maintain a certain level of power and control in the care-seeking journey was interpreted as a response to injustices (Carroll, 2004), which was undertaken by mothers in order to prevent their daughters’ health from further declining and to help guide their daughter on the path towards appropriate and necessary treatment. As the system exercises control and power
over mothers and daughters in the care-seeking journeys, this thesis demonstrates how that power functions in mothers’ lives and the resistance and negotiation that occur.

As mothers maintained hope for the future and made recommendations for improvements to the system, the experience of becoming marginalized and losing control in the depression care-seeking journey is understood as potentially avoidable if changes are enacted. Thus the social world and the functioning of social systems are perceived to be malleable and can thus be re-organized and changed to promote a better future (Carroll, 2004; Creswell, 2013).

Mothers’ narratives illustrate the influence of gender roles on women’s parenting experiences (Smith & David, 1975), as all mothers in this thesis were in some way targeted, blamed, judged, and/or ignored by those they interacted with in the care-seeking journey. This connects to Smith and David’s (1975) examination of women’s experiences with psychiatry, which included mothers’ care-seeking experiences when they had a child with mental health challenges that overlaps with the experiences presented in this thesis project. It showed the vulnerability of mothers when their daughter is struggling with depression, but it also highlighted the ways in which they resisted marginalization and fought to become empowered while also maintaining hope for the future. As mothers’ stories were told through their journey maps and quotations, and re-told through the chronologically organized narrative summaries (Ollerenshaw & Creswell, 2002), it is hoped that their stories will influence social action and change towards efforts to diminish marginalization and maximize mothers’ sense of empowerment in care-seeking.

5.2. Interpretation
Many of the themes and subthemes in this thesis project are consistent with those identified in the literature (Blum, 2007; Boydell et al., 2006; Byrne et al., 2008; Clarke, 2012; Clarke, 2013; Coates, 2016; Francis, 2012a; Francis, 2012b; Harden, 2005; Highet, McNair, Davenport, & Hickie, 2004; Highet et al., 2005; Hoskins & Lam, 2001; Jackson & Mannix, 2004; McDonald et al., 2007; Smith & Estefan, 2014; Stapley et al., 2016; Svensson et al., 2013; Widmark et al., 2013). The findings addressed the main research question: What are the care-seeking experiences of mothers of adolescent girls with depression in Atlantic Canada? The answers to the guiding questions were also exemplified through the findings and will be discussed in this section. The guiding questions are: What power dynamics do mothers experience in the mental health system, education system, and family while seeking care for their daughters? What types of supports are needed for mothers of daughters with depression to facilitate the care-seeking journey?

The ways in which the journeys of mothers and daughters are influenced by these power dynamics are shown through subthemes such as receiving blame in the mental health system, being ignored in the education system, and internalizing blame and feelings of guilt in the family life. These themes are also evident in the wider literature (Blum, 2007; Clarke, 2012; Coates, 2016; Francis, 2012a; Harden, 2005; Highnet et al., 2005; Jackson & Mannix, 2004; Smith & Estafan, 2014; Stapley et al., 2016).

In contrast, some examples of the theme entitled becoming empowered include questioning professional treatment in the mental health system, advocating & educating about mental health in the education system, and understanding daughters’ mental health needs in the family life. The literature also identifies these themes in mental health care-
seeking journeys (Blum, 2007; Boydell et al., 2006; Clarke, 2013; Harden, 2005; Hoskins & Lam, 2001). Tensions in power and control are reflected through quotations from mothers’ narratives and through their narrative summaries.

5.2.1. Identifying depression. Three of the mothers in the sample did not initially notice symptoms of depression and self-harm in their daughter, whereas four of the mothers were aware of mental health issues fairly early in the depression onset. This is in contrast to the findings in the literature suggesting that mothers either do not initially notice their child’s challenges with mental health or they do notice changes in their child but attribute them to hormonal factors (Highet et al., 2005; Stapley et al., 2016). Mothers who participated in this thesis project may have had greater initial understanding about what symptoms to look for in a depressed young person, or symptoms may have been more obvious than those in other research studies as daughters had other mental health challenges in addition to depression. The methods chosen to explore the care-seeking journeys may have also influenced the depth with which mothers described the initial recognition of depression.

5.2.2. Daughter’s condition and mother’s accounts not taken seriously.

Mothers’ experiences of marginalization and loss of control in the mental health system were illustrated through the daughter’s condition and mothers’ accounts of not being taken seriously by many health care professionals, which is evident in various other research studies (Blum, 2007; Clarke, 2012; Francis, 2012b; Harden, 2005; Highet et al., 2005; Stapley et al., 2016). When mothers in my thesis and those in other studies (Clarke, 2012; Highet et al., 2005; Stapley et al., 2016) presented early concerns about their child to the family doctor, they were often attributed to changes in adolescent hormones until
severe issues arose, such as school refusal, self-harming behaviour, and/or suicidal ideation. This phenomenon also reportedly occurs with other disorders such as ADHD where mothers’ early concerns were dismissed and the child did not receive a diagnosis until much later in their development, meaning that they missed out on critical opportunities for early intervention (Blum, 2007).

Parents in Harden’s (2005) study felt “deskilled” (p. 211) by the medical profession because their concerns were ignored, their child was not referred to the appropriate services, or their child’s treatment was significantly delayed. The findings of mothers feeling ignored, not being referred to appropriate services, and delayed treatment for the child were supported by the findings from the narratives in my research. Mothers in other studies reported experiencing frustration that other people, including health providers, didn’t take mental illness as seriously as physical illness (Coates, 2016; Clarke, 2012; Francis, 2012a), which were also reflected through the findings in this thesis.

5.2.3. Blame. Mothers in this and other studies receive judgment, criticism, and blame for their child’s mental health challenges (Coates, 2016; Harden, 2005; Hightet et al., 2005; Jackson & Mannix, 2004; Smith & Estefan, 2014). Mothers in this thesis experienced blame from mental health clinicians for their parenting styles and socialization of their child, which is a finding supported by other studies as well (Blum, 2007; Coates, 2016; Harden, 2005; Highnet et al., 2005; Jackson & Mannix, 2004; Smith & Estafan, 2014). As blame of mothers can be viewed as resulting from a wider stigmatization of mental health challenges, mothers’ perceived stigma associated with needing professional help for their child was found as a barrier to care (Boydell et al.,
2006). Some mothers in this thesis project also considered the effects of stigma before beginning the care-seeking journey in the mental health system, and they internalized feelings of guilt that their child was suffering without receiving appropriate intervention. The themes of blame, and resulting guilt and shame, are reflected in previous research on parents’ experiences seeking care for their child with depression (Byrne et al., 2008; McDonald et al., 2007).

5.2.4. Lack of guidance and information. As shown in the findings of this thesis, mothers reported a lack of resources for guidance and information on what to do and where to go when they first found out about their daughter’s depression and began seeking care, which is consistent with findings from Boydell et al.’s (2006) study where parents’ lack of information and guidance acted as a barrier to accessing care. Previous literature also shows that parents have difficulties understanding what their child is experiencing, and that they often are unable to obtain answers to their questions from their child or from service providers (Coates, 2016; Stapley et al., 2016). These studies suggest that mothers need more guidance from health care professionals about parenting strategies, rules to enforce, coping strategies, and ways to find support to reduce feelings of isolation (Stapley et al., 2016; Byrne et al., 2008; Clarke, 2013).

5.2.5 ‘Falling through the cracks’. Mothers’ perceptions that their daughters and themselves were “falling through the cracks” in the system were evident in this thesis. Findings from this thesis and from other studies illustrate that mothers are frustrated that there is no clear pathway to care for adolescents with depression, decreasing the ease with which their child receives the support and services that they need (Byrne et al., 2008; Clarke, 2013; Harden, 2005). Parents need professional guidance and peer support
to help them deal with their child who is self-harming (Byrne et al., 2008), a theme that was also shown through mothers’ narratives in this thesis. Mothers often found it difficult or impossible to access this guidance and support partly due to their concerns and requests being neglected by the system, such as when Karen was never contacted by community mental health after trying to make a counseling appointment for herself to help her cope with her daughter’s depression.

Themes evident in this research project and in the wider literature suggest that emergency departments are not fully responsive to youths’ and parents’ needs (Highet et al., 2004). Most of the mothers in this thesis reported fractured and unsatisfactory treatment, if any treatment at all, in hospital emergency departments. These circumstances lead to the perception of falling through the cracks, or being forgotten about or left behind, at a time when mental health care is most needed.

5.2.6. Ignored. Mothers’ narratives in this thesis reflected the theme of being ignored in the education system by educators like principals or people working on the school board. This theme was only evident in one other study on mothers’ experiences in care-seeking (Clarke, 2012), reporting that mothers’ explanations about their child’s mental health diagnoses and needs were denied or ignored by some of the school staff and accommodations for their child were not made. Mothers participating in this research were specifically asked about their experiences in the education system, which may have influenced their description of issues such as being ignored more than in other studies where they may not have been directly asked about this aspect of the care-seeking journey.
5.2.7. Lack of understanding about mental health needs. The experiences of mothers in the school system illustrated a theme of general lack of understanding about mental health needs of youth, including how best to support the student and parents. This lack of support and understanding is evident in other research studies that describe the mental health care-seeking journeys of mothers (Blum, 2007; Byrne et al., 2008; Stapley et al., 2016). Parents reportedly also experience blame and judgment from educators in the school system (Stapley et al., 2016) and had difficulties informing the staff at the school about the child’s problems because of limited understanding and expected stigma (Byrne et al., 2008).

5.2.8. Disempowered mothering. The theme of disempowered mothering that was experienced by mothers in this thesis project was echoed in the literature, but was often identified as helplessness or powerlessness in other studies (Byrne et al., 2008; Coates, 2016; Harden, 2005; Stapley et al., 2016). The name of this subtheme was changed from the original title of helpless parenting, as I wanted to be cautious about not contributing to further marginalization of mothers or portraying them as helpless. Upon reconsideration I felt that what was considered helplessness in the literature and originally in this thesis was actually demonstrating disempowerment of mothers on a systemic level.

Parents are often challenged with knowing how to discipline their child when their child is depressed and/or self-harming, and the family routine often starts to revolve around the child with mental health issues (Byrne et al., 2008). Mothers in this thesis sample did not speak at length about challenges with disciplining their child, but did
express a sense of lost control and disempowerment in the mothering role due to their daughter’s mood changes and depression symptoms.

Some mothers in this thesis project did speak about changed family routine that had to revolve around their depressed daughter, and expressed concern that they were neglecting their other children and roles, which is also evident in the literature (McDonald et al., 2007; Svensson et al. 2013). Other studies have demonstrated that parents often experience a great deal of worry for their depressed child and can become especially concerned when their child is self-harming (Byrne et al., 2008; Harden, 2005; Stapley et al., 2016). These findings are reflected through the narratives in this research, illustrating that mothers often feel that they have done all they can do to help their daughter and have exhausted all resources, leading to feelings of disempowerment.

5.2.9. Lack of support. Lack of support in the family life was expressed by many of the mothers, especially single mothers, in this thesis project and was also present in the experiences of parents in previously published studies (Blum 2007; Byrne et al., 2008; Clarke, 2012; Francis, 2012a; Stapley et al., 2016). Mothers in previous studies and in this thesis expressed that they felt they were dealing with their child’s issues alone and had challenges with managing the roles of mother, caregiver, advocate, partner, and worker in addition to looking after their depressed child (Francis, 2012a; Stapley et al., 2016). Mothers in this thesis project also discussed some family members’ disapproval in getting treatment for their daughter, or disbelief in the severity of the daughter’s issues, expressing that the child just needed more discipline—a theme appearing in the wider literature as well (Blum, 2007; Clarke, 2012; Francis, 2012a; Stapley et al., 2016).
A theme in previous studies that is not discussed at length in this thesis is challenges to the marriage caused by disagreements over parenting the child with mental health issues (Clarke, 2012; Francis, 2012b; Svensson et al., 2013). Mothers in this thesis did not discuss their marriages in great detail; however, a few mothers noted that they felt that their separation or divorce might have caused them to miss some changes in their daughter’s mental health, and several discussed the lack of paternal involvement in their daughters’ lives and mental health journeys.

Parents in other studies recommended increased parental support (Boydell et al., 2006) and peer support (Byrne et al., 2008) to assist in the care-seeking experience, suggesting a lack of support in their current situation. They thought that more support would be helpful because parents often felt isolated due to expected and/or received judgment and stigma from family and friends, and others in their social circles who they would normally utilize for support (Byrne et al., 2008; Francis, 2012a). This was also evident in many mothers’ narratives in this thesis.

5.2.10. Internalizing blame and feelings of guilt. A pertinent theme in the literature is mothers’ tendency to blame themselves for causing their child’s mental health problems, mostly attributing fault to their own parenting, and feeling like a failure (Blum, 2007; Francis, 2012a; Harden, 2005; Jackson & Mannix, 2004; Stapley et al., 2016). This theme was evident in mothers’ narratives in this thesis and was understood in a way that participants were internalizing the blame that they received from outside sources, such as family members and health care professionals.

Some mothers tend to self-blame for issues that are beyond their control, which can affect their own health and wellbeing (Jackson & Mannix, 2004). Mothers in this
thesis and in the current literature report feelings of guilt and self-blame that their child was suffering and had not received appropriate support or treatment sooner (Blum 2007; Byrne et al., 2008; Harden, 2005; Hoskins & Lam, 2001). Participants in other studies (Francis, 2012b; Harden, 2005; Smith & Estefan, 2014; Stapley et al., 2016) also blamed themselves for changes in the family routines resulting from their depressed child, which was not a major finding in this thesis but could be linked to the sub-theme of disempowered mothering. Several mothers in this thesis project experienced tension and distress from these feelings of internalized blame and guilt at certain points along their journeys.

5.2.11. Questioning professional treatment. When mothers speak about instances of becoming empowered in the care-seeking journeys, a theme that appeared in several narratives and in the literature (Blum, 2007; Harden, 2005) is mothers’ questioning and challenging of mental health professionals. Mothers in Blum’s (2007) study challenged health professional’s medication dosages for their child when they noticed that their child was experiencing negative effects, and they also critiqued psychiatric knowledge and practice after doing their own research (Harden, 2005). Mothers in this thesis and parents in Harden (2005)’s study expressed concerns to health providers about their child’s hospital care and treatment. However, Harden (2005)’s findings showed that parents sometimes chose to take their child off medication when they found conflicting information between doctors and through their own research, which was a theme that was not expressed by the mothers in this thesis.

5.2.12. Advocating and fighting for appropriate care. Mothers in this thesis were strong advocates for their daughters and fought for proper care when their daughters
were not receiving it. This advocacy role is present in previous research as well (Blum 2007; Boydell et al., 2006; Clarke, 2013). Mothers managed their child’s medication effects and appointments and did their own research on treatment and medications, as found in two other studies (Blum, 2007; Clarke, 2013). Advocating was considered a facilitator for care, sometimes resulting in decreased wait periods and greater access to services (Blum, 2007; Boydell et al., 2006; Clarke, 2013). This finding was also reflected in mothers’ experiences through this narrative study.

5.2.13. Actively resisting blame. The finding that mothers actively resisted blame from the mental health system was only located in one other study (Blum, 2007). Mothers advocated and researched about the best options for care for their child and were thus able to actively defend their child’s issues and need for treatment as well as their own choices they made as mothers (Blum, 2007). This was exemplified throughout mothers’ narratives of becoming empowered in the mental health system.

5.2.14. Advocating and educating about mental health. Mothers in this thesis became empowered through advocating not only in the mental health system, but also in the education system, in order to ensure that appropriate accommodations and supports were in place for their daughters. This finding was also present in the literature (Blum, 2007; Boydell et al., 2006; Clarke, 2013). Mothers acted as “vigilantes” in the education system, advocating and educating staff in order for their child to receive appropriate services in school (Blum, 2007, p. 212). Thus, mothers’ advocating efforts in the education system were often able to facilitate their child’s care (Boydell et al., 2006; Clarke, 2013), which was a theme reflected in this thesis when mothers found alternatives or collaborated with staff at their daughters’ school.
5.2.15. Finding alternatives. Mothers in this thesis study became empowered in the education system through finding alternatives to regular public school and either advocating for their daughter to attend an Alternative Education program or begin homeschooling or tutoring. This finding was also present in Clarke (2013)’s study where mothers found alternatives to public school, such as Catholic or private school, when their child’s mental health needs were not being met or their child was too overwhelmed in the school social environment.

5.2.16. Collaboration and flexibility. The theme of collaboration and flexibility of the child’s school was in contrast to what is shown in Blum’s (2007) study that explores mothers’ experiences seeking mental health care and accommodation for their child in the education system. Blum (2007) found that mothers experienced a lack of collaboration and flexibility even when they became advocates in the education system, and always faced tensions between themselves and those working at their child’s school. Mothers in this thesis did experience tension, but they also spoke about collaboration and flexibility, which normally referred to the efforts made by educators in the alternative education program rather than the public school, as an aspect of their empowerment and a facilitator in the care-seeking journey.

5.2.17. Turning point: re-examining maternal role. As mothers in this thesis re-examined their maternal role, they shifted the main responsibility of management and care for the depression to their daughter and became empowered through their journeys in consciously releasing a certain level of control. This theme also arose in other studies where mothers released some control over managing their child’s condition and treatment as their child developed and aged (Francis, 2012a; Harden, 2005).
In Harden (2005)’s study, parents “renegotiated the parental caregiving role” (p. 219) through acceptance of the condition, integration of the condition into the family life, and entrusting their child to take some responsibility to manage their depression themselves, which were processes similarly expressed by several mothers in this thesis project. In another study, mothers of adolescent girls with eating disorders also re-examined their roles and eventually allowed their daughters to take most of the responsibility to guide themselves towards recovery (Hoskins & Lam, 2001). Once mothers in this thesis felt that they had done all they could to help their daughter, the re-examination process often occurred and they ultimately recognized their daughter’s central role in the pathway towards mental health.

5.2.18. Understanding daughters’ mental health needs. One way that the mothers in this sample became empowered was through gaining knowledge about their daughter’s depression and needs. Mothers in another study (Hoskins & Lam, 2001) also spoke about this process which was connected to a turning point, in that mothers learned through their own research and experience what they could do to best support their daughters on their journey towards mental health.

5.2.19. Communication. This finding differs from what is evident the literature, where several mothers in this thesis explained how communication with their daughter and other family members became stronger throughout the care-seeking journey. Previous literature suggests that most mothers experience communication challenges with their depressed child, such as the child becoming withdrawn from the parent or the parent not knowing how to discipline and talk to their child with depression (Byrne et al., 2008; Stapley et al., 2016). In Stapley et al. (2016)’s study, a lack of communication between
parent and child concerning what the child was experiencing led to parents’ feelings of helplessness. Findings from other studies suggest that parents wanted more open communication (Byrne et al., 2008) and began to question their relationship with their child when they found out that the child hadn’t told them about depression and self-harm (McDonald et al., 2007). Mothers in this thesis did not describe a communication breakdown, although it may have happened along some of their journeys, but rather focused on aspects of the journey where their connection with their daughter and others in their family was strengthened by open communication.

5.2.20. Influence of social class and capital. Mothers in this thesis had differences in social class and capital, as shown through their indication of household income in relation to the size of their family in Table 1. However, their stories were still connected through the overarching themes of marginalization and loss of control or becoming empowered, and the examples of each. This is also shown in Blum (2007)’s study where mothers in the sample differed greatly in social and cultural capital but still shared several similar experiences accessing care for their child.

Examples of similarities in the experiences of all mothers in the sample regardless of social class were receiving blame, being ignored and frustrated with people working in the education system, and feeling disempowered in the mothering role. They also shared experiences of advocating and educating so that their daughters received appropriate treatment and accommodations, as well as speaking up and questioning professionals about their daughters’ care and how their daughters were being treated.

Mothers’ narrative summaries also suggest ways in which their experiences might differ based on social class, which is a similar finding by Lareau (2003). Some mothers in
this thesis discussed paying for private counseling for themselves and their daughter while their daughter waited for a specialist appointment to arrive, or paying for a private tutor when their daughter could not go to school. Instances such as these could suggest differences in mothers’ experiences based on socioeconomic status, where some mothers’ did not have the same options for care as others. Thus there are some differences among mothers’ experiences, but overall there were significant similarities and patterns that could be traced to all mothers’ stories.

5.3. Participants’ Recommendations

The third overarching theme in the findings section entitled hope for the future compiled the main recommendations from mothers for improving the system’s functioning and easing the depression care-seeking journeys. This overarching theme was divided into three subthemes entitled consistency, collaboration, and education. These subthemes represented the recommended changes at the provincial mental health and education systems level that mothers felt would facilitate the journeys of mothers and daughters and provide evidence for the development of higher quality supports and services. Mothers in previous research studies have made similar recommendations for improving the system in other contexts, and these will also be included and discussed in this section.

5.3.1. Consistency. Mothers all spoke about the benefits of more consistency in mental health care, and most spoke about how it was in issue in their province. One mother, Tanya, was very satisfied with the consistency of care in her province and expressed numerous times the helpfulness of the consistency factor of care in the journey. This included having services in one building, having service providers be consistent and
reliable in contacting patients for appointments or rescheduling, and offering parental support that was consistent and timed appropriately with the child’s support. Conversely, some of the issues with continuity of care in other mothers’ narratives included lack of availability of mental health providers in the school and health settings, long wait periods where daughters would not have any supports in place, and not being contacted or called back by mental health professionals after trying to self-refer or trying to schedule appointments.

Another research study suggests that parents judge the quality of mental health services on the service providers’ commitment to helping their child and finding the appropriate treatment for them, as well as the service provider’s availability to help and their communication with parents (Widmark et al., 2013). This is related to the mothers’ recommendations in this sample, where they expressed that consistency and continuity of care was a major area for improvement at the provincial level.

5.3.2. Collaboration. Mothers in this thesis recommended better collaboration and improved integration between service providers and parents, and between systems such as education and health that would lead to a more efficient and holistic approach to their daughter’s depression treatment. There were differences in information and care approaches between the health and education systems, and in many cases mothers felt that their daughter’s health providers were not communicating with one another or were not communicating with their daughters’ school in any way, meaning that the mother had to advocate and educate in both the mental health and education system.

This discord between the health and education systems was also evident in the literature (Blum 2007) where mothers reported that neither system wanted to take on
more responsibility than they felt they had to for providing appropriate services and early intervention efforts for mental health. The need for better integration and collaboration of services was also expressed in Boydell et al. (2006)’s study were parents in rural communities explained that this would assist in access and care for their child’s mental health challenges. The literature suggests that parents advocate for stronger links between health care providers working in the mental health care system as well, as another way that parents judge the quality of these services is by the perceived communication and coordination that is occurring within the system (Widmark et al., 2013).

5.3.3. Education. Mothers’ recommendations all included emphasis on the need for increased education about youth mental health, symptoms, causes, and options for services and care. They wanted this education for health care providers, educators and others working in the school system, as well as the general public. This recommendation for more education was linked to their perception of the need for decreased stigmatization of youth mental health issues and the need for treatment, better availability of resources for parents and families about the options available for help, improved early intervention efforts, and more sympathetic and supportive approaches of health care providers and educators.

Mothers in other research studies also made the recommendation for better youth mental health education (Boydell et al., 2006; Byrne et al., 2006; Highet et al., 2005; Stapley et al., 2016). Findings from Highet et al. (2005) suggest that community mental health education could be delivered through schools and health care organizations so that there is an increased understanding among the public about depression effects on youth and options for treatment. Another study also suggested that schools could serve as
the starting point for mental health education, as well as creation of simplified online resources (Stapley et al., 2016).

Parents in another study recommended that information and education on self-harm should be available at health centers, as they often had challenges in understanding why it was happening and what they could do or where they could go to get help for their child (Byrne et al., 2008). As was shown in this thesis and reflected in the literature, the parenting role in the care-seeking journey is made more difficult by the lack of general knowledge about youth mental health, its symptoms, and the supports available (Highet et al., 2004). This lack of education is linked to a multitude of preventable roadblocks, such as mothers being blamed, their concerns being dismissed, and lack of support, that mothers face with their daughters along their care-seeking journeys.

5.4. Contributions & Directions

One of the expected contributions of this research is to improve understanding among health care professionals, educators, and the general public through presentations of the care-seeking journeys of Atlantic Canadian mothers who have a daughter with depression. This research could lead to greater awareness of the barriers that mothers face when seeking care and support, and influence preventative measures for the future. It highlights the need for health care professionals and educators to involve the mother and family in the youth’s care in a more collaborative, supportive, and sympathetic process. I am hopeful that this will help to influence systemic changes in terms of health care providers' and educators’ approaches to care with children, youth, and their parents and other caregivers.
A limitation of this research is that it did not include mothers of daughters who did not have a depression diagnosis but self-identified with depression, as inclusion criteria was for mothers of daughters with a formal depression diagnosis only. Participants from the ACCESS-MH study whose daughters self-identified with depression may have been in the process of seeking diagnosis and treatment for their daughter and could have offered differing views on the care-seeking experience.

Another limitation of the study was that I was not able to conduct the interviews, although I did conduct many others in the larger ACCESS-MH study. One of the markers of validation in qualitative research is prolonged engagement in the field (Creswell, 2013), which I have had through two years of experience with the ACCESS-MH study and with interviewing mothers and other participants. I have also had prolonged engagement with the data used in this thesis and with the journey mapping tools. I believe that it did not have a great influence on my interpretation of the narrative journeys of these mothers as I utilized many other methods to ensure rigour, but it is an important point of consideration. It was important in this thesis project that mothers’ accounts were taken at face value where the facts they presented were considered truths in their journeys, which means that there is trust that their stories would be fairly consistent independent of interviewer characteristics.

Another limitation of this research is that the transition from the child and youth mental health system to the adult system was not discussed, as most participants’ daughters hadn’t made the transition yet. Mothers’ narratives did not focus on this aspect of the journey but it may have offered more information on some of the challenges that mothers faced. Also, the impact of anxiety and the daughters’ other mental health
conditions, as well as various other features present in mothers’ narratives, could not be incorporated in order to constrain the scope of this thesis.

A final limitation was that some participants in this thesis project were interviewed three years ago, suggesting that the present experience with care could differ in some ways from how it was at the time of these interviews. However, the literature remains consistent in illustrating mothers’ challenges seeking care for a child with mental health issues.

One of the strengths of this thesis is that it addresses the dearth of research on mothers’ experiences with care-seeking for a child with depression, specifically within Atlantic Canada. It outlines the major issues that mothers face and includes their personal recommendations, inviting their unique voices and experiences to be heard. It contributes novel findings to the depression journeys and treatment literature in Atlantic Canada.

The contextual element is another strength, where data was collected in participants’ real-world settings such as their homes or workplaces, and includes in-depth analysis through the use of visual and interview methods. The contextual feature of this research presents mothers’ and daughters’ journeys as interconnected and holistic as they occur in the participants’ lives. The journey maps provided a visual portrait of the interconnectedness of the depression care-seeking process illustrating the barriers, facilitators, institutions, and key individuals that mothers and daughters encounter when seeking care.

Another strength of this research is that it was a part of the larger ACCESS-MH study, which helped to facilitate connections and recruitment to a wide variety of participants. It also meant that I was able to receive training and experience working with
qualitative research, and data collection and analysis materials were already developed and readily available. My work in recruiting, planning, and conducting interviews with parents, youth, and service providers for the ACCESS-MH study enhanced my understanding of the Atlantic Canadian mental health system through this multi-vocal approach. These rich experiences and opportunities prepared me to write this thesis using a critical narrative approach, as I gained multiple perspectives on the Atlantic Canadian mental health system and was able to understand and appreciate the power of these stories.

5.5. Dissemination of Findings

A summary of the findings for the larger ACCESS-MH study will be sent to participants. I aim to publish and present this research at various conferences related to mental health and education. The ACCESS-MH study provides online information about the thesis projects that are a part of the study and also distributes information through videos and written publications. Distribution at this level also occurs with appropriate decision-makers and government officials, which is intended to assist with dissemination of the research report.

5.6. Future Research

The findings of this thesis suggest several other areas of possible exploration for future research. The findings of this thesis were separated in two of the overarching themes (marginalization and loss of control, and becoming empowered) by mothers’ experiences in the mental health system, education system, and family life. One suggestion for future research would be to explore the experiences of mothers in each of these social institutions separately. As mothers in this thesis discussed in their interviews
their experiences with each system in great detail, it could not all be included in this thesis and separate studies would likely be ideal for more in-depth analysis of the subthemes.

Thus three qualitative studies could be conducted that would involve completing interviews and journey maps with mothers about the different branches of the depression-care seeking journeys. The first would explore their experiences seeking depression care for their daughters in the mental health system, the second would explore their experiences seeking care for daughters in the education system, and the third would explore the ways in which the depression care-seeking journey affects the role of mothers and their connection to other family members.

As some of the mothers’ interviews were conducted three years ago, it would be beneficial to revisit the journeys of these mothers through a second interview to see if and how their care-seeking journeys with their daughters have changed. The second phase of the longitudinal ACCESS-MH study will conduct a second round of interviews with many participants, and I would suggest following up with the participants whose interviews were used in this thesis research. Researchers can revisit the mothers’ journeys that they had explained in their initial interview and re-examine their journey maps with participants. They can then ask participants what aspects of the journey have changed or stayed the same as well as what types of barriers and facilitators exist in their journeys at present if they are still ongoing.

Another suggestion for future research would be an exploration of the experiences of mothers of daughters who are self-diagnosed with depression and in the process of receiving a diagnosis, to see how their experiences differ or coincide with
those of the mothers in this thesis. The narratives and experiences of mothers of daughters diagnosed only with depression and no other diagnoses would also be an area of interest and need, in order to illustrate differences and similarities with those presented in this thesis project. A final suggestion for future research is to examine fathers’ experiences in the care-seeking journeys to explore the ways in which their roles can be increased and valued, so that they can assist in moving towards more supportive and less divided parenting roles.

5.7. Conclusion

The seven narrative journeys that were presented in this thesis illustrated the experiences of mothers and their daughters with seeking and accessing mental health care for their daughters’ depression in Atlantic Canada. The participants’ journeys in this thesis narrate the ways in which mothers experience loss of control in areas along the care-seeking journey while also becoming and remaining empowered in other areas. By drawing on critical and feminist theories to conduct narrative and thematic analysis, the narrative summaries, visual journey maps, and theme webs exemplified three main themes. These themes were marginalization and loss of control, becoming empowered, and hope for the future with unique examples of the first two themes in the mental health system, education system, and family life. The power dynamics that mothers and daughters experienced within social institutions were the focus within the analysis.

Mothers’ narratives in this thesis detailed the ways in which they were marginalized and lost a certain level of control in their interactions with others as they sought care for their daughters’ depression. Examples of this theme include receiving blame from the mental health system, being ignored in the education system, and
experiencing a lack of support in the family life. Conversely, it also shows how mothers fought to become empowered in the journey, through examples such as questioning professional treatment in the mental health system, advocating and educating about mental health in the education system, and communication in the family life. Mothers’ narrative journeys also showed that they maintained hope for the future through their three recommendations of consistency, collaboration, and education that they felt would facilitate depression care-seeking journeys.

It is hoped that this thesis will influence greater understanding of the challenges that mothers face, give insight into the ways in which support and care for mothers of young daughters with depression can be improved, and provide evidence for the importance of adhering to a streamlined child and youth mental health system. This thesis contributes to the dearth of depression literature in the Atlantic Canadian context and the relative lack of research valuing mothers’ voices and experiences. It is hoped that it will lead to changes in the mental health and education systems that promote empowerment, rather than marginalization and blame, of mothers whose daughters experience depression.

One mother’s quotation exemplifies the positive outlook that the participants maintained through the varied challenges they faced. It is my hope that this thesis will decrease the setbacks that mothers spoke of and promote more consistent and steady steps forward. Zoe’s quotation wonderfully illustrates these mothers’ strong-willed mindsets that helped them through obstacles and kept their focus on the journey ahead: “Through every year she lives, she gains another skill in order to help herself. And as
long as we're moving forward with a few little steps backwards, that, you know, we're still moving forward.”
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Appendix A: Parent Recruitment Poster

HAS YOUR CHILD’S LIFE BEEN TOUCHED BY MENTAL HEALTH CHALLENGES?

DO YOU HAVE A CHILD BETWEEN 5 AND 18 YEARS OLD WHO IS EXPERIENCING: ANXIETY, DEPRESSION, AUTISM SPECTRUM DISORDERS, CONDUCT DISORDER, OR EATING DISORDERS?

DO YOU WANT TO TELL YOUR STORY?

CALL OR SEND AN EMAIL TO:

Brandi Bell
1-855-861-5127 (toll free) or brandi@upei.ca

We are gathering stories from parents/guardians in PEI, NB, NS, and NL whose children are making journeys through the mental health system. People don’t often have the chance to hear from parents and guardians on this topic.

"Should you choose to participate, any information you share will be kept confidential"

For more information on the project, contact Dr. Kate Tilleczek (902-620-5127 or ktilleczek@upei.ca).

The Research Ethics Boards of UPEI, UNB, SMU, and MUN have approved this research project. 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</th>
<th>REB</th>
<th>Contact Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>PEI</td>
<td>UPEI</td>
<td></td>
<td>(902) 620-5104, <a href="mailto:reb@upei.ca">reb@upei.ca</a></td>
</tr>
<tr>
<td>NB</td>
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<td></td>
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<td>SMU</td>
<td></td>
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</tr>
<tr>
<td>NL</td>
<td>Health Research Ethics Authority (MUN)</td>
<td></td>
<td>(709) 777-6974, <a href="mailto:info@hrea.ca">info@hrea.ca</a></td>
</tr>
</tbody>
</table>
Appendix B: Interview Checklist

ACCESS-MH Patient Journeys - Checklist

Prior to the interview
- Digital recorder (in full working order) [take 2 if available]
- Digital camera (in full working order)
- Extra batteries
- Receipt book
- Honoraria, child care & travel costs (if applicable and prearranged)
- Participant ID code (put on Face Sheet and say into recorder at beginning of interview) [get this from Brandi]
- Consent/Assent forms (x2 – one copy for us, one for participant)
- Face Sheets (x2 – one copy for participant to follow if needed, one to be filled in; both to be returned)
- Interview protocol
- Journey Mapping Kit
- Certificate of Volunteer Participation (if applicable – for child/youth & parent/guardian participants)
- List of Services (if applicable – for child/youth & parent/guardian participants)

After the interview
- According to the participant’s consent form, take photographs of their images and journey map.
- For child/youth and parent/guardian participants: Enter the participant’s name on the Certificate of Volunteer Participation and give document to participant.
- For child/youth and parent/guardian participants: Provide them with the List of Services.
- For child/youth participant: Provide honorarium and applicable travel or child care costs and have them sign the receipt book.
- For parent/guardian participant: Provide any applicable travel or child care costs and have them sign the receipt book.

Return to local field coordinator
- Digital recorder(s)
- Digital camera
- Journey Mapping Kit
- Signed consent form
- Extra consent forms
- Completed Face Sheet
- Extra Face Sheets
- Receipts for honoraria, child care, and/or travel payment
Appendix C: Parent Interview Protocol

Parent Patient Journeys Interview – Time I

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 child’s life when you first felt they would need support for their mental health? (family, school, friends, community, spiritual, other)
   - What happened next? (probe with each of family, school, friends, community, spiritual, etc.)
   - 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 your child? (at all levels- ACCESS and CARE)
   - What would you have liked to have seen happen? (at all levels)
     - What kind of support do you wish had been available in the beginning? (e.g., more information on support services or wait times, financial support, people to talk to, etc.)
     - What would you do differently?

B) Entering the system (or not)
   - After this initial phase, what happened when you and your child were looking for support for their mental health? (family, school, friends, community, spiritual, other)
   - What happened next? How long did you wait? What did you 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?
   - What care services were available to you? How were those services coordinated? Was there any repetition in what was offered (redundancy)? How do you think services could be improved?
     - Did you pay for any services? Are you willing to pay for a better or faster service? How much?

C) Exits and Returns
   - Were there any times in which your child left the system? Why? What happened?
   - Did your child return? Why, how, what happened?
D) Recommendations and Directions (prospective)

- If you could speak to family doctors (therapists, teachers, other parents, kids, others) what would you like them to know about your child’s journey?
- If you could make three recommendations for fixing the youth mental health system, what would they be?
  - What services should be provided? Which services should be redesigned to work better for you?
- 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 D: Parent Consent

ACCESS-MH Patient Journeys - Parent 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/](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 child’s journey with mental health. Prior to the interview, you will be asked to find 3-5 visual images that you feel represent your child’s 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/your child’s 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 child’s 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 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 or your child’s 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:

<table>
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</tbody>
</table>
## Consent

<table>
<thead>
<tr>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>I agree, or give consent, to participate in an interview</td>
<td></td>
</tr>
<tr>
<td>I agree, or give consent, 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 consent, to being audio-recorded as part of this study</td>
<td></td>
</tr>
<tr>
<td>I agree, or give consent, to have my selected images photographed as part of this study</td>
<td></td>
</tr>
<tr>
<td>I agree, or give consent, 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 consent, 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 consent, 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
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: _______________________________________________
Appendix E: Parent Face Sheet

ACCESS-MH Patient Journeys - Parent/Guardian 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? ___ under 22 ___ 22-30 ___ 31-40 ___ 41-50 ___ 51-60 ___ 61+

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
Part 2 – ABOUT YOUR FAMILY AND HOUSEHOLD

What is your marital status?

__ single  __ married  __ common-law relationship
__ separated  __ divorced  __ widowed
__ other. Please specify: ________________

How many children do you have? ____________

How old is/are your son(s)? ____________  daughter(s)? ____________

How often do your children live with you?

__ full-time
__ 50% of the time
__ on weekend and holidays
__ other amount. Please specify: ________________
__ do not live with me

Who is/are the individuals directly involved in the raising of your child(ren)? Check as many as apply. If parents are the same gender, check twice.

__ 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)
__ maternal grandmother  __ maternal grandfather
__ paternal grandmother  __ paternal grandfather
__ maternal aunt  __ maternal uncle  __ maternal cousins
__ paternal aunt  __ paternal uncle  __ paternal cousins
__ other. Please specify: ________________

How many of your children have experienced mental health challenges? ____________

Are any of your children participating in this study?

__ yes; How many? ____________
__ no
__ not sure
In which of the following categories does your household income fall?

__ less than $10,000
__ $10,000 to less than $20,000
__ $20,000 to less than $30,000
__ $30,000 to less than $40,000
__ $40,000 to less than $50,000
__ $50,000 to less than $60,000
__ $60,000 to less than $70,000
__ $70,000 to less than $80,000
__ $80,000 to less than $90,000
__ $90,000 to less than $100,000
__ $100,000 or more
__ no income
__ declined

Part 3 – ABOUT YOUR EDUCATION AND WORK

Do you currently have a job? ___ yes ___ no

If 'yes':
Where do you work? ________________________
Job title: ________________________
How long have you been in this position? _________

What are your current educational qualifications? (check as many as apply)

__ High School diploma
__ Trade School
__ College diploma/Some university education
__ Undergraduate university degree
__ Graduate degree (please specify degree/major): ________________________
__ Other graduate degree (please specify degree/major): ________________________
__ None of the above
Part 4 – ABOUT MENTAL HEALTH
Do you have a child (or have care of a child) with a formal diagnosis from a health professional (e.g., psychiatrist, psychologist) for a mental health condition? ____ Yes ____ No
If ‘yes’, what is/are your child’s diagnosis(es)? (check as many as apply)

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Date Received (month/year)</th>
<th>To what extent does this mental health condition create problems for your child in everyday life?</th>
</tr>
</thead>
<tbody>
<tr>
<td>__Anxiety</td>
<td></td>
<td>Not at All</td>
</tr>
<tr>
<td>__Depression</td>
<td></td>
<td>Not at All</td>
</tr>
<tr>
<td>__Autism spectrum disorder</td>
<td></td>
<td>Not at All</td>
</tr>
<tr>
<td>__Conduct disorder</td>
<td></td>
<td>Not at All</td>
</tr>
<tr>
<td>__Eating disorder</td>
<td></td>
<td>Not at All</td>
</tr>
<tr>
<td>__Other (please specify):</td>
<td></td>
<td>Not at All</td>
</tr>
</tbody>
</table>

If ‘no’, do you have a child who currently SELF-IDENTIFIES as having any of the following mental health conditions? And since when has your child self-identified with the condition? (check as many as apply)

<table>
<thead>
<tr>
<th>Condition</th>
<th>Since (month/year)</th>
<th>To what extent does this mental health condition create problems for your child in everyday life?</th>
</tr>
</thead>
<tbody>
<tr>
<td>__Anxiety</td>
<td></td>
<td>Not at All</td>
</tr>
<tr>
<td>__Depression</td>
<td></td>
<td>Not at All</td>
</tr>
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<td>__Autism spectrum disorder</td>
<td></td>
<td>Not at All</td>
</tr>
<tr>
<td>__Conduct disorder</td>
<td></td>
<td>Not at All</td>
</tr>
<tr>
<td>__Eating disorder</td>
<td></td>
<td>Not at All</td>
</tr>
<tr>
<td>__Other (please specify):</td>
<td></td>
<td>Not at All</td>
</tr>
</tbody>
</table>
Have you paid for any care services for your child’s mental health? __ yes __ no
If yes, approximately how much have you paid in total? ____________

Would you be willing to pay for:
   faster services? __ yes __ no
       Why or Why Not?
       __________________________ __________________________
       __________________________ __________________________
       __________________________ __________________________
If yes, how much? _________

   better services? __ yes __ no
       Why or Why Not?
       __________________________ __________________________
       __________________________ __________________________
       __________________________ __________________________
If yes, how much? _________

THANK YOU FOR COMPLETING THIS FORM!
Appendix F: Certificate of Volunteer Participation

Certificate of Volunteer Participation

Name: __________________________ Date: ________________

Thank you for your volunteer participation in our research project *Barriers and Facilitators in Access to Child/Youth Mental Health Services*. Volunteers are the backbone of social science research; without you, we could not do our work.

We are sincerely grateful for the time you have dedicated to our project. You have willingly shared your experiences with us and helped us to ask informed questions of other young people in Atlantic Canada. We hope that the opportunity has been as valuable to you as it was to our research team.

You have been part of an important and ground-breaking research project. The information you have shared has provided valuable insight regarding the impact that mental health conditions have on children, caregivers, service providers (e.g., health, education, social development), and society. This information will help educators, government, and communities develop programs and policies to enhance the life experiences of young people.

Thank you again for your time and expertise. We trust that your future employers and educators will also see the value in your volunteer work with us. We will keep you informed about the work we are doing and invite you to visit our website to learn more at [http://access-mentalhealth.ca/](http://access-mentalhealth.ca/).

Sincerely,

Kate Tilleczek, PhD
[katetilleczek.ca](mailto:katetilleczek.ca)
Professor and Canada Research Chair
Director, Young Lives Research – UPEI
Research Scientist (Adjunct)
Hospital for Sick Children, Toronto, Canada
Appendix G: Interview Debriefing Script

ACCESS-MH Patient Journeys - Interview Debriefing Script

That is all the questions that I have for you. Do you have anything else you like to add or any questions for me?

Thank you very much for sharing your journey with me. It is very important to us that we hear from children, youth, parents and service providers to learn more about what it is like for children and youth to experience mental health challenges and the mental health system.

[consult completed consent form]

Before you leave, I am going to take photographs of the images you brought and of your journey map (according to consent). [take photos]. Would you like to take your images with you or should I keep them?

We know that talking about these things can be difficult. Here is a list of resources in case you’d like to talk to someone. [provide laminated card with list of resources tailored to province, including local CMHA information]

Thanks again for your time. Here is a Certificate of Volunteer Participation (for child/youth and parent participants) and some compensation for your time/funds to cover your costs. [provide certificate; have participant sign receipt and then provide cash]

We will send you information about the study at a later time according to what you put on your consent form. In the meantime, if you (or your parents) ever have any questions about the research, feel free to contact us using the information on the copy of the consent forms that you (and your parents) have.
Appendix H: Prince Edward Island Resource Cards

<table>
<thead>
<tr>
<th>ACCESS-MH: Resources on PEI</th>
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</tr>
</thead>
<tbody>
<tr>
<td><strong>Please call 911 in the case of an emergency.</strong></td>
<td><strong>Please call 911 in the case of an emergency.</strong></td>
</tr>
<tr>
<td><strong>Kids Help Phone:</strong> 1-800-668-6868</td>
<td><strong>Kids Help Phone:</strong> 1-800-668-6868</td>
</tr>
<tr>
<td><strong>Website:</strong> kidshelpphone.ca</td>
<td><strong>Website:</strong> kidshelpphone.ca</td>
</tr>
<tr>
<td>Find More: <a href="http://www.kidshelpphone.ca/ResourcesAroundMe/Canadian">www.kidshelpphone.ca/ResourcesAroundMe/Canadian</a> Mental Health Association - PEI</td>
<td>Find More: <a href="http://www.kidshelpphone.ca/ResourcesAroundMe/Canadian">www.kidshelpphone.ca/ResourcesAroundMe/Canadian</a> Mental Health Association - PEI</td>
</tr>
<tr>
<td><strong>Phone:</strong> (902) 566-3034</td>
<td><strong>Phone:</strong> (902) 566-3034</td>
</tr>
<tr>
<td>Websites: pei.cmha.ca</td>
<td>Websites: pei.cmha.ca</td>
</tr>
<tr>
<td>pei.cmha.ca/mental-health/find-help/Island Help Line</td>
<td>pei.cmha.ca/mental-health/find-help/Island Help Line</td>
</tr>
<tr>
<td><strong>Phone:</strong> 1-800-218-2885 (Toll-Free)</td>
<td><strong>Phone:</strong> 1-800-218-2885 (Toll-Free)</td>
</tr>
<tr>
<td>McGill Community Mental Health Centre</td>
<td>McGill Community Mental Health Centre</td>
</tr>
<tr>
<td><strong>Phone:</strong> (902) 368-4911</td>
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</tr>
</tbody>
</table>

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<tr>
<td><strong>Website:</strong> kidshelpphone.ca</td>
<td><strong>Website:</strong> kidshelpphone.ca</td>
</tr>
<tr>
<td>Find More: <a href="http://www.kidshelpphone.ca/ResourcesAroundMe/Canadian">www.kidshelpphone.ca/ResourcesAroundMe/Canadian</a> Mental Health Association - PEI</td>
<td>Find More: <a href="http://www.kidshelpphone.ca/ResourcesAroundMe/Canadian">www.kidshelpphone.ca/ResourcesAroundMe/Canadian</a> Mental Health Association - PEI</td>
</tr>
<tr>
<td><strong>Phone:</strong> (902) 566-3034</td>
<td><strong>Phone:</strong> (902) 566-3034</td>
</tr>
<tr>
<td>Websites: pei.cmha.ca</td>
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