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Predictors of Engagement in Community-Based Therapy for Youths with Mood and Anxiety Disorders

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A thesis submitted in partial fulfillment of the requirements for the Master of Science degree in Epidemiology and Biostatistics

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Abstract

The First Episode Mood and Anxiety Program (FEMAP) aims to identify and treat youths with mood and anxiety disorders. This thesis sought to identify factors associated with engagement in FEMAP, based on extensive data collected by FEMAP researchers. A logistic regression model was built from candidate variables using purposeful selection. Of the 366 participants offered treatment, 87% engaged in FEMAP. Quantity of alcohol consumed per occasion, gender, and anxiety sensitivity were found to be significant predictors of engagement. Gender and anxiety sensitivity interacted with each other such that at low anxiety sensitivity levels, the odds of engaging in FEMAP was higher for females than for males. At high anxiety sensitivity levels, the odds of females engaging was less than that of males. FEMAP may use this information to identify individuals who are less likely to engage in treatment to facilitate improved engagement.

Keywords

Engagement, adherence, mood disorders, anxiety disorders, major depressive disorder, bipolar disorders, youths, mental health treatment, community-based treatment

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Table of Contents

Abstract.....	i
Acknowledgments.....	ii
Table of Contents.....	iii
List of Tables.....	vii
List of Figures.....	viii
List of Appendices.....	ix
Chapter 1.....	1
1 Introduction.....	1
1.1 Research Aim.....	1
1.2 Thesis Layout.....	1
Chapter 2.....	2
2 Background.....	2
2.1 Mental Disorders.....	2
2.1.1 Mood Disorders.....	2
2.1.2 Anxiety Disorders.....	4
2.2 Prevalence and Impact.....	4
2.2.1 Worldwide Prevalence.....	4
2.2.2 Canadian Prevalence.....	5
2.3 Treatment.....	6
2.4 Engagement.....	7
2.5 Literature Review.....	9
2.5.1 Definitions of Engagement in Therapy.....	9
2.5.2 Engagement and Treatment Outcomes.....	11

2.5.3	World Health Organization Framework	11
Chapter 3	27
3	Methods.....	27
3.1	First Episode Mood and Anxiety Program	27
3.1.1	FEMAP Eligibility Criteria.....	28
3.1.2	Previous FEMAP Research.....	29
3.1.3	Innovation II.....	31
3.2	Current Research Study	32
3.2.1	Research Objectives.....	33
3.2.2	Population	33
3.2.3	Variables	33
3.3	Statistical Analysis.....	43
3.3.1	Univariate Analysis.....	43
3.3.2	Missing Data	43
3.3.3	Associations Among Covariates	45
3.3.4	Multivariable Analysis.....	46
3.3.5	Model Fit and Diagnostics	48
3.4	Summary.....	49
Chapter 4	50
4	Results	50
4.1	Sample Characteristics.....	50
4.2	Missing Data	52
4.3	Cronbach's alpha results.....	52

4.4	Univariate Analyses	52
4.5	Associations Among Covariates	55
4.5.1	Associations Among Continuous Covariates.....	55
4.5.2	Associations Among Categorical Covariates.....	55
4.5.3	Associations Among Continuous and Categorical Covariates	56
4.6	Purposeful Selection of the Logistic Regression Model.....	57
4.7	Model Fit and Diagnostics	59
4.7.1	Assessing Linearity Assumption.....	59
4.7.2	Goodness of Fit.....	60
4.7.3	Outliers and Influential Observations	61
4.7.4	Multicollinearity	62
Chapter 5	63
5	Discussion	63
5.1	Summary of Study Findings	63
5.1.1	Descriptive Results	63
5.1.2	Univariate Results.....	64
5.1.3	Multivariable Results	64
5.2	Study Strengths	66
5.3	Study Limitations.....	66
5.4	Recommendations for Future Research	68
5.5	Study Implications and Contributions	70
5.6	Conclusion	70
References	71

Appendices.....	86
Curriculum Vitae	94

List of Tables

Table 3.1 FEMAP Innovation II Data Collection Schedule	32
Table 4.1 Sample Characteristics (N = 366).....	51
Table 4.2 Results of Questionnaire Imputation	52
Table 4.3 Univariate Analyses	54
Table 4.4 Final Logistic Regression Model.....	58
Table 4.5 Odds Ratio Estimates and Confidence Intervals.....	58
Table 4.6 Multicollinearity	62

List of Figures

Figure 3.1 FEMAP Pathway	28
Figure 4.1 Odds Ratio comparing females to males	59
Figure 4.2 Linearity of ASI-R.....	60
Figure 4.3 Outlying and Influential Points	61

List of Appendices

Appendix A Descriptive Statistics – Age	86
Appendix B Descriptive Statistics – Ethno-racial Background	86
Appendix C Descriptive Statistics – Parental Education	87
Appendix D Descriptive Statistics – Parental Marital Status	87
Appendix E Descriptive Statistics – Marijuana Use	88
Appendix F Descriptive Statistics – Other Illicit Drug Use	88
Appendix G Descriptive Statistics – Tobacco Use	89
Appendix H Descriptive Statistics – Quantity of Alcohol Consumption	89
Appendix I Descriptive Statistics – Satisfaction with Previous Mental Health Care	90
Appendix J Descriptive Statistics – Trauma History	90
Appendix K Associations Among Continuous Covariates (Pearson Correlation Coefficient)	90
Appendix L Chi-square Tests of Association Among Categorical Covariates (p-value).....	91
Appendix M Between group differences in g Continuous and Categorical Covariates (t-tests)	92

Chapter 1

1 Introduction

Mood and anxiety disorders are common chronic disorders in Canada affecting much of the population. Many mood and anxiety disorders have their onset in youth, a time of important life transitions.

The First Episode Mood and Anxiety Program (FEMAP) is a community-based treatment center designed to address the needs of youth. FEMAP conducts outreach, identification and treatment. Part of the treatment protocol included the collection of extensive information including demographic factors and outcome measures such as illness severity and functioning levels.

The proportion of engagement in mental health treatment amongst youth varies widely. An understanding of the characteristics that differ among engagers and non-engagers is not agreed upon in the literature though such information could allow treatment providers to identify those likely not to engage and implement strategies to improve engagement.

1.1 Research Aim

The research aims are as follows:

1. To calculate the proportion of patients who are offered treatment at FEMAP and engage in treatment.
2. To investigate the predictors of engagement in treatment using logistic regression.

1.2 Thesis Layout

The chapters are laid out as follows: chapter two provides background information on mental illness, treatment, engagement and a review of predictors of engagement from the literature; chapter three describes FEMAP, the program from which the data were obtained, and the study methods; chapter four describes the study results; and chapter five concludes with a discussion of the research findings.

Chapter 2

2 Background

2.1 Mental Disorders

The World Health Organization (WHO) defines mental health as “a state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community” (World Health Organization, 2012, p. 12).

Conversely, mental illnesses or mental disorders include a wide range of conditions that affect mood, thinking, or behaviours and are associated with substantial distress and impaired functioning (Government of Canada, 2006). Examples of mental illnesses include mood, anxiety, and psychotic disorders such as depression, bipolar disorder, obsessive-compulsive disorder, post-traumatic stress disorder, schizophrenia, eating disorders, and addictive behaviours. Mental illnesses can occur at any age; however, half have their onset in childhood and early adolescence and three quarters occur by age 24 (Kessler et al., 2005).

2.1.1 Mood Disorders

Mood disorders are mental illnesses that encompass depressive disorders and bipolar disorders.

2.1.1.1 Depressive Disorders

Major depressive disorder (MDD), defined by the occurrence of at least one major depressive episode (MDE), is a type of depressive disorder. An MDE is characterized by a depressed mood or loss of interest or pleasure in most activities for a period of at least two weeks, and at least four other symptoms experienced most of the day nearly every day. These symptoms include a change in sleep, appetite, or weight, impaired concentration, feelings of guilt or worthlessness, and thoughts of suicide (American Psychiatric Association, 2013). MDD has three severity levels: mild, moderate, and severe. The level of severity is determined by the number and severity of symptoms and

the degree of functional impairment. MDD is often a chronic and episodic illness with repeated episodes having the potential to occur throughout one's lifetime. Within five years, 60% of those who have experienced a first MDE have a recurrent episode (Mueller et al., 1999). Furthermore, recurrent episodes become more likely with an increase in the number of past episodes (Hardeveld, Spijker, De Graaf, Nolen, & Beekman, 2010; Mueller et al., 1999; Solomon et al., 2000).

Dysthymic disorders are another type of depressive disorder. They are characterized by a depressed mood most of the day, and for the majority of days for at least two years, or an irritable mood for at least one year for children and adolescents only. At least two of the following additional symptoms must be present: poor appetite, overeating, insomnia, hypersomnia, low energy, fatigue, low self-esteem, poor concentration, difficulty making decisions, or feelings of hopelessness (American Psychiatric Association, 2013).

2.1.1.2 Bipolar Disorders

Bipolar disorders are another type of mood disorder consisting of episodes of mania with or without MDEs. Manic episodes are characterized by an elevated or irritable mood persisting for at least one week. At least three other symptoms must be present and may include increased self-esteem, decreased need for sleep, increased talkativeness, and distractibility (American Psychiatric Association, 2013). There are two subtypes of bipolar disorder. Bipolar I disorder requires the occurrence of at least one manic episode and often involves MDEs, though these are not required for a bipolar I diagnosis. Bipolar II disorder is characterized by instances of MDEs and hypomanic episodes (American Psychiatric Association, 2013). Hypomanic episodes are characterized by the same symptoms as manic episodes; however, the duration requirement is only four days, and the episode is not severe enough to cause impaired functioning (American Psychiatric Association, 2013). Even more so than MDD, bipolar disorders are episodic. Over 90% of individuals will experience recurrent episodes (Langlois, Samokhvalov, Rehm, Spence, & Connor Gorber, 2011). Bipolar disorders are chronic illnesses that require long term management (Yatham et al., 2013). Age of onset generally occurs between ages 19 and 23 (Chengappa et al., 2003; Perlis et al., 2004).

2.1.2 Anxiety Disorders

Anxiety disorders are characterized by excessive and irrational worrying and may include the following symptoms: fatigue, headaches, muscle tension, muscle aches, difficulty swallowing, trembling, sweating, or hot flushes. Anxiety disorders include social anxiety disorder (also called social phobia), panic disorder, and generalized anxiety disorder. Social anxiety disorder involves a persistent fear of social and performance situations in which embarrassment may occur (American Psychiatric Association, 2000). Panic disorder is characterized by the occurrence of panic attacks followed by at least one month of concern about having subsequent panic attacks (American Psychiatric Association, 2000). A panic attack is a period of intense fear or discomfort with at least four of the following additional symptoms present: heart palpitations, chest pains, nausea, trouble breathing, shortness of breath, chills, hot flushes, trembling or shaking, feeling dizzy, faint or lightheaded, numbness or tingling sensation, feeling detached from oneself, feelings of unreality, fear of losing control, or fear of dying. Generalized anxiety disorder involves excessive worrying about day to day events for a period of at least six months that is difficult to control. At least three of following symptoms must also be present: restlessness, feeling on edge, easily fatigued, difficulty concentrating, irritability, muscle tension, or sleep disturbances (American Psychiatric Association, 2000). Onset of anxiety disorders occurs early in life, typically childhood or adolescence, depending on the specific disorder (Canadian Psychiatric Association, 2006; Kessler et al., 2005).

2.2 Prevalence and Impact

2.2.1 Worldwide Prevalence

In 2001, the WHO estimated that approximately 450 million people were suffering from a mental illness (World Health Organization, 2001b) and that number had risen to 615 million by 2013 (World Health Organization, 2016b). Mental illnesses are the leading cause of disability worldwide (World Health Organization, 2016a).

Worldwide, suicide is the second most common cause of death among young people (World Health Organization, 2013). Depression is among the largest single cause of disability worldwide (Whiteford et al., 2013; World Health Organization, 2013).

Furthermore, mental illnesses may be experienced at a young age and disrupt important life transitions (Ratnasingham, Cairney, Rehm, Manson, & Kurdyak, 2012).

2.2.2 Canadian Prevalence

In Canada, the burden of illness from mental disorders is extremely high. One in five Canadians will experience a mental illness in their lifetime (Smetanin, P., Stiff, D., Briante, C., Adair, C., Ahmad, S., & Khan, 2011). Furthermore, one in seven Canadians used health services for mental illnesses during 2009 to 2010 (Public Health Agency of Canada, 2015). In Ontario, the burden of mental illness and addictions exceeds that of all cancers (Ratnasingham et al., 2012). It has been estimated that by 2030, mental health issues will be the leading cause of disability in Canada (Mathers & Loncar, 2006).

Mood and anxiety disorders are the most prevalent mental illnesses. The burden of depression is higher than the combined burden of four major cancers: lung, colorectal, breast, and prostate (Ratnasingham et al., 2012). The annual prevalence of mood and generalized anxiety disorder was estimated based on the 2012 Canadian Community Health Survey (CCHS). Individuals aged 15 and over were sampled and asked whether they had been diagnosed with a mood or anxiety disorder by a health professional. The 12-month prevalence of major depressive disorder, bipolar disorders, and generalized anxiety disorder were 4.7%, 1.5%, and 2.6%, respectively. The prevalence of depression was stratified by age and sex. The one-year prevalence in females was 9.0%, 6.8%, 5.6%, and 1.8% for age groups 15 to 24 years, 25 to 44 years, 45 to 64 years, and 65 years and older, respectively. In males the prevalence is consistently lower in each age group. The one-year prevalence was 5.3%, 4.1%, 3.4%, and 1.4% in each respective age group. For both males and females, the prevalence is highest amongst those aged 15 to 24 years (Pearson, Janz, & Ali, 2013).

Anxiety and depressive disorders are often comorbid conditions. Approximately one quarter (24.9%) of Canadians with past year MDD also reported generalized anxiety disorder (Patten et al., 2015). Another study in the United States (US) found that 21% of adults with MDD also had an anxiety disorder, but of those with anxiety, 48% also had

MDD (Gwynn et al., 2008). Worldwide, estimates of any comorbid anxiety disorder with past year MDD range from 48.0% to 53.3% (R. C. Kessler et al., 2015).

Each of MDD, bipolar disorders, and anxiety disorders are associated with an increased risk of suicide. The rates of suicide are between 10 and 20 times higher for those with MDD, bipolar disorder, or anxiety disorder compared to the general population (Canadian Psychiatric Association, 2006; Langlois et al., 2011; Patten et al., 2015; Yatham et al., 2013).

2.3 Treatment

Treatment for mental illnesses typically includes psychotherapy and pharmacotherapy. Alternative therapies include exercise therapy, light therapy and relaxation techniques such as yoga or meditation (Cooney et al., 2013; Cramer et al., 2008; Perera et al., 2016). Psychotherapy involves interactions between the therapist and patient outside of the use of medication. Currently, cognitive behavioural therapy (CBT) is the most common psychotherapy treatment with abundant evidence supporting its use (Harrington, Whittaker, Shoebridge, & Campbell, 1998; James, James, Cowdrey, Soler, & Choke, 2015; Scaini, Belotti, Ogliari, & Battaglia, 2016). CBT can be delivered by different practitioners such as a psychiatrist, psychologist, social worker, or other mental health care providers; and in different formats e.g. individual, group, or self-directed (Canadian Psychiatric Association, 2006). Pharmacotherapy uses medications to treat illness and can include antidepressants, anti-anxiety medications, or mood stabilizing medications, amongst others.

For individuals who are not responsive to psychotherapy or pharmacotherapy, electroconvulsive therapy (ECT) and repetitive transcranial magnetic stimulation (rTMS) are therapeutic options (MacQueen et al., 2016). ECT involves the delivery of electric pulses to the brain causing a generalized seizure while the patient is anesthetized, which can alleviate the symptoms of MDD and other mental illnesses. rTMS delivers magnetic pulses to the brain that can change the activity of the brain cells and improve the symptoms of mental illness (Barker, Jalinous, & Freeston, 1985; Croarkin et al., 2010;

George et al., 2010) in similar ways to ECT, but without the need for anesthesia or a generalized seizure.

Both the Canadian Network for Mood and Anxiety Treatments (CANMAT) and the Canadian Psychiatric Association (CPA) provide practice guidelines for the treatment of mood and anxiety disorders, produced by assembling effectiveness and safety information on available treatments (Antony et al., 2006; Kennedy et al., 2016; MacQueen et al., 2016; Parikh et al., 2016; Yatham et al., 2013).

Though efficacious treatments exist for mood and anxiety disorders, adolescents' engagement with and adherence to those treatments is low.

2.4 Engagement

The terms engagement and disengagement are used in the literature with varying meanings and conceptualizations. Often engagement, adherence, and compliance are used interchangeably, and none of these terms have standard definitions or a standard way of measuring them.

Adherence is used to describe the degree to which medical instructions are followed and appointments are attended. The WHO defines adherence to long term therapy as “the extent to which a person’s behavior – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider” (De Geest & Sabaté, 2003, p. 17). Taking prescribed medications and attending clinical appointments are frequently considered measures of adherence. The timeframe for measuring adherence ranges from short, measured in weeks, to long, measured in years.

Compliance is used in a similar manner to adherence but the term compliance has a negative connotation when applied to patients' uptake of health care. The term invokes images of patients passively following directions laid out for them (Vermeire, Hearnshaw, Van Royen, & Denekens, 2001). Furthermore, the term compliance may even carry the implication that the patient was coerced into treatment (Vuckovich, 2010).

Engagement is used to refer to a more complex process of involvement with health services. In the literature, the concepts of engagement and disengagement in mental health treatment have been defined in several different ways. Dixon et al. state that the goal of engagement is to “develop a trusting relationship between the treatment team and the client. Engagement is successful when a client identifies the program as his or her service provider” (Dixon, Krauss, Kernan, Lehman, & DeForge, 1995, p. 685). Mowbray et al. define engagement as “the first stage which must be completed before clients can successfully move into the stages that follow: persuasion, active treatment, and relapse prevention” (Mowbray, Cohen, & Bybee, 1993, p. 338). Hall et al. measured aspects of engagement including appointment keeping, client-therapist interaction, communication/openness, client perceived usefulness of treatment, collaboration with treatment, and compliance with medication (Hall, Meaden, Smith, & Jones, 2001). O’Brien et al. define engagement as a “complex phenomenon encompassing factors that include acceptance of a need for help, the formation of a therapeutic alliance with professionals, satisfaction with the help already received, and a mutual acceptance and working towards shared goals” (O’Brien, Fahmy, & Singh, 2009). The definition provided by MacBeth et al. is similar: engagement is a “multifactorial concept that encompasses the acceptance of the treatment, therapeutic rapport and collaborations towards a shared goal of both functional and clinical recovery” (MacBeth, Gumley, Schwannauer, & Fisher, 2013). Similar to adherence, engagement can be measured by attendance at clinical appointments. The timeframe for measuring engagement also ranges from short, measured in weeks, to long, measured in years. Perhaps the key feature distinguishing adherence from engagement in these definitions is that taking prescribed medications is rarely the sole marker of engagement by researchers in mental health therapy.

The definition of engagement in this thesis is most closely aligned with that of Mowbray, in which engagement is “the first stage which must be completed before clients can successfully move into the stages that follow: persuasion, active treatment and relapse prevention” (Mowbray et al., 1993, p. 338). Engagement is the first step towards the acceptance of treatment, formation of a therapeutic alliance, and adherence to therapy.

2.5 Literature Review

The literature was searched using the terms adherence, nonadherence, compliance, non-compliance, engagement, disengagement, and dropout specifically for adolescents and young adults undergoing treatment for mood and anxiety disorders. The search was conducted in PubMed and PsycINFO databases, limited to English publications, observational studies thus excluded randomized controlled trials, and had no date restrictions. As discussed earlier, these terms represent overlapping concepts that are used synonymously in the literature. Given the significant overlap in the concepts, the varying definitions, and the similarity amongst predictors, we will discuss the adherence and engagement literature as a whole. When referencing specific studies, we will use the term cited by the original author (adherence, engagement, or compliance). The findings of this literature review pertain to youth experiencing mood and anxiety disorders, not necessarily a first-episode, treated in both in- and out-patient settings. Studies focused on adults were not included. The goals of the literature review were 1) identify different approaches to defining engagement in therapy for youth diagnosed with mood and anxiety disorders and 2) identify predictors of engagement in therapy for youth with mood and anxiety disorders, interpreting the findings using the WHO framework on adherence.

2.5.1 Definitions of Engagement in Therapy

2.5.1.1 Medication Adherence

Studies that assessed medication adherence used a variety of measures, such as blood tests, requiring patients to bring in medication bottles to conduct pill counts, self-reported adherence by the patient or guardian, provider reported adherence, the Medication Adherence Rating Scale (Lucca, Ramesh, Parthasarathi, & Ram, 2015), and retrospective review of inpatient medication records (Timlin, Hakko, Riala, Räsänen, & Kyngäs, 2014). The thresholds for adherence to medication also vary in the mental health literature. Poor medication adherence has been defined as 10 or more missed medication doses (Coletti, Leigh, Gallelli, & Kafantaris, 2005) or as taking prescribed medication less than 25% of the time (DelBello, Hanseman, Adler, Fleck, & Strakowski, 2007; Patel,

DelBello, Keck, & Strakowski, 2005). Partial adherence has been defined as taking medication 25% to 75% of the time and full adherence as taking medication more than 75% of the time (DelBello et al., 2007; Patel et al., 2005; Timlin et al., 2014). Others have defined full adherence as taking medication at least 80% of the time (Fontanella, Bridge, Marcus, & Campo, 2011; Stewart & Baiden, 2013). Others defined full adherence as those who answered “yes” (Pogge, Singer, & Harvey, 2005) or “all the time” (Munson, Floersch, & Townsend, 2010) when asked whether they take their medication as prescribed. Subjective measurement of adherence such as self-report are subject to recall bias though one study used a shorter time frame to minimize recall bias (Coletti et al., 2005).

It has been shown that providers overestimate adherence and patients who report nonadherence more accurately describe their behaviour than those who claim adherent behaviour (De Geest & Sabaté, 2003). Furthermore, the dichotomization of medication adherence at a given level has been criticized as artificial because the percent of the medication dose may not correspond to a biological cut-off due to continuous dose-response relationships (De Geest & Sabaté, 2003).

2.5.1.2 Engagement in Psychotherapy

Treatments that involve psychotherapy have used terms such as “compliance”, “engagement”, and “follow-through”. When a patient unilaterally chooses to stop treatment without the agreement of the therapist, for reasons other than symptom improvement, it has been referred to as dropout, noncompliance, or disengagement (Baruch, Gerber, & Fearon, 1998; de Haan, Boon, Vermeiren, Hoeve, & de Jong, 2015; Ghaziuddin, King, Hovey, Zaccagnini, & Ghaziuddin, 1999). Measurement methods employed in the aforementioned studies included medical record review or telephone interview with the patient or guardian. Studies that used a telephone interview differed on the timing of the interview after initial engagement. Interviews took place three months after discharge from hospital (Granboulan, Roudot-Thoraval, Lemerle, & Alvin, 2001), six to eight months after discharge (Ghaziuddin et al., 1999), or between 90 days and 18 months post-discharge (Pogge et al., 2005). In some studies, the length of time between

initial treatment and measurement of engagement was not given (Baruch et al., 1998; de Haan et al., 2015).

In the literature, proportions engaging (i.e. engagement, adherence, or compliance) in therapy ranged from 33% to 78% (Coletti et al., 2005; de Haan et al., 2015; DelBello et al., 2007; Fontanella et al., 2011; Ghaziuddin et al., 1999; Granboulan et al., 2001; King, Hovey, Brand, Wilson, & Ghaziuddin, 1997; Laurier, Lafortune, & Collin, 2010; Moses, 2011; Munson et al., 2010; Pelkonen, Marttunen, Laippala, & Lönnqvist, 2000; Stewart & Baiden, 2013; Timlin et al., 2014). Variations in definitions and measurements may account for the wide range of proportions. This idea is consistent with de Haan et al.'s 2013 study investigating reasons for the large variations in dropout percentages found in child and adolescent mental health treatment. They identified two factors, study design and definition of dropout (de Haan, Boon, de Jong, Hoeve, & Vermeiren, 2013). Study design refers to whether a study was an efficacy study (experimental study design) or an effectiveness study (observational study design) (de Haan et al., 2013).

2.5.2 Engagement and Treatment Outcomes

Despite differences in the definition and measurement of engagement, there is agreement that it is an important part of efficacious treatment. Poor adherence to treatment is associated with poorer outcomes such as increased risk of relapse and increased hospitalization (Bobier & Warwick, 2005; Fontanella et al., 2011).

Understanding factors that are associated with engagement may help treatment providers identify those most likely to disengage before it occurs, and to develop strategies to help patients remain engaged, complete treatment, reach full remission, and reduce the possibility of relapse.

2.5.3 World Health Organization Framework

The World Health Organization (WHO) published a 2003 report entitled 'Adherence to long-term therapies: evidence for action'. In the report, the authors' focused on defining adherence, reviewing adherence rates and reviewing factors that affect adherence for nine

chronic conditions. In the report, the WHO authors specify a framework for understanding adherence that consists of five dimensions, 1) social and economic, 2) health care team and system-related, 3) condition-related, 4) therapy-related, and 5) patient-related factors. The framework is used to organize the factors that affect adherence for all chronic illnesses and although the framework is not specific to mental illness, depression is one of the nine chronic illnesses reviewed. (De Geest & Sabaté, 2003). The WHO framework is a useful guide to a review of the literature on factors that influence adherence to mental health therapies amongst youth.

2.5.3.1 Social and Economic Factors

The WHO dimension of social and economic factors includes socioeconomic status, illiteracy, low level of education, unemployment, lack of effective social support networks, long distance from treatment center, and high cost of medication. For some of these factors the mechanism that explains the relationship to adherence is straightforward, for example high cost of medication may reduce adherence for youth from low income families. The mechanism for other factors is less clear.

Age

In the WHO framework, age is considered a social and economic factor. It is unclear how age may affect adherence. Age is a marker for developmental stage. For those at younger ages, it may signal a lack of independence and reliance on parents for the means to attend therapy. Age may also signal the maturity level, knowledge and beliefs about therapy that may influence adherence. The literature is mixed on whether or not age is a predictor of engagement. Some studies have identified younger age as a predictor of engagement (de Haan et al., 2015; Fontanella et al., 2011; Pelkonen et al., 2000). Though Pelkonen et al. investigated individuals who were accepted to treatment but never attended compared to those who were accepted and attended treatment, there was no association with age (Pelkonen et al., 2000). Others have found that older age is associated with engagement (Baruch et al., 1998; Munson et al., 2010; Stewart & Baiden, 2013), whereas some studies found no association (Coletti et al., 2005; Granboulan et al., 2001; King et al., 1997; Moses, 2011). The ages of youths in these studies ranged from 12 to 24 years,

Gender

Despite prevailing belief that female patients are more compliant with mental health treatment, gender has rarely been found to be associated with adherence to mental health treatment. In fact, a study conducted at a Dutch Youth Mental Health Care Center found that male gender was associated with adherence (de Haan et al., 2015). Interestingly, most studies found no association between gender and engagement (Baruch et al., 1998; DelBello et al., 2007; Fontanella et al., 2011; Ghaziuddin et al., 1999; Granboulan et al., 2001; King et al., 1997; Moses, 2011; Munson et al., 2010; Pelkonen et al., 2000; Stewart & Baiden, 2013). The studies did not distinguish between gender and sex, and did not specify how data were obtained. For example, studies did not collect information on biological sex in addition to gender and likely assumed 100% overlap between the two. The term gender is used because the mechanism used to explain engagement is likely socio-cultural (gender) rather than biological (sex).

Ethno-racial Background

The WHO report states these findings about ethno-racial background: “Race has frequently been reported to be a predictor of adherence, regardless of whether the members of a particular race are living in their country of origin or elsewhere as immigrants. Often, cultural beliefs are the reason behind these racial difference, but no less often, social inequalities confound these findings” (De Geest & Sabaté, 2003, p. 42). Different cultures may have different health beliefs that can influence adherence. For example, some cultures may attach a large degree of stigma to mental illness. Individuals from certain ethno-racial backgrounds also face significant social and economic disadvantages, for example as members of a minority group, immigrants, or non-native English-speakers, all of which could reduce the quality and effectiveness of health services and influence adherence. Several studies investigated either race or ethnicity as a predictor of adherence for youths with mood and anxiety disorders. The majority did not find a significant association (DelBello et al., 2007; Ghaziuddin et al., 1999; King et al., 1997; Moses, 2011; Munson et al., 2010; Patel et al., 2005). Three studies did find an association between ethno-racial background and adherence. Ethnic minority status predicted continuation versus dropout from a community-based program in England (Baruch et al., 1998). The association was small but significant. In a Dutch study the

opposite result was found; for adolescents an ethnic minority status was a predictor of dropout, defined as leaving treatment without agreement of the treatment-provider (de Haan et al., 2015). Similarly, a US-based study compared adherence in non-Hispanic white patients to minorities and found that non-minority race was a strong predictor of adherence to antidepressant treatment (Fontanella et al., 2011). Differences in levels of acculturation across the studies may influence findings. Health system factors influencing the affordability of treatment may also have resulted in divergent findings.

Socioeconomic Status/Parental Education

It is important to note when investigating the influence of socioeconomic status (SES) on adherence, that SES may be measured in a variety of ways including income, occupation, education or a combination of these measures. SES may be a marker of the affordability of therapy, and this differs by health system. Public financing of mental health services means these may be provided for free at the point of care, otherwise services may require fees. A high cost at the point of care would make individuals with lower SES less likely to adhere to treatment. Even with no cost at the point of care, parents in lower status occupations may have inflexible work schedules and thus may not be available to help youth attend appointments. Alternatively, parental education may correlate with engagement in therapy because advanced education may be a marker of the acceptability of therapy. Previous research indicated that parents have the capacity to influence adherence behaviours. Coletti et al. found a relationship between parent perceptions of effectiveness of medication and missed medication (Coletti et al., 2005). A low SES has been associated with nonadherence in previous studies (de Haan et al., 2015; DelBello et al., 2007; Pelkonen et al., 2000). These studies used parental education level and occupation and did not report parental income. De Haan et al. conducted their investigation in the Netherlands. SES was determined using the Dutch National Centre for statistic information and classified using two variables, parent's highest level of occupation and highest level of parent education, each categorized into three levels. Only parental occupation was associated with dropouts. Those with parents in the highest occupation level had the fewest dropouts, and those with parents in the lowest occupation level had the most dropouts. There was no significant association between parental education and adherence (de Haan et al., 2015).

The Four Factor Index of Social Status' education, occupation, sex, and marital status has been used to measure social status (Hollingshead, 1975). A US-based study found an association between low SES, as measured by the Four Factor Index of Social Status, and poor adherence to treatment for bipolar disorder (DelBello et al., 2007). SES in patients in Finland was measured using a scale based on the occupation of the guardian of the adolescent and found dropout was associated with low SES (Pelkonen et al., 2000). Other studies found no association between SES and adherence (Granboulan et al., 2001; King et al., 1997). Granboulan et al. categorized parents' SES into three levels but did not provide additional details. King used parental employment and education similar to de Haan et al. A higher parental education measured in years of education was a strong predictor of commitment to medication treatment in adolescents (Moses, 2011). A study in the US used income as a predictor and found that an annual family income greater than 50,000 USD was associated with adherence (Munson et al., 2010).

Familial Relationships

The nature of familial relationships may influence adherence. Youths in families with positive relationships may have better emotional support or experience less stigma about mental health services, leading to greater adherence to therapy. However, both null and positive results have been found for familial relationships and adherence. Timlin et al. used the clinician-rated Global Assessment of Relational Functioning (GARF), a measure of family functioning, and found significant positive associations between family functioning and adherence (Timlin et al., 2014). Moses used the Multidimensional Scale of Perceived Social Support to measure social and family support. The family subscale ranged from 1.25 to 7, and higher scores were associated with greater commitment to continuing medication in a logistic regression analysis (Moses, 2011). Two studies did not find any association between familial relationships and engagement. When conflict between adolescents and parents was investigated, no association with compliance was found (Granboulan et al., 2001). Nor was an association found between adolescents' perceptions of family functioning measured using the Family Assessment Device and treatment follow-through (King et al., 1997).

Parents' Marital Status

Parental marital status may be related to adherence although the mechanism is unclear. It is possible that parental marital status is a marker of income, the availability of a parent to take youth to appointments, or the nature of familial relationships. Some studies investigated parental marital status and found no association with adherence (Ghaziuddin et al., 1999; Granboulan et al., 2001; King et al., 1997). Ghaziuddin et al. found no relationship between adherence and family living arrangement (biological parent, single parent, biological and step-parent, or non-parent). King et al. found that family caregiver structure (two biological parents, single biological parent, biological and step-parent, or non-parent) was not indicative of adherence in suicidal adolescents (King et al., 1997). In Parisian adolescents following a suicide attempt, parental separation at the time of attempt was not associated with adherence (Granboulan et al., 2001).

Summary

The social and economic factors investigated in the literature included age, gender, ethno-racial background, socioeconomic status and parental education, familial relationships, and parental marital status. The mechanism for how each factor influences adherence is not clear and these may act through multiple, complex pathways. Complex mechanisms may explain the variation in the direction of the results. We did not find studies examining other factors specified in the WHO framework such as distance from the treatment center and cost of medication in this population.

2.5.3.2 Patient-related factors

Patient-related factors have been the focus of many studies. According to the WHO framework, “patients’ knowledge and beliefs about their illness, motivation to manage it, confidence (self-efficacy) in their ability to engage in illness-management behaviours, and expectations regarding the outcome of treatment and the consequences of poor adherence, interact in ways not yet fully understood to influence adherence behaviour.” (De Geest & Sabaté, 2003, p. 44). For example, substance use, forgetfulness, lack of perceived need for treatment, lack of perceived effect of treatment, misunderstanding and non-acceptance of the disease, misunderstanding of treatment instructions, hopelessness

and negative feelings, frustration with health care providers, and feeling stigmatized by the disease may all influence adherence behaviours.

According to De Geest and Sabate, authors of the WHO report, substance use is a patient-related that induces an altered mental state which influences adherence behaviours (De Geest & Sabaté, 2003). Pogge et al. suggest that substance use is a form of self-medication that influences medication adherence because medications may interfere with the rewarding properties of recreational drugs and as a result patients discontinue medication to allow for experiencing the rewarding properties of other substances. The authors also propose that substance use behaviour may reflect a general tendency to reject authority and medical advice (Pogge et al., 2005).

Marijuana Use

Cannabis use defined as any use of cannabis during the 12 months preceding admission has been found to be significantly associated with nonadherence for youth inpatients in adult mental health facilities (Stewart & Baiden, 2013). On the other hand, DelBello et al. did not find an association between adherence and cannabis use disorder (DelBello et al., 2007).

Other Illicit Drug Use

Granboulan et al. found that illicit drug use was associated with improved compliance to post-discharge follow-up care in adolescents who attempted suicide (Granboulan et al., 2001). The measure of illicit drug use was not reported.

Other studies explored the role of substances using a diagnosis of substance use disorder as a predictor and found it to be negatively associated with adherence to mental health treatment (Pelkonen et al., 2000; Pogge et al., 2005). Fontanella et al. investigated the acute and maintenance phases of mental health treatment separately and found that the negative association between substance use disorder and antidepressant adherence was significant only in the maintenance phase (Fontanella et al., 2011).

Tobacco Use

Daily use of tobacco was associated with medication nonadherence in youth inpatients in

adult mental health facilities (Stewart & Baiden, 2013). Granboulan et al. did not find any association between tobacco use and follow-up care in adolescents who had attempted suicide, though the definition and measure of tobacco use was not reported (Granboulan et al., 2001).

Alcohol Use

Stewart et al. investigated the role of alcohol use defined as consumption of alcoholic beverages in the two weeks preceding admission, as a predictor of adherence. Alcohol use was found to be significantly associated with nonadherence for youth inpatients in adult mental health facilities in univariate analyses but did not remain significant when adjusted for other variables (Stewart & Baiden, 2013). DelBello et al. examined adherence using alcohol use disorder as a covariate but the association did not reach statistical significance, though none of the six adolescents with an alcohol use disorder were adherent (DelBello et al., 2007). Granboulan et al. did not find a significant association between follow-up and alcohol use greater than once per week (Granboulan et al., 2001).

Satisfaction with Previous Mental Health Care

Though patient satisfaction with care has been found to be associated with adherence to medical treatment (Marshall & Hays, 1994), no studies were identified that investigated the association between satisfaction with previous mental health services and engagement in current mental health treatment.

Belief About Mental Health Treatment

Positive attitudes and beliefs about mental health treatment have consistently been found to be strongly associated with adherence. Perhaps the consistent findings reflect a more direct pathway from belief about mental health treatment to adherence; patients who have a strong belief about the effectiveness of mental health treatment may be more motivated to adhere to treatment. Pogge et al. measured belief about medication efficacy during phone interviews. Adherence to medications and beliefs about efficacy were significantly correlated (Pogge et al., 2005). Munson et al. measured attitudes about mental health treatment using the adapted Attitudes toward Seeking Mental Health Services (Munson et

al., 2010). Adolescents with positive attitudes were more likely to be fully adherent to treatment.

Self-referral

The allowance for patient self-referral to mental health therapy is a health system factor that differs by country, region and possibly by practitioner. When self-referral is allowed, patient self-referral may serve as a proxy for the patient's motivation in pursuing treatment. Few programs allow youths to self-refer. Most treatment programs require a referral from a health professional, consequently this factor has not been frequently investigated in the literature. Two studies investigated programs that allow for self-referral. The study by Baruch et al. used data from a community-based program in London, England for individuals aged 12 to 25 years that allowed for self-referral (Baruch et al., 1998). Those who self-referred were more likely to continue treatment. In a Finland-based program, initial contact typically began with a telephone call from the adolescent, their parent, or a health care professional (Pelkonen et al., 2000). No differences were found in dropout rates amongst patients referred by a health care professional compared to other referral methods.

Summary

Patient-related factors such as substance use, beliefs about treatment and self-referral have been investigated as predictors of adherence. Belief about mental health treatment has been identified as a significant predictor of adherence in both studies we identified. Other patient-related factors, such as substance use and self-referral had mixed findings.

2.5.3.3 Condition-related factors

Condition-related factors are those related to the particular illness for which treatment is being provided. In the WHO framework, condition-related factors include aspects of the illness such as severity of symptoms, level of disability, availability of treatments, and co-morbid illnesses.

Severity of Illness – Depression

Comorbid depression or depression severity may influence a patient's motivation to

adhere to treatment and attend appointments, and depression can affect memory and other aspects of cognitive functioning. Symptoms of depression may also include social withdrawal and hopelessness resulting in nonadherence behaviours (DiMatteo, Lepper, & Croghan, 2000). Severity of depression has been investigated as a predictor of treatment engagement with mixed results. Amongst Parisian adolescents who had attempted suicide, those with better treatment compliance had higher scores on the Center for Epidemiologic Studies – Depression Scale than their less compliant counterparts (Granboulan et al., 2001). In a study of adolescents with psychiatric illnesses who had been hospitalized, no association was found between severity of illness and post-discharge medication compliance (Ghaziuddin et al., 1999). The adolescents had been diagnosed with depressive disorders, disruptive behaviour, and anxiety disorders; however, the measure used for severity of illness was not indicated. Conversely, Stewart et al. found that higher scores on the Depression Rating Scale were associated with medication nonadherence in adolescents treated in inpatient facilities in Ontario (Stewart & Baiden, 2013). In a study of former adolescent psychiatric inpatients, symptom severity was measured on admission by the patients' primary therapist using the Derogatis Psychiatric Rating Scale. No association was found between symptom severity and adherence (Pogge et al., 2005).

Severity of Illness – Anxiety

A relationship between anxiety and adherence is not well-established with the literature providing mixed results. The mechanism behind a potential association is also unclear although anxiety may affect cognition thus affecting adherence. Higher levels of anxiety as measured on the Zung Anxiety Scale were associated with greater adherence to therapy in adolescents who had attempted suicide (Granboulan et al., 2001), yet in female participants treated with psychotropic medication, anxiety was negatively associated with compliance attitudes and behaviours (Laurier et al., 2010). Fontanella et al. and Ghaziuddin et al. investigated the association of anxiety disorders with medication adherence and found no significant association, nor was an association found by DelBello et al. in adolescents with bipolar disorders (DelBello et al., 2007; Fontanella et al., 2011; Ghaziuddin et al., 1999). Different types of anxiety disorders have very different symptoms which may explain the null results. Some anxiety disorders such as social

phobia may hinder adherence whereas obsessive-compulsive disorder may result in behaviours that improve adherence (DiMatteo et al., 2000).

Functioning

Functioning has been measured using several questionnaires including the Global Assessment of Functioning Scale (GAF) and the Global Assessment Scale (GAS). Functioning may influence adherence via similar mechanisms to disease severity. The GAF is used to report overall functioning by assessing psychological, social, and occupational functioning. Higher scores indicate better functioning. Though no longer endorsed in the Diagnostic and Statistical Manual of Mental Disorders-5 (DSM-5), it was the previously endorsed rating scale in the DSM-IV (Gold, 2014). There is little research on the relationship between functioning and engagement. Baruch et al. found no relationship between GAF scores and adherence in their treatment population (Baruch et al., 1998). Pelkonen et al. investigated the patients' psychosocial functioning using the GAS and found no differences in scores between those who did or did not drop out (Pelkonen et al., 2000).

Summary

Severity of depression, severity of anxiety, and functioning are condition-related factors that potentially influence adherence to therapy although the literature results are mixed.

2.5.3.4 Health-care team and health system related factors

Health system and health care team factors reflect how care is provided and determine the availability of services, length of appointments, reimbursement levels for services and medications, training of providers, availability of multidisciplinary care, and support to caregivers. According to the WHO framework, "The health care delivery system has the potential to affect patients' adherence behaviour. Health care systems control access to care. For example, health systems control providers' schedules, length of appointments, allocation of resources, fee structures, communication and information systems, and organizational priorities" (De Geest & Sabaté, 2003, p. 37). The quality of the health care team can also influence adherence behaviours through the knowledge level of the health

care providers, delivery of care and education to the patient, and the quality of the relationship between patient and physician.

Although health-care team and health system related factors are important, in this literature review we found that factors within this dimension were rarely investigated as predictors of adherence for youth with mental health conditions.

A possible explanation for this lack of research is that cohort studies were conducted in a single center. Investigators focused on one patient population would not have variation in system-level factors. Health system factors were also not investigated in population-based studies, where the opportunity for variation in system-level factors was greater. One potentially important system-level factor is wait time. Longer wait-times may influence engagement if patient's health status, beliefs and attitudes change during the wait period for services.

2.5.3.5 Therapy-related factors

Factors related to the treatment offered and received may affect adherence. According to the WHO framework, the complexity of the medical regimen, duration of treatment, previous treatment failures, frequent changes in treatment, immediacy of beneficial effects, side effects, and availability of medical support to deal with side effects can impact the adherence behaviours of the patient.

Side effects

Side effects have been associated with nonadherence in past studies of inpatients. Rapid weight gain during hospitalization was found to be associated with nonadherence in the treatment of adolescent inpatients (Pogge et al., 2005). Other side effects investigated by Pogge et al. such as dry mouth, memory changes, sleepiness, and akathisia, had no association with nonadherence. Stewart et al. found that youths who reported experiencing past medication side effects were significantly less likely to adhere to treatment (Stewart & Baiden, 2013). Side effects was not investigated as a predictor of adherence in any of the outpatient studies reviewed; however, 30% of noncompliant patients cited side effects as the reason for discontinuing medication (Ghaziuddin et al.,

1999). The number of compliant patients who experienced side effects is not reported so it is unknown whether this is a significant factor that differs among adherence and non-adherent patients. In another study, 32% of participants expressed worries about medication side effects (Moses, 2011).

Medication type

Medication type has been investigated as a predictor of adherence in several studies. Medication type may influence adherence because of side effects that result from different medications, perceived efficacy of some medication over others, or stigma associated with some types of medication. The literature results on medication type are mixed perhaps due to the large number of types of medications included in the studies and the heterogeneity in diagnoses. A prescribed sleep agent was associated with greater adherence in the acute phase of treatment while the type of antidepressant, selective serotonin reuptake inhibitor compared to others, had no association with adherence (Fontanella et al., 2011). In male patients, the use of a mood stabilizer was significantly associated with higher scores on attitudes toward medication (Laurier et al., 2010). The same study found that female patients taking Clonidine had poorer compliance behaviours (Laurier et al., 2010). Another study found that dropping out of treatment early was associated with not receiving a psychotropic medication (Pelkonen et al., 2000). Many studies investigated a potential relationship with type of medication and adherence but did not find significant associations. Ghaziuddin et al. compared each of antidepressants, mood stabilizers, neuroleptics, and tricyclic antidepressants to not taking these medications and found no significant associations with compliance (Ghaziuddin et al., 1999). When adherence to antipsychotics was compared to adherence to mood stabilizers and anticonvulsants no association was found. Nor was an association found between olanzapine, quetiapine, and risperidone (Patel et al., 2005). Pogge et al. also did not find differences in adherence for those prescribed olanzapine compared to risperidone (Pogge et al., 2005).

Summary

Therapy-related factors can only be investigated if the definition of adherence occurs after therapy has taken place and if the therapy was systematically recorded and was fairly constant throughout treatment. Perhaps these limitations explain the lack of studies investigating side effects despite findings that patients justify discontinuing medication because of side effects (Ghaziuddin et al., 1999; Moses, 2011). The findings on medication types are mixed. As previously mentioned, there were several types of medications investigated for several diagnoses and this heterogeneity may explain the lack of consistent findings. Studies investigating other therapy-related factors such as frequent changes in treatment and immediacy of beneficial effects were not found in this literature search.

2.5.3.6 Summary

In the literature, engagement, adherence, and compliance are overlapping concepts that are often considered synonymous. Even when the same term is used, definitions and measurements vary. Due to the similarities amongst the concepts, varying definitions, and varying measures, we have interpreted the literature holistically, summarizing the predictors and the strength and directions of associations.

As discussed earlier, the definition of engagement in this thesis is most closely aligned with that of Mowbray et al., in which engagement is “the first stage which must be completed before clients can successfully move into the stages that follow: persuasion, active treatment and relapse prevention” (Mowbray et al., 1993, p. 338). Engagement is the first step towards acceptance of treatment, formation of a therapeutic alliance, and adherence to therapy. We will use attendance at the initial clinical appointment, given that youth were previously screened and deemed eligible for such an appointment, as an indicator of engagement in FEMAP treatment. We recognize that attendance is only a proxy for engagement in treatment. O’Brien et al. suggest that “whilst physical presence or attendance is necessary, engagement is a more complex phenomenon encompassing factors that include acceptance of a need for help, the formation of a therapeutic alliance with professionals, satisfaction with the help already received and a mutual acceptance and working towards shared goals” (O’Brien et al., 2009, p. 559). Although attendance is

not sufficient for engagement, it is a valid measure, because it is a necessary condition of engagement.

We have found that engagement research largely focuses on the patient-related and social and economics dimensions. Demographic variables such as ethnicity and socioeconomic status are frequently investigated in adherence studies.

We found that system-wide factors are rarely investigated. This is likely because, health care team and system-related factors can only be investigated where there is variation in those factors. This would require multi-center studies so that these factors could be varied systematically. We also found that for single-center studies, authors rarely provided details of relevant system-wide factors, such as the cost of therapy and coverage levels.

We found little consensus on the strength and direction of any of those associations (patient-related, social and economic). The reason for variation in the literature is unclear. It is possible that these factors are not associated with engagement and studies find varying results by chance. However, the studies differed in terms of sample size, treatment setting, and region. Study sample size ranged widely from 32 people to 3,681 people. For cohort studies, the samples sizes ranged from 32 to 352 people (Baruch et al., 1998; Coletti et al., 2005; de Haan et al., 2015; DelBello et al., 2007; Ghaziuddin et al., 1999; Granboulan et al., 2001; King et al., 1997; Laurier et al., 2010; Moses, 2011; Munson et al., 2010; Patel et al., 2005; Pelkonen et al., 2000; Pogge et al., 2005; Timlin et al., 2014) while the two cross-sectional studies included 1,650 people and 3,681 people (Fontanella et al., 2011; Stewart & Baiden, 2013). The majority (9) of studies were conducted in the U.S., two in Canada, two in Finland, and one from each of the UK, The Netherlands, and France. Health system factors undoubtedly vary widely by country; however, health system factors were not reported in each study. Furthermore, the treatment settings included two community-based settings (Baruch et al., 1998; de Haan et al., 2015), one psychiatric in-patient setting (Timlin et al., 2014), one youth care center (Laurier et al., 2010), one adult mental health facility (Stewart & Baiden, 2013), and one study investigated intensive care management though the description of the setting is incomplete (Moses, 2011). Several studies recruited patients

who had been admitted to hospital though none clarified how much of the treatment took place in hospital and post-discharge (DelBello et al., 2007; Ghaziuddin et al., 1999; Granboulan et al., 2001; King et al., 1997; Patel et al., 2005; Pogge et al., 2005). One of the population-based studies did not include the treatment setting other than to say in- and out-patients were included (Fontanella et al., 2011). The remaining studies included only outpatients but the setting (hospital, doctor's office, community or other) was not described (Coletti et al., 2005; Munson et al., 2010; Pelkonen et al., 2000).

Even with the literature search limited to youths receiving treatment for mood and anxiety disorders, the study populations differed in potentially important characteristics which may have influenced findings. Most of the studies included patients aged 12 to 18 years with the exception of Baruch et al. who included ages 12 to 24 years, Coletti et al. included patients from ages 12 to 19 years, De Haan et al. who included patients aged 12 to 20 years, and Pelkonen et al. who included patients aged 12 to 22 years (Baruch et al., 1998; Coletti et al., 2005; de Haan et al., 2015; Pelkonen et al., 2000). Despite knowledge that developmental and social changes continue to occur well into the 20s, few studies included participants in their 20s. Although only mood and anxiety disorders were included there was still variation amongst the diagnoses of the study populations. Two studies included only patients with a depressive disorder (Fontanella et al., 2011; Munson et al., 2010), three included only patients with a diagnosis of bipolar disorder (Coletti et al., 2005; DelBello et al., 2007; Patel et al., 2005), two specified patients with suicidality (Granboulan et al., 2001; King et al., 1997), and the remainder either did not specify the diagnoses or included several diagnoses.

The lack of Canadian studies is evident from the literature review, as is the paucity of data on youth engagement to mood and anxiety disorders treatment in community-based settings.

Chapter 3

3 Methods

This study was a secondary analysis of data collected from the First Episode Mood and Anxiety Program (FEMAP). Ethics approval was obtained from the Research Ethics Board (REB) of Western University for all FEMAP research projects resulting from the collection of data. Pre-specified factors were investigated for their association with engagement in FEMAP.

3.1 First Episode Mood and Anxiety Program

FEMAP is a community-based program in London, Ontario. FEMAP was founded by Dr. Elizabeth Osuch in 2006 in response to the lack of mental health services available to youths. “Adolescent mental health is everybody’s business and nobody’s responsibility” (World Health Organization, 2012, p. 20). This quote encapsulates the state of adolescent mental health in the World Health Organization’s review of international organizations’ initiatives for adolescent mental health between 2000 and 2010. Since 2006, FEMAP has grown to include four psychiatrists, one clinical psychologist, one addictions counsellor, three research staff, and two administrative staff, some of whom are full-time and the remainder are part-time.

During FEMAP’s infancy, outreach was conducted by collaborating with nearby educational institutes including Fanshawe College, the Thames Valley District School Board, the London District Catholic School Board, and the Student Development Centre and Student Health Services at the University of Western Ontario. This was done to make health professionals and potential patients aware of the services offered by FEMAP. FEMAP also worked to reach potential patients by creating a website and pamphlets containing information about mood and anxiety disorders and FEMAP’s services. FEMAP relocated to a renovated house in the community in 2009, providing a less stigmatizing environment (Osuch, Vingilis, Fisman, & Summerhurst, 2016). Previously, FEMAP had been located at University Hospital in London, Ontario. It was thought that

the new community-based, youth-friendly setting would encourage engagement in the program.

3.1.1 FEMAP Eligibility Criteria

FEMAP treats patients aged 16 to 25 years with a suspected or diagnosed mood and/or anxiety disorder. Individuals currently involved with the criminal justice system, those with a major medical illness such as multiple sclerosis or uncontrolled diabetes, significant learning disability, or primary substance abuse problem are excluded from enrollment. Additionally, individuals who have had lifetime medication treatment amounting to more than 18 months are not eligible for treatment in FEMAP.

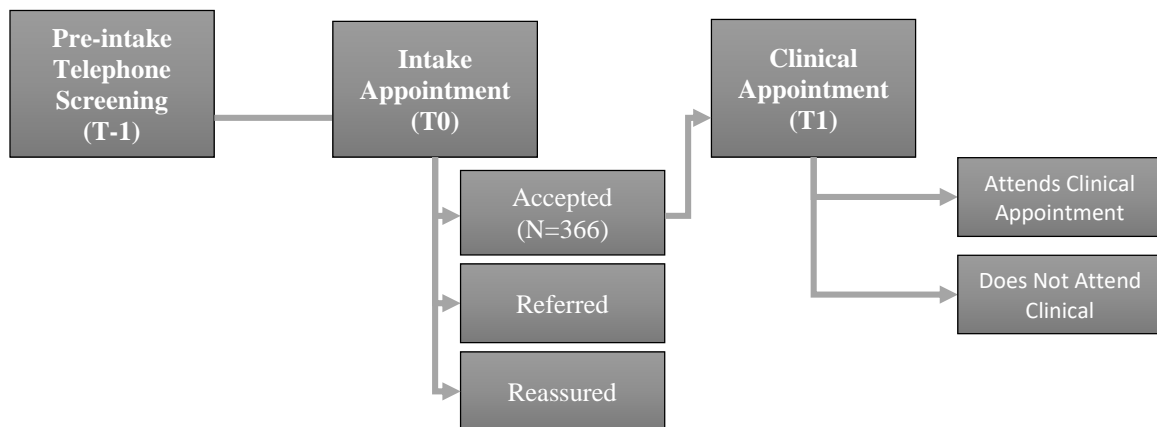


Figure 3.1 FEMAP Pathway

The pathway through care at FEMAP typically begins with a phone call. (See Figure 3.1). Youth, their parent, physician or another health care professional make the initial contact with FEMAP, but ultimately, the FEMAP staff member conducts the pre-intake screening with the youth him/herself. A trained interviewer conducts the pre-intake telephone screening consisting of five-questions and assesses the inclusion and exclusion criteria discussed previously. A licensed clinical social worker then conducts the intake appointment to evaluate the specific needs of the youth, their level of symptom severity and immediacy of need for care, as well as the ways in which symptoms are affecting the youth's life.

Following the intake appointment, a case conference is held with a minimum of two licensed clinicians to determine the best course of action. The youth may be accepted into FEMAP, referred to a more appropriate service, or in rare instances when specialist healthcare services are deemed unnecessary, youth are reassured that no further care is required. Youth are provided with a list of resources and crisis center phone numbers. More recently, as the waiting list for treatment has become longer, some have been provided with recommendations for alternative treatment, such as going to their family doctor, or seeing a psychologist. This option has been reserved for straightforward cases in which no treatment has been previously tried. Other options include contacting the Sexual Assault Center of London, the Prevention and Early Intervention Program for Psychoses, or others. For those accepted into FEMAP, a clinical appointment is scheduled in person or by phone or text. A social worker makes three attempts, each separated by approximately one week, to contact the individual to schedule a clinical appointment. Not all youth accepted into FEMAP engage in treatment by attending the clinical appointment.

3.1.2 Previous FEMAP Research

FEMAP has treated well over 1,000 patients since it began operating in 2006. Through the years, several small projects and larger grant-funded research projects have facilitated data collection to allow for appraising the effectiveness of the program. FEMAP researchers were twice awarded funding from the Academic Medical Organization of Southwestern Ontario (AMOSO) Innovation fund in both 2009 and 2013, hereafter called Innovation I and Innovation II. FEMAP is funded solely by research grants thus all patients in Innovation II partake as research participants. Innovation II study data will be the subject of this thesis; however, findings from previous research on Innovation I are important to understand the FEMAP population and effectiveness of the program.

3.1.2.1 Innovation I

FEMAP previously conducted a formative evaluation of its mental healthcare delivery model to assess whether the program was reaching the target audience and properly implementing intake and assessment processes (Ross, Vingilis, & Osuch, 2012). Ninety-

three participants who arrived at FEMAP during a 12-month period from 2009 to 2010 provided information for that evaluation. Demographic characteristics of the initial population showed that 32% were male, 82% Caucasian, and 71% reported some previous mental health care. FEMAP patients were experiencing significant symptomology. Thirty-nine percent of participants presented with combined depression and anxiety symptoms, 28% indicated primarily depression symptoms, 16% indicated primarily anxiety symptoms, 9% bipolar symptoms, 7% post-traumatic stress disorder symptoms, and 2% alternative or indeterminate diagnosis. Furthermore, the participants were experiencing significantly impaired functioning, missing an average of 2.6 days of school or work per week, and functioning at reduced levels for 4.2 days of the week. Eighty-one percent of patients presented with moderate to severe depressive symptoms and 95% presented with high levels of trait anxiety indicating that the outreach was successful in targeting youths in need of specialty services. Preliminary evaluations of FEMAP demonstrated patients' significant improvements in school, work, and social functioning (Ross et al., 2012).

An additional process evaluation was conducted to again ascertain whether FEMAP was reaching the target population and achieving the desired health outcomes (Osuch et al., 2015). A total of 548 youths arriving at FEMAP between October 2009 and November 2012 consented to participate in the research. Of the 548 youths in the Innovation I cohort, 399 were treated at FEMAP and the remaining 149 were referred to alternative sources of care or, rarely, were reassured only. The treated population was 61% female, 60% arrived without a physician's referral, and 63% had received prior treatment. The breakdown of diagnostic categories was 34% diagnosed with depression and anxiety, 30% diagnosed with a depressive disorder, 16% diagnosed with an anxiety disorder, 10% diagnosed with a bipolar disorder, and remaining diagnoses each comprised less than 5% of the population.

On this previous cohort of patients, FEMAP researchers examined predictors of follow-through for both patients accepted to FEMAP and those who were reassured or referred. Individuals were contacted at least three months following the pre-intake assessment and asked whether they followed-through with their recommended treatment.

Those who answered affirmatively were considered to have followed through. Researchers investigated the association between gender, presumptive diagnosis at intake, lifetime marijuana use, physician referral or no physician referral, accepted versus referred or reassured, parental marital status, the Adult Attention Deficit and Hyperactivity Disorder Self-Report Scale score, and Emotion Regulation Questionnaire score on loss to follow-up. Logistic regression analysis indicated lifetime use of marijuana and having unmarried and non-cohabitating parents was associated with loss to follow-up, whereas contacting FEMAP through a route independent of a physical referral was protective against loss to follow-up (Osuch et al., 2015).

3.1.3 Innovation II

Innovation II is a more recent cohort of FEMAP patients recruited between May 2013 and July 2015. Innovation II differs from Innovation I in that only patients accepted to FEMAP provided follow-up data, but also in the process of delivering care, FEMAP collected information on patients. The wait time between being accepted into FEMAP and having a clinical appointment with a physician varied from 5 to 446 days with a median wait time of 44.5 days. For Innovation I follow-up, all patients who presented to FEMAP were contacted, including those who were referred to other services, but not for Innovation II. In Innovation II, follow-up was conducted only on patients offered treatment. Additionally, questionnaires provided to the Innovation II cohort differ from those previously used. Notably, Innovation II included a trauma history questionnaire, a patient satisfaction questionnaire and the Inventory of College Students' Recent Life Experiences questionnaire to allow investigation of these factors as predictors of treatment outcomes.

3.1.3.1 Data Collection

Innovation II used a structured interview protocol for intake and follow-up procedures. (See Figure 3.1). Data collection for research occurs during the initial brief phone-screening interview, at pre-intake (T-1), at intake (T0), at the clinical evaluation (T1), two months after clinical evaluation (T2), and four months after the clinical evaluation (T3). (See Table 3.1). Participants are asked to complete surveys in person or online

using fillable portable document format (PDF) forms, at different time points (See table 3.1.). The pre-intake questionnaires are generally filled out online using fillable PDF forms, though some participants choose to fill them out on computers at FEMAP.

Table 3.1 FEMAP Innovation II Data Collection Schedule

Questionnaire	Pre-intake Screening T-1	Intake Appointment T0	Clinical Appointment T1	2 Months T2	4 Months T3
Demographics Survey	X*	X [†]			
Inventory of College Students' Recent Life Experiences (ICSRLE)		X			
Trauma History Questionnaire (THQ)		X			
Anxiety Sensitivity Index – Revised 36 (ASI-R)	X	X	X	X	X
Montgomery-Åsberg Depression Rating Scale – Self Report (MADRS-S)	X	X	X	X	X
Adolescent Alcohol and Drug Involvement Scale – Self Report (AADIS)		X			
Short-Form Patient Satisfaction Questionnaire (PSQ)	X*	X [†]			
Sheehan Disability Scale (SDS)	X	X	X	X	X

*Prefix '20' participants only

[†]Prefix '22' participants only

FEMAP participant identifications were prefixed with either a “20” or “22”. The only difference between the two groups of patients was the timing of the questionnaires clarified below. Data on predictors of engagement was taken from the intake (T0) collection time, with the exception of the group of patients with the “22” prefix, for whom the demographic questionnaire and Patient Satisfaction Questionnaire (PSQ) were only available for the pre-intake (T-1) time point. Data on engagement in therapy was taken from clinical records on whether or not the patient attended the clinical appointment (T1). The “20” and “22” participants were otherwise identified and treated identically.

3.2 Current Research Study

Mental health conditions are prevalent among youth. FEMAP offers therapy tailored to youth, based in a community setting with no requirement for physician referral. The goal of the study was to contribute to understanding of the factors that influence engagement of youth in mood and anxiety disorders treatment, specific to a community-based treatment center in Canada

3.2.1 Research Objectives

The research aims are as follows:

1. To calculate the proportion of patients who engaged in FEMAP of those who were offered treatment at FEMAP.
2. To investigate the predictors of engagement in treatment.

3.2.2 Population

Youths with suspected or diagnosed mood or anxiety disorder, meeting FEMAP's treatment criteria make up the study sample. Between May 2013 and July 2015, 400 patients completed the intake process for FEMAP and were either accepted, referred, or reassured only. Of the 400 patients, 366 were accepted into FEMAP and make up the study sample.

3.2.3 Variables

3.2.3.1 Outcome Variable

The thesis is focused on predictors of engagement in therapy for those offered treatment at FEMAP. Much of the research has focused on adherence to treatment amongst youth, whereas little research has investigated engagement in treatment. As noted in chapter 2, adherence and engagement have often been used interchangeably in the literature, and similar factors that distinguish those who adhere to treatment from those who do not also distinguish individuals who engage in treatment from those who do not. Our definition of engagement is aligned with that of Mowbray et al., in which engagement is “the first stage which must be completed before clients can successfully move into the stages that follow: persuasion, active treatment and relapse prevention” (Mowbray et al., 1993, p. 338).

This study will compare individuals who were accepted into FEMAP and engaged in the program to those who were accepted to the program but did not engage. Individuals who arrived for their clinical appointment will be considered engaged in therapy. Individuals offered treatment at FEMAP who did not attend a clinical appointment,

despite attempts to schedule or reschedule an appointment, will be considered not to have engaged in therapy.

3.2.3.2 Explanatory Variables

Innovation II data collection allows for investigating the impact of several variables as predictors of engagement. These variables include age, gender, ethno-racial background, parental marital status, parental socioeconomic status as indicated by parental education level, quantity of alcohol use per occasion, tobacco use, marijuana use, other illicit drug use, self-referral, severity of illness, and functioning. FEMAP data also allow for investigating the impact of additional variables that have not been investigated previously in relationship to adherence or engagement amongst youth. The additional variables include trauma history, satisfaction with previous mental health care, and daily hassles.

Age

FEMAP inclusion criteria required a participant's age to be within 16 to 25 years. Patients were asked for their age in years in the demographics questionnaire. For the analysis, age was categorized into ages 16 to 18 and ages 19 to 25. These categories reflect the groupings used to distinguish adolescent and adult studies in the literature. (See Appendix A.)

Gender

Within the demographics questionnaire, participants were asked to indicate their sex. The options presented were male or female. Although the demographics questionnaire asked for the participant's sex we use the term gender because we expect gender and sex were 100% correlated in the study sample and it is gender that has been investigated for association with engagement in previous studies. As well, the mechanism for the association is likely socio-cultural rather than biological.

Ethno-racial Background

FEMAP collected individuals' ethno-racial backgrounds in the demographics questionnaire. Multiple responses were encouraged as patients were instructed to, "please check all that apply". Response options included Aboriginal (First Nations, Metis, or

Inuit), Latin American (e.g. Argentina, Mexico Nicaragua), East Asian (China, Japan, Korea, Taiwan), Indo-Caribbean (Guyanese with origins in India), South Asian (India, Sri Lanka, Pakistan), Middle Eastern (Egypt, Iran, Israel, Saudi Arabia), South East Asian (Vietnam, Malaysia, Philippines), White Canadian or White American, White European (England, Greece, Sweden, Russia), Black Canadian or African American, or Black African (Ghana, Kenya, Somalia).

The majority of FEMAP's population selected White Canadian or White American or White European and not any other category. Due to the limited sample size of the remaining categories, the ethno-racial variable was recoded into a binary variable. (See Appendix B.) Individuals who selected only White Canadian or White American or White European were grouped together into a "white ethno-racial background" category and anyone who selected anything else was grouped into an "other ethno-racial background" category. The other ethno-racial background category included those who selected mixed ethno-racial backgrounds including those who selected White Canadian or White American or White European and another ethno-racial category.

Socioeconomic Status as indicated by Parents' Education Level

On the demographics questionnaire administered at intake, FEMAP provided seven possible responses for parent's level of education: less than seventh grade, junior high school (9th grade), partial high school (10th or 11th grade), high school graduate, partial college, standard college or university graduation and graduate professional training. FEMAP asked the participants to respond for each of their parents.

For analyses, the responses were recoded to obtain the highest level of education of either parent, consistent with the variable household level of education from the Canadian Community Health Survey (Statistics Canada, 2014). The categories were combined and dichotomized due to the limited sample size. Using the upper cut-off used by De Haan et al., the variable was dichotomized into those with at least one parent having a college or university degree and those with neither parent having a college or university degree. (See Appendix C.)

Parents' Marital Status

The demographics questionnaire asked “What best describes your parents?” and the options were married, separated, divorced, widowed, and common law/unmarried living together. These categories were regrouped into two groups: married (married and common law/unmarried, living together and unmarried) and unmarried (separated, divorced, and widowed). (See Appendix D.) These groupings reflect those used in FEMAP’s previous publication (Osuch et al., 2015).

Substance Use

The Adolescent Alcohol and Drug Involvement Scale – Self-Report (AADIS) is a research and screening tool for adolescent alcohol and drug use. Part A of the survey asks about pattern of use for 13 substances with eight response levels, “never used”, “tried but quit”, “several times a year”, “several times a month”, “weekends only”, “several times a week”, “daily”, and “several times a day”. Part B of the survey contains 14 multiple choice questions about usage that are scored using weights. Higher scores represent higher levels of alcohol and drug involvement. The AADIS is intended to be used as a research instrument and/or screening tool and has not been validated for diagnosis, although a score of greater than or equal to 37 merits further assessment for substance use disorder (Moberg, 2005).

FEMAP researchers modified the original questionnaire. In part B, responses to questions about alcohol and drug use were separated to obtain more detailed information. As a result, it is not possible to apply the available scoring weights to the questionnaire data in order to calculate an AADIS score.

At intake, FEMAP collected information about substance use, including drugs and alcohol, using the AADIS.

Marijuana Use

We used question 3 of part A of the AADIS which asked participants to select their “marijuana or hashish (weed, grass, blunts)” use on an eight-item scale from never to several times a day. For analyses, the responses were dichotomized into never used versus any use ever. The first response option after “never used” was “tried but quit”.

This response option is somewhat ambiguous because the term “quit” may imply a habit was formed that required quitting. The response groups individuals who used the substance on one occasion with those who were former potentially frequent users. The grouping used reflects the potential mechanism of a rejection of authority or medical advice (Pogge et al., 2005). (See Appendix E.)

Other Illicit Drug Use

Questions 4 through 13 of the AADIS part A asked about illicit drug use other than marijuana such as LSD, ecstasy, cocaine, and others. Participants answered on an eight-point scale from never used to several times a day. The results were combined and dichotomized into never used any illicit drugs other than marijuana versus any illicit drug use other than marijuana. The grouping is the same as that utilized for marijuana use. (See Appendix F.)

Tobacco Use

We used question 1 of part A of the AADIS which asked participants to select their “smoking tobacco (cigarettes, cigars)” use on a scale with eight response options from never used to several times a day. For analyses, the responses were dichotomized into never used versus any use ever consistent with the other substance use variables. (See Appendix G.)

Quantity of Alcohol Consumed per Occasion

Alcohol use was captured by a few questions of the AADIS. Alcohol use history was reported in part A with the same response options as the previous substance use questions. Part B contains 14 questions about usage including frequency, type of alcohol consumed, with whom it is consumed, how the alcohol is obtained, and amount typically consumed per occasion. Question 9 in Part B of the AADIS was used to determine the quantity of alcohol consumed per occasion. The question asked, “When you drink alcohol, how much do you usually drink?” The response options were 1 drink, 2 drinks, 3-4 drinks, 5-9 drinks, and 10 or more drinks. For analyses, the results were dichotomized into 4 drinks or fewer and 5 drinks or more. (See Appendix H.) This questions was selected amongst the many options because the variable is consistent with the Drug Use

Among Ontario Students definition of binge drinking (Boak, Hamilton, Adlaf, & Mann, 2015). Binge drinking is defined by the Public Health Agency of Canada as five or more drinks per occasion for males and four or more for females (Public Health Agency of Canada, 2016).

Satisfaction with Previous Mental Health Care

The Short-Form Patient Satisfaction Questionnaire (PSQ) is a tool developed by the RAND Corporation to assess seven dimensions of patient satisfaction with general health care practitioners. It correlates well with the 50-item patient satisfaction questionnaire from which it was derived (Marshall & Hays, 1994). Patients answer 18 questions regarding their satisfaction with medical care they have received using five-point Likert scales. The PSQ scoring algorithm provides summary scores for each of the seven dimensions.

For Innovation II, FEMAP researchers administered the PSQ during the pre-intake appointment for “22” patients and during the intake appointment for “20” patients. FEMAP researchers made several modifications to the original questionnaire. In the original questionnaire, part A contained questions about the frequency of using different general practitioner services and part B included 18 items on patient satisfaction with general practice. FEMAP researchers removed items 1, 2, 5, 7, 9, and 18, and changed the wording on the remaining 12 items to reflect mental health care in Canada.

Due to the changes made to the PSQ, the scoring for the PSQ cannot be retrieved. Thus patient’s satisfaction with previous mental health services was measured using a single item from the questionnaire, the statement, “The mental health care I have received has been just about perfect.” This is similar to the measurement used in a 2003 study investigating the relationship between satisfaction and quality of mental healthcare (Edlund, Young, Kung, Sherbourne, & Wells, 2003). The five response options were categorized into three groups: 1) not applicable, 2) satisfied (agreed or strongly agreed), and 3) dissatisfied (uncertain, disagreed, or strongly disagreed). (See Appendix I).

It was assumed that those who responded not applicable did so because they had never received mental health services. To investigate whether this was indeed the case a

subset of mental health care services listed in part A, psychiatric unit in hospital, outpatient hospital mental health service, private mental health professional, and community mental health services, were chosen as services whose use would be solely for mental health services in comparison to others (e.g. family doctor, high school guidance counselor) which could be accessed for other needs. Investigations showed that only four of the 56 participants reporting that the question about satisfaction with overall mental health care was not applicable had used one of the services listed above.

Self-Referral

FEMAP maintains records on how patients were referred to the program. The referral categories were non-traditional referral (e.g. self-referral, parent referral, post-secondary school services) based on responses to the pre-intake telephone screening interview or physician referred based on FEMAP's receipt of a physician referral.

Trauma History

The literature review did not reveal any previous studies on the association between trauma history and adherence. FEMAP; however, collected trauma history using the Trauma History Questionnaire (THQ). A link between trauma and adherence has not been established but it is possible that having experienced trauma may affect how patient-provider relationships are formed and therefore affects engagement. The THQ was developed to collect information on past exposure to events that could be traumatic and lead to development of post-traumatic stress disorder (PTSD) (Hooper, Stockton, Krupnick, & Green, 2011). The questionnaire has been successfully implemented across a variety of populations with differing trauma histories (e.g. residents of battered women's shelter, police officers, Holocaust survivors, adult survivors of childhood trauma and abuse, and people with life-threatening illnesses). The THQ was developed to measure traumatic events in an adult population, as classified by the Diagnostic and Statistical Manual of Mental Disorders. The questions focus on three domains of trauma: 1) crime-related events, 2) general disaster and trauma, and 3) unwanted physical and sexual experiences.

FEMAP measured trauma experience by administering the THQ at intake (T0). FEMAP adapted the THQ for use in the youth population by changing the wording of some of the questions. FEMAP also changed the response options to “Never”, “Before age 16”, “Between age 16 and 1 year ago” and “Within past year”, for items 1 to 18 only. Questions 19 to 24 were altered to ask only whether or not the event occurred. On the original questionnaire the responses ask for whether the event occurred, the number of times, and approximate age(s).

There is no official scoring method for the THQ (Hooper et al., 2011); however, researchers have commonly counted the different types of trauma. Because of the changes to the THQ, the number of times a traumatic event occurred cannot be identified. The options “Never”, “Before age 16”, “Between age 16 and 1 year ago”, and “Within past year” are not mutually exclusive. For example, a 17-year-old participant having experienced a traumatic event during the past year could select “Between age 16 and 1 year ago” and “Within past year” for the same event. Instead we used the method of Spertus et al., in which the total number of types of trauma experienced were calculated, and range between 0 (no trauma experienced) and 3 types (at least one of each type of trauma: crime-related, general disaster and trauma, and unwanted physical and sexual experiences, experienced). This range was then divided into low trauma (0 or 1 types) and high trauma (2 or 3 types) (Spertus, Burns, Glenn, Lofland, & Lance McCracken, 1999). (See Appendix J.)

Inventory of College Students’ Recent Life Experiences (ICSRLE)

Daily hassles were not measured by previous studies; however, it is available in this dataset and may be associated with adherence. Daily hassles may be a patient-related factor measuring barriers to treatment that affect engagement. Alternatively, it may be associated with motivation for treatment and be associated with engagement through that pathway. The Inventory of College Students’ Recent Life Experience (ICSRLE) is a measure of daily hassles developed using a Canadian student population (Kohn, Lafreniere, & Gurevich, 1990). The scale measures a construct called “hassles”. The ICSRLE contains 49 questions about daily hassles that a college student may have experienced. Individuals rate the intensity of the experience for each item over the past

month on a scale from 1 (not at all part of my life) to 4 (very much part of my life). Previous studies have used the ICSRLE with good internal consistency (Bodenhorn, 2007; Kohn et al., 1990; Osman, Barrios, Longnecker, & Osman, 1994). The alpha coefficient was 0.88 when completed by Canadian undergraduate students (Kohn et al., 1990). When completed by undergraduate students attending an American university the alpha coefficient was 0.92 (Osman et al., 1994). Thirty-seven of the items are used for the following subscales: developmental challenge, time pressure, academic alienation, romantic problems, assorted annoyances, general social mistreatment, and friendship problems. Higher scores indicate more frequent problems.

FEMAP researchers modified the questionnaire to better suit their population, which includes high school students and employed youth not in school. Where questions made reference to academics, FEMAP included terms for work as well. Additionally, the question about conflict with teaching assistants and the question about interruptions of school work were removed. Thus the total score, obtained by summing the items, ranges from 47 to 188 rather than 49 to 196. We used the modified ICSRLE as a measure of hassles where higher scores indicate more hassle.

Severity of Illness – Depression

The Montgomery – Åsberg Depression Rating Scale (MADRS-S) is a self-rated depression scale used to assess the presence and severity of a depressive episode. The level of distress for each of nine items is scored from 0 (none at all) to 3 (maximum). The sum of the scores on the nine items provides an overall score where higher scores indicate higher levels of depression. Cut-off values for remission have been established by previous studies and suggest using a value of less than or equal to 10 (Cunningham, Wernroth, Von Knorring, Berglund, & Ekselius, 2011; Hawley, Gale, & Sivakumaran, 2002; Riedel et al., 2010; Zimmerman, Posternak, & Chelminski, 2004).

We incorporated the total score on the MADRS-S into our analyses, with higher scores indicating more depressive symptoms. Two previous studies have calculated Cronbach's alpha as 0.84 in adult populations diagnosed with MDD (Cunningham et al., 2011; Fantino & Moore, 2009).

Severity of Illness – Anxiety

The Anxiety Sensitivity Index – Revised (ASI-R) is a survey that measures anxiety sensitivity, which is the fear of anxiety-related sensations (Taylor & Cox, 1998). Thirty-six items about different forms of anxiety and anxiety-provoking scenarios are rated from 0 (very little) to 4 (very much). The score from each item is summed to obtain a total score ranging from 0 to 144, where a higher score indicates higher levels of anxiety sensitivity. There are six sub-scales: 1) fear of cardiovascular symptoms, 2) fear of respiratory symptoms, 3) fear of gastrointestinal symptoms, 4) fear of publicly observable anxiety reactions, 5) fear of dissociative and neurological symptoms, and 6) fear of cognitive dyscontrol, each of which had moderately large correlation with the Beck Anxiety Inventory (Taylor & Cox, 1998). The total score, ranging from 0 to 144, on the ASI-R was used for analyses, with higher scores indicating greater anxiety sensitivity. Excellent internal consistency ($\alpha=0.95$) was found in a sample of undergraduate students (Arnau, Broman-Fulks, Green, & Berman, 2009) as well as a sample of patients with diagnosed anxiety disorders (Deacon & Abramowitz, 2006).

Functioning

The Sheehan Disability Scale (SDS) is a 5-item questionnaire used to assess functional impairment. The first three questions ask the individual to score the extent to which their symptoms have disrupted work or school, social, and family life from 0 (not at all) to 10 (extremely). Respondents can skip the first question and select “I have not worked or been in school”. These scores can be analyzed individually or can be summed to provide an overall score ranging from 0 to 30. Questions four and five inquire about lost productivity but do not form part of the scoring procedure (Leon, Shear, Portera, & Klerman, 1992).

The SDS was used to measure functioning, with higher scores indicating greater disability. In the absence of specific guidelines for scoring the first question with the option “I have not worked or been in school”, the average of the remaining two items were used to obtain a total score. (See section 3.3.2.1 for further details.)

3.3 Statistical Analysis

All statistical analyses were conducted using SAS software version 9.4 (“SAS,” 2013). Descriptive statistics were calculated for the explanatory variables and are described as mean (standard deviation) in the case of continuous variables and as proportions for categorical variables.

3.3.1 Univariate Analysis

Each variable was individually investigated for association with the outcome, engagement in FEMAP. Chi square tests were performed for categorical variables with all cell counts greater than five and Fisher’s Exact test used for those with an expected cell count of less than five. T-tests were performed for continuous factors. Associations at the $\alpha=0.05$ significance level were flagged.

3.3.2 Missing Data

In any data collection we expect to have missing values. Missing values can occur for a multitude of reasons such as computer error, responder fatigue, or refusal to answer specific questions.

Data can be classified as missing completely at random (MCAR), missing at random (MAR), or missing not at random (MNAR). MAR occurs when the distribution of missing values does not depend on the value of missing data but may depend on the observed data. MCAR depends on neither observed nor missing data. MNAR occurs when the distribution of missing values depend on the missing value (Schafer & Graham, 2002). We describe our approach to missing questionnaire items and missing study data in the sections that follow.

3.3.2.1 Missing Questionnaire Items

Missing responses to questionnaire items on the Anxiety Sensitivity Index (ASI-R), Montgomery-Åsberg Depression Rating Scale (MADRS-S), Sheehan Disability Scale (SDS), and Inventory of College Students’ Recent Life Experiences (ICSRLE) were imputed using person mean substitution. Person mean substitution is a method of imputation that takes the mean of each participants’ non-missing responses and

substitutes that value for missing values. The underlying assumption is that the missing items would have had the same score as the mean of the non-missing items. In contrast to item mean substitution which imputes the mean value of the other respondents for a missing question, the method of person mean substitution has been shown in simulation studies to perform well in questionnaires consisting of several similarly scaled items (Gil & Kromrey, 2013; Hawthorne & Elliott, 2005; Shrive, Stuart, Quan, & Ghali, 2006).

Each measure meets the assumptions required for the person mean substitution method to be optimal; the item responses are scored on the same scale, each question contributes equally to the overall score, and all questions measure a single construct. On the ASI-R, each of the 36 items is scaled from 0 to 4 and summed to calculate an overall score. Similarly, the MADRS-S has nine items, each scaled from 0 to 3 and summed to provide an overall score. The SDS has three items each scaled from 0 to 10 and summed, and the ICSRLE has 47 summed items each scaled from 1 to 4. Each of the questions on the ASI-R, MADRS-S, SDS, and ICSRLE measure the underlying construct of the questionnaire (Downey & King, 1998; Fayers, Curran, & Machin, 1998; Leon et al., 1992).

For the Trauma History Questionnaire (THQ), we performed logical imputation. Twenty-four potentially traumatic events are listed, and for each event there are four check-boxes: “Never”, “Before age 16”, “Between age 16 and 1 year ago”, and “Within past year”. If the event occurred the respondent should leave “Never” blank and use the other boxes to indicate the timing of the event. To indicate that a particular event was never experienced the respondent should check the box indicating “Never” and leave the other three options blank. If a participant left all of the boxes unchecked to all items, the responses to all 24 items were considered missing. (This applied to three participants.) Other times, a participant may have answered the majority of questions and left the remainder of the items blank. In these cases, logical imputation was used to assign “Never” to the other missing items. In this instance, it was assumed that blank items were skipped because the event had not occurred and thus no further details were provided. A sensitivity analysis was performed to test the impact of this assumption. The entire

analysis was repeated assigning the occurrence of an event if it was left blank. It was noted earlier that these responses are not mutually exclusive; someone who is aged 17 and experienced a trauma at age 16 could select “between age 16 and 1 year ago” and “within past year” for a single event. The number of times the event occurred was not factored into the trauma measure so this limitation is not expected to have caused problems.

Logical imputation was used for the quantity of alcohol consumed per occasion as well. There were 49 missing values for the quantity of alcohol consumed; however, this question did not allow the participant to indicate that they do not consume alcohol. Upon investigation of the participants’ responses to question 1, “how often do you use alcohol?”, 45 of these 49 participants indicated that they never consume alcohol. For these participants, 4 drinks or fewer was imputed, and the remaining were left as missing and imputed using single imputation as described below.

3.3.2.2 Missing Study Data

In the regression analysis we avoided complete case analysis, the deletion of any observation that has any missing value. Complete case analysis is acceptable if the data is missing completely at random but has the drawback of reducing the usable sample size. Where possible, we conducted logical imputation when questions were redundant and the accurate response could be deduced. We performed single imputation for variables in which less than 5% of the study sample had missing values. This has the advantage of using all of the data but the disadvantage of also reducing variance. All of the variables had less than 5% missing values.

3.3.3 Associations Among Covariates

The associations among covariates were investigated. Pearson correlations were used to test associations between pairs of continuous variables. Chi-square tests were used to test associations between pairs of categorical variables. T-tests were used to test associations between pairs of continuous and categorical variables. The Pearson correlation

coefficient threshold value of 0.6 (or -0.6) was used as a cut-off indicating a strong association between continuous variables (“Correlation and regression,” 2016).

3.3.4 Multivariable Analysis

A logistic regression model was built to identify the factors associated with engaging in therapy amongst youth offered treatment at FEMAP. Innovation II data collection afforded the opportunity to consider a variety of risk factors, as outlined in the preceding sections of this chapter. The first step in fitting the regression model was selecting variables for inclusion. To identify potential predictors of engaging in therapy a review of the literature was conducted (see chapter 2). Informed by the results of the literature review and the results of the previous Innovation I study on loss to follow-up, a set of predictor variables was selected including age, gender, ethno-racial background, parental marital status, parental education, referral, quantity of alcohol consumed per occasion, tobacco use, marijuana use, other illicit drug use, severity of anxiety, severity of depression, and functioning. Novel variables collected by FEMAP that had not been investigated previously in the literature (trauma history, satisfaction, and ICSRLE) were also included in the predictor variables.

One goal of fitting a regression model is parsimony, that is, ensuring that variables are only included in the regression model if they are significantly associated with the outcome and/or confound the relationship between another variable and the outcome. Several methods have been proposed for choosing amongst candidate variables when fitting a regression model. Popular methods such as forward selection, backward elimination, or stepwise selection employ rules such as p-value cut-offs to perform variable selection. The forward selection method enters variables into a null model that meet an entry significance criterion while the backward elimination method begins with a full model and sequentially removes variables that do not contribute at a specified significance level. The stepwise selection method combines the previous two methods, allowing variables to be either included or removed with each iteration (Vittinghoff, Glidden, Shiboski, & McCulloch, 2012). Selection criteria based on critical p-values have been criticized for ignoring confounding variables. The change in estimate approach is an additional criterion based on the degree to which a variable confounds the relationship

between another variable and the outcome in a regression model (Greenland, 1989; Mickey & Greenland, 1989). Purposeful selection combines p-value cut-offs and change in estimate to select variables for inclusion in regression models that are strongly associated with the outcome or confound the relationship between the outcome and another variable (Hosmer, Lemeshow, & Sturdivant, 2013). Purposeful selection has been shown to be advantageous for logistic regression models used for risk factor analysis and outperforms automated variable selection for sample sizes ranging from 240-600 (Bursac, Gauss, Williams, & Hosmer, 2008).

3.3.4.1 Purposeful Selection Method

1. Univariate analyses were performed on each predictor variable and those that were identified as associated with the outcome with a p-value of 0.25 or less were candidates for inclusion in the logistic regression model. A higher p-value at this initial stage has been shown to be more reliable (Maldonado & Greenland, 1993; Mickey & Greenland, 1989).
2. A multivariable model was fit containing all candidate variables identified from step 1. The covariate with the highest p-value was identified and compared to a retention p-value (0.10). If the covariate's p-value was larger than the cut-off value set for retention, then it was removed and a new model fit, otherwise it remained in the model. The fit of the reduced model was compared to the larger model using the partial likelihood ratio test.
3. The change in the coefficients between the reduced and original models was calculated. A 15% change in any coefficient after the removal of a covariate was indicative of a potential confounding effect with the variable whose coefficient was greatly changed by its removal. If the percent change in any coefficient exceeded 15% the covariate remained in the model, otherwise it was removed. Steps 2 and 3 were repeated until the highest p-value in the model was below the retention cut-off.

4. The original variables that were not candidates for the first model were entered into the model one by one to determine if they were significant factors in the presence of the others already in the model. The non-candidate variables were retained in the model if the significance test was 0.15 or below. In a simulation study using a sample size similar to ours, 15% change in coefficients and 0.15 retention criteria for non-candidate variables resulted in the most accurate models (Bursac et al., 2008).
5. Continuous variables remaining in the preliminary main effects model were examined for the assumption of linearity with the logit of the outcome. (See section 3.3.5.1.)
6. We pre-specified interaction terms with gender, based on plausibility of an interaction between gender and another variable with respect to engagement. Interactions with gender that were significant at the 0.05 significance level were entered into the model one at a time.
7. The model was assessed for goodness of fit, multicollinearity, and influential observations. (See section 3.3.5.2.)

3.3.5 Model Fit and Diagnostics

3.3.5.1 Assessing Linearity Assumptions of the Logistic Regression Model

In order to test the relationship between continuous variables and the logit of the outcome, we investigated scatter plots of the mean predicted probability of the outcome for each value of the continuous variable on the y-axis and the continuous variable, on the x-axis. The scatter plots were smoothed using a local regression function and the resulting graph was visually inspected to ensure the relationship was linear.

3.3.5.2 Goodness of Fit

The goodness of fit of the model was tested using the Hosmer-Lemeshow test. The Hosmer-Lemeshow test calculates the observed and expected frequencies for each decile

of predicted probability. A Pearson chi-square statistic is used and the p-value calculated. The null hypothesis is that there is no difference between the observed and expected frequencies. A small p-value indicated that there are large differences in the observed and expected frequencies and the model is a poor fit while a large p-value cannot tell us that the model is a good fit just that we failed to find evidence of a poor fit.

3.3.5.3 Outlying and Influential Observations

Outliers are observations with large residuals (whose predicted and observed values greatly differ). Leverage measures how far an independent variable is from the mean value. Observations with high leverage can be problematic if they are also influential. This can occur when the observation with leverage is an outlier and removing the point significantly changes the regression coefficients.

Plots of the leverage, the change in Pearson chi-square statistic, deviance statistic, and the change in the beta coefficients all versus the predicted probabilities were used to assess outlying and influential points (Hosmer et al., 2013). Plots were also visually inspected to identify influential observations.

3.3.5.4 Multicollinearity

Multicollinearity occurs when the covariates have linear dependencies on each other. Multicollinearity can cause inflated standard errors and incorrect parameter estimates (Allison, 2012a). To investigate multicollinearity, the variance inflation factor (VIF), the amount by which the variance is inflated due to multicollinearity, was calculated for each independent variable in the model. A VIF of one indicates that the covariates are linearly independent (Mansfield & Helms, 1982). Covariates with a VIF greater than ten were investigated for possible removal from the model.

3.4 Summary

The purposeful selection approach allowed us to choose from amongst candidate variables, that were identified using literature review, to understand the factors that predict engagement in treatment amongst FEMAP patients.

Chapter 4

4 Results

FEMAP offered treatment to 366 patients, of whom 320 (87.4% [83.6, 90.4]) engaged in treatment and 46 (12.6%) did not.

4.1 Sample Characteristics

Sample characteristics are summarized in table 4.1. The study sample was mostly female (66.9%) with a mean age of 19.2 (SD 2.6). Approximately half of the sample (50.3%) was between the ages of 16 and 18. The majority identified their ethno-racial background as white (77.1%). More than half of the participants indicated their parents were married or living common law (55.0%), with the remainder indicating their parents were divorced, separated, or widowed. Participants who reported at least one parent had a college or university degree represented 75.4% of the sample. More than 80% of the patients arrived at FEMAP through non-traditional referral routes (e.g. self, high school guidance counsellor, community crisis services). Nearly three quarters of the participants (69.3%) drank four or fewer alcoholic beverages per occasion. Approximately one third of the participants (31.9%) reported using illicit drugs other than marijuana at least once, nearly two thirds (65.8%) reported ever using marijuana, and a little over half (51.9%) had smoked cigarettes or cigars at least once. Slightly more than half (51.8%) of the patients experienced low trauma exposure (zero or one type of traumatic experience). To ascertain satisfaction with previous mental health care participants were asked about treatment received before entering FEMAP. In response to the statement, “the mental health care I have received has been just about perfect”, Fifty-six (15.4%) participants chose the not applicable option. 12.4% of participants agreed or strongly agreed with the statement. The majority of respondents (87.6%) indicated they strongly disagreed, disagreed, or were uncertain in response to the statement. The p FEMAP sample had Anxiety Sensitivity Index (ASI-R) scores that ranged widely from 0 to 143 out of a possible 144 points. The mean total ASI-R score was 55.8 (SD 32.0). The mean total score on the Montgomery-Åsberg Depression Rating Scale (MADRS-S) was 12.3 (SD 4.5). The mean total score on the Sheehan Disability Scale (SDS) 17.3 (SD 7.3) and the

mean score on the Inventory of College Students' Recent Life Experiences (ICSRLE) was 105.7 (SD 23.4).

Table 4.1 Sample Characteristics (N = 366)

Variables	Mean (SD) or Number (%)
Age (N=366)	
16 – 18 years	184 (50.3)
19 – 25 years	182 (49.7)
Gender (N=366)	
Male	121 (33.1)
Female	245 (66.9)
Ethno-racial background (N=362)	
White	279 (77.1)
Other	83 (22.9)
Parents' Marital/Cohabitation Status (N=360)	
Married, common law or living together	198 (55.0)
Divorced, Separated, or widowed	162 (45.0)
Parental education (N=358)	
Less than a college or university degree	88 (24.6)
At least a college or university degree	270 (75.4)
Referral (N=366)	
Traditional (Physician) Referral	71 (19.4)
Non-traditional Referral	295 (80.6)
Satisfaction with previous mental health care (N=363)	
Not applicable	56 (15.4)
Not satisfied	269 (74.1)
Satisfied	38 (10.4)
Quantity of Alcohol Typically Consumed per Occasion (N=362)	
4 drinks or less	251 (69.3)
5 or more drinks	111 (30.7)
Tobacco Use (N=364)	
Never	175 (48.1)
Any use ever	189 (51.9)
Marijuana Use (N=365)	
Never	125 (34.3)
Any use ever	240 (65.8)
Other Illicit Drug Use (N=364)	
Never	248 (68.1)
Any use ever	116 (31.9)
Trauma (N=363)	
Low Trauma (0-1 types)	188 (51.8)
High Trauma (2-3 types)	175 (48.2)
Severity of illness	
Anxiety (ASI-R score) (N=366)	55.8 (32.0)

Variables	Mean (SD) or Number (%)
Depression (MADRS-S score) (N=366)	12.3 (4.5)
Functioning (SDS Score) (N=363)	17.3 (7.3)
Daily Hassles (ICSRLE Score) (N=365)	105.7 (23.4)

4.2 Missing Data

Following imputation of missing questionnaire items, the frequency of missing values was investigated for each explanatory variable. No variable had more than 5% missing values. Pre-imputed values did not greatly differ from post-imputed values after using person mean substitution (see table 4.2).

Table 4.2 Results of Questionnaire Imputation

Questionnaire	Pre-imputed value Mean (SD)	Post-imputed value Mean (SD)
Anxiety Sensitivity Index	55.6 (31.8)	55.8 (32.0)
Sheehan Disability Scale	16.9 (7.3)	17.3 (7.3)
Montgomery-Åsberg Depression Rating Scale	12.3 (4.5)	12.3 (4.5)
Inventory of College Students' Recent Life Experiences	105.3 (23.3)	105.7 (23.4)

4.3 Cronbach's alpha results

The Cronbach's alpha coefficient was calculated for each of the ICSRLE, MADRS-S, and ASI-R. Despite the changes made to the ICSRLE the alpha coefficient remained high; a value of 0.93 was found for the modified ICSRLE given to the participants of FEMAP. The alpha coefficient for the MADRS-S was calculated to be 0.84. The Cronbach's alpha of 0.96 calculated from the ASI-R in this sample also demonstrates excellent internal consistency.

4.4 Univariate Analyses

The majority of FEMAP participants engaged in treatment; however, 46 (12.6%) participants did not engage and did not attend their first or any clinical appointments.

The results of the chi-square tests and t-tests for unadjusted associations between each covariate and the outcome are reported in table 4.3. Results of the univariate analysis indicated that only the total score on the ASI-R was significantly associated with engagement at the $p < 0.05$ level. No other covariates were statistically significantly associated with engagement in FEMAP, although gender, quantity of alcohol consumed per occasion, and functioning were significant at the $p < 0.10$ level.

Table 4.3 Univariate Analyses

Characteristic	Engagement Status (N=366)		p-value
	Non-engaged n=46 (12.6%)	Engaged n=320 (87.4%)	
	Mean (SD) or Number (%)	Mean (SD) or Number (%)	
Gender			0.0522
Female	25 (10.2)	220 (89.8)	
Male	21 (17.4)	100 (82.6)	
Age			0.1242
16 to 18 years	28 (15.2)	156 (84.8)	
19 to 25 years	18 (9.9)	164 (90.1)	
Ethno-racial background			0.3597
White	33 (11.7)	249 (88.3)	
Other	13 (15.5)	71 (84.5)	
Parents' Marital/Cohabitation Status			0.9338
Married	25 (12.4)	176 (87.6)	
Unmarried	21 (12.7)	144 (87.3)	
Parental education			0.1937
Degree	31 (11.3)	244 (88.7)	
No degree	15 (16.5)	76 (83.5)	
Referral			0.9757
Traditional referral (physician)	9 (12.7)	62 (87.3)	
Nontraditional referral	37 (12.5)	258 (87.5)	
Satisfaction with previous mental health care			0.1084*
Not applicable	11 (19.6)	45 (80.4)	
Satisfied	2 (5.3)	36 (94.7)	
Not satisfied	33 (12.1)	239 (87.9)	
Quantity of Alcohol Consumed per Occasion			0.0723
4 drinks or less	26 (10.4)	225 (89.6)	
5 or more drinks	19 (17.1)	92 (82.9)	
Tobacco Use			0.6024
Never	20 (11.4)	155 (88.6)	
Any use ever	25 (13.2)	164 (86.8)	

Engagement Status (N=366)			
Characteristic	Non-engaged	Engaged	p-value
	Mean (SD) or Number (%)	Mean (SD) or Number (%)	
Marijuana Use			0.6359
Never	14 (11.2)	111 (88.8)	
Any use ever	31 (12.9)	209 (87.1)	
Other Illicit Drug Use			0.3635
Never	28 (11.3)	220 (88.7)	
Any use ever	17 (14.7)	99 (85.3)	
Trauma			0.7536
Low trauma	25 (13.1)	166 (86.9)	
High trauma	21 (12.0)	154 (88.0)	
Severity of Illness			
Anxiety (ASI-R score)	45.7 (29.7)	57.3 (32.1)	0.0214**
Depression (MADRS-S score)	11.9 (4.2)	12.4 (4.6)	0.5486**
Functioning (SDS Score)	15.6 (7.5)	17.5 (7.2)	0.0981**
Daily Hassles (ICSRLE Score)	107.0 (21.9)	105.5 (23.6)	0.6820**

*Fisher's Exact Test used due to expected cell counts below 5

**t-tests

4.5 Associations Among Covariates

4.5.1 Associations Among Continuous Covariates

Pearson correlations illustrated that there were no strong linear associations among continuous covariates (ASI-R, MADRS-S, SDS, and ICSRLE scores.) (See Appendix K for detailed results.)

4.5.2 Associations Among Categorical Covariates

Chi-square tests showed that there were significant associations among categorical variables. All of the substance use variables were significantly associated with one another. Any use of one substance was associated with any use of another or with a higher quantity of alcohol consumption. Any usage of tobacco, marijuana, or other illicit

drugs was significantly associated with high trauma. Age group was also associated with all of the substance use variables, indicating that more of the 19 to 25 year olds had ever used tobacco, marijuana, or other illicit drugs, and drank more alcoholic beverages per occasion. Age group was also associated with ethno-racial background. A significantly greater proportion of 19 to 25 year olds identified their ethno-racial background as non-white. Significantly more patients who reported ever using tobacco, marijuana, or any other illicit substance reported not being satisfied with previous mental health care. A significantly greater proportion of married parents also had at least a college or university degree or more education compared to unmarried parents. Significantly more patients of unmarried parents had experienced high trauma compared to patients of married parents. Significantly more patients of parents with less than a college or university education drank five or more alcoholic beverages per occasion and reported ever having used an illicit substance other than marijuana. (See Appendix L for detailed results.)

4.5.3 Associations Among Continuous and Categorical Covariates

T-tests revealed significant associations among continuous and categorical covariates. Gender was significantly associated with total ASI-R score, total ICSRLE score, and total MADRS-S score. Females had significantly higher ASI-R, ICSRLE, and MADRS-S scores compared to males. Patients of parents with less than a college or university degree had significantly greater functional impairment than patients of parents with a college or university degree. Patients of unmarried parents reported significantly greater functional impairment compared to patients of married parents. Patient who drank five or more alcoholic beverages per occasion had higher ICSRLE scores. Patients reporting any tobacco use ever had higher ASI-R, ICSRLE, and MADRS-S scores. Patients who had ever used marijuana had higher ICSRLE and MADRS-S scores compared to patients who had never used marijuana. Patients who had reported any illicit drug use other than marijuana also had higher ICSRLE and MADRS-S scores. Patients who had experienced high trauma also had significantly higher scores on the ASI-R and ICSRLE than those who had experienced low trauma. Satisfaction with previous mental health care was significantly associated with total MADRS-S score. Patients who reported being satisfied

with care also reported lower MADRS-S scores compared to those who reported not being satisfied with previous care or answered not applicable. Patients who reported not being satisfied with previous mental health care had significantly higher scores on the ICSRLE than those who were satisfied with previous care or answered not applicable. (See Appendix M for detailed results.)

4.6 Purposeful Selection of the Logistic Regression Model

In step 1 of the purposeful selection method, only the variables age, gender, parental education, total score on the ASI-R, total score on the SDS, quantity of alcohol consumed per occasion, and satisfaction had an association with engagement signified by a p-value below the cut-off of 0.25. In step 2, a multivariable model was fit with these variables. The variables age, parental education, satisfaction, and total score on the SDS were removed because the p-value in the multivariable model exceeded the 0.10 cut-off and removal of the variables did not change the coefficient estimates of any remaining variables by 15% or greater. In step 3, gender, total score on the ASI-R, and quantity of alcohol consumed were retained in the multivariable model. After testing each non-candidate variable, no additional main covariates were added to the model. Thus, the preliminary main effects model included gender, ASI-R, and quantity of alcohol consumed. After testing interaction terms between gender and the other main effects, the interaction between gender and ASI-R was significant at $p < 0.05$, and thus the interaction between ASI-R score and gender was added to the model. The final model is presented in table 4.4.

Table 4.4 Final Logistic Regression Model

	Estimated Regression Coefficient	p-value	Odds Ratio	95% Confidence Interval	
Gender					
Male			reference		
Female	1.6842	0.0095	5.388*	1.509	19.237
ASI-R Score	0.0346	0.0057	1.035**	1.010	1.061
Quantity of Alcohol consumed per occasion					
5 drinks or more	-0.6790	0.0439	0.507	0.262	0.982
4 drinks or less			reference		
Gender*ASI-R	-0.0318	0.0247	-	-	-

*at an ASI-R score of 0

**odds ratio for unit increase in ASI-R score for males

These results show that the odds of engaging in FEMAP is nearly 50% lower (95% CI [0.26, 0.98]) for an individual who drinks five or more alcoholic beverages per occasion compared to someone who drinks four or fewer per occasion. The presence of an interaction term between gender and ASI-R score indicates that the odds of engaging in FEMAP comparing females to males depends on the ASI-R score. When the ASI-R score is 0, the odds of a female participant engaging in FEMAP is more than five times (95% CI [1.51, 19.24]) the odds of a male participant engaging in FEMAP. However, as the ASI-R score increases, the odds ratio comparing female to male participants decreases. At around the median score on the ASI-R, the odds of a female or male participant engaging in FEMAP is equal. Beyond the median score, the odds of a male participant engaging in FEMAP is greater than the odds of a female participant engaging. The results are presented in table 4.5 and figure 4.1.

Table 4.5 Odds Ratio Estimates and Confidence Intervals

ASI-R score	Estimated Odds ratio	95% Confidence Limits	
Female vs male at ASI-R = 0	5.39	1.51	19.24
Female vs male at ASI-R = 32	1.95	0.93	4.09
Female vs male at ASI-R = 52.5	1.01	0.44	2.33
Female vs male at ASI-R = 78	0.45	0.12	1.71
Female vs male at ASI-R =143	0.06	0.003	1.16

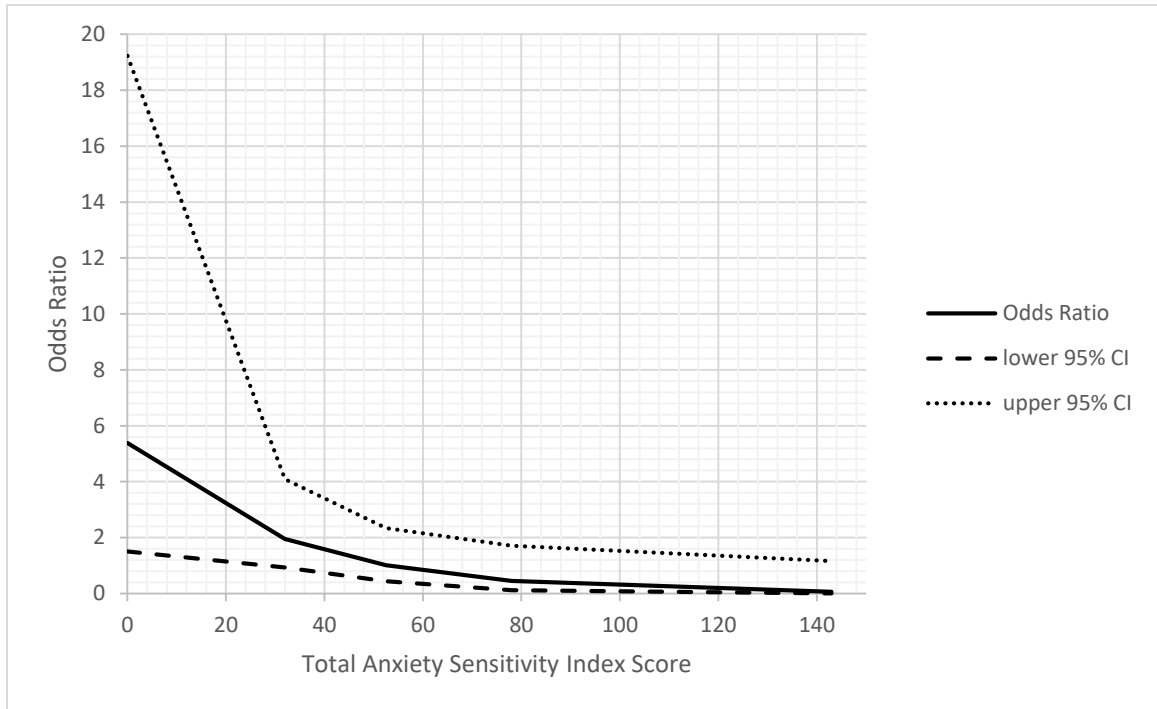


Figure 4.1 Odds Ratio comparing females to males

4.7 Model Fit and Diagnostics

4.7.1 Assessing Linearity Assumption

Visual inspection of the smoothed scatterplot (figure 4.2) assessing the linear association between ASI-R and the outcome confirmed the assumption that the total ASI-R score is linearly related to the log-odds of engagement.

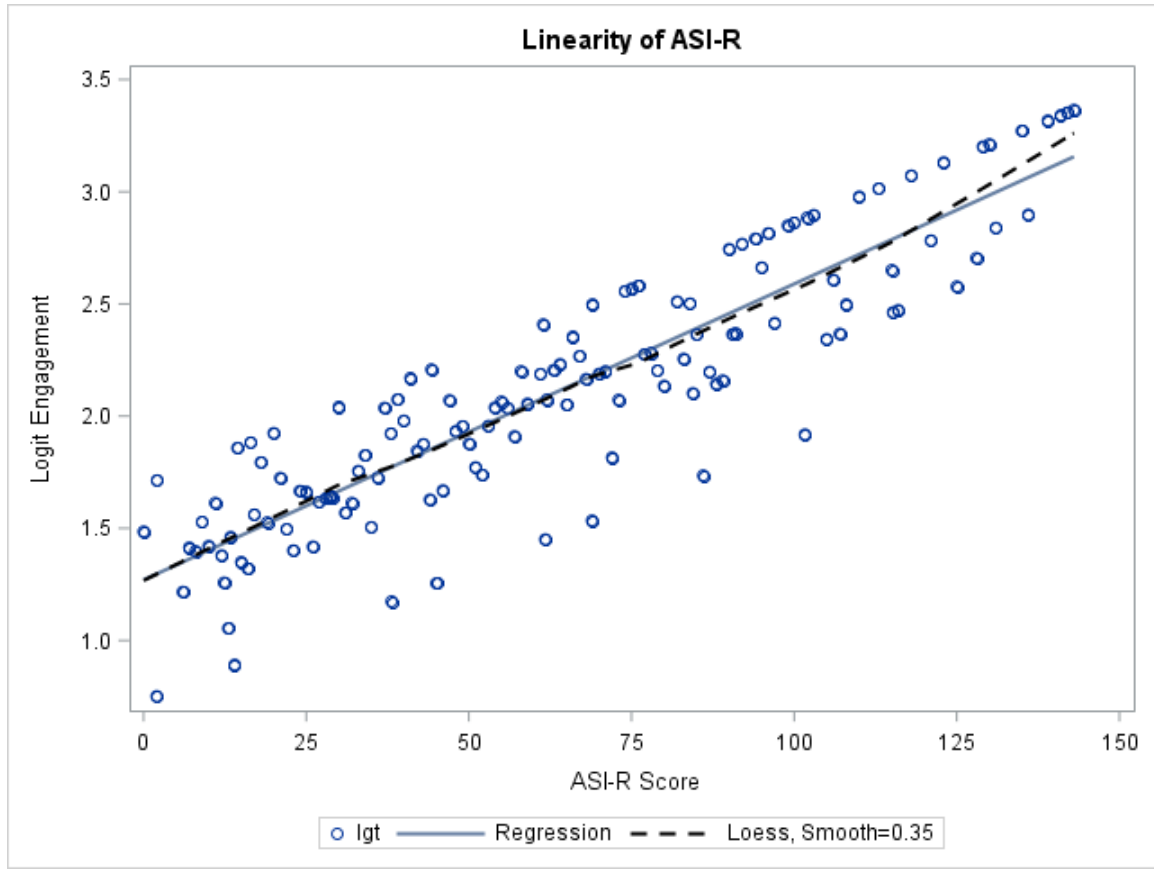


Figure 4.2 Linearity of ASI-R

4.7.2 Goodness of Fit

The resulting p-value of 0.95 from the Hosmer-Lemeshow goodness of fit test indicates no evidence of a lack of fit of the model.

4.7.3 Outliers and Influential Observations

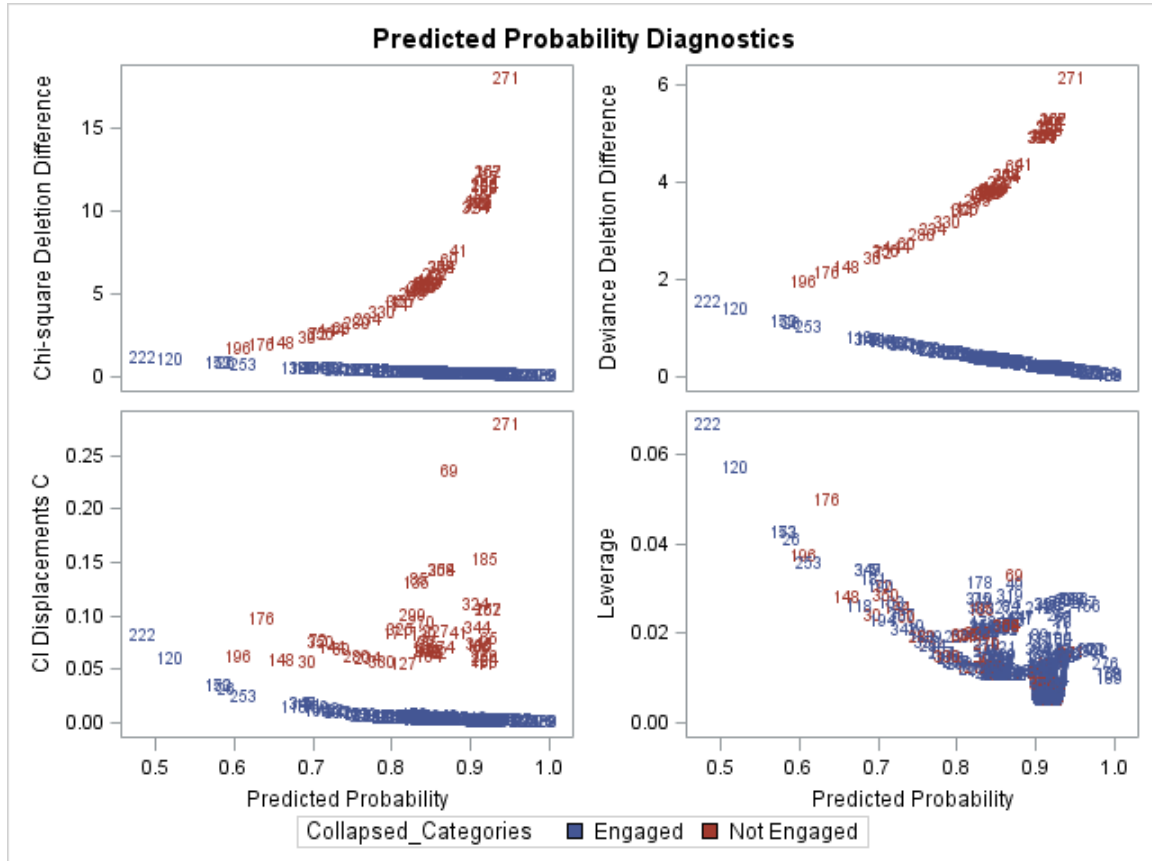


Figure 4.3 Outlying and Influential Points

Observation 271 was identified from the plots of the difference in the Pearson chi-square statistic, difference in deviance statistics, and the plot of the confidence interval (CI) displacements C plots as a potential outlier. Observation 69 was identified as a potential outlier from the plot of the CI displacements C plot. Observations 222, 120, and 176 were identified as potentially influential from the leverage plot. (See figure 4.3.)

All three observations with high leverage were male participants with low ASI-R scores. The refitted model after the removal of each of these observations resulted in a less than 20% change in any estimated coefficient. Upon inspection all observations had data within acceptable ranges and none were suspected of being incorrect. Therefore, no observations were removed from the analysis.

4.7.4 Multicollinearity

The only variable with a variance inflation factor (VIF) greater than 10 was the interaction term. With interaction terms, a high VIF is anticipated and can be safely ignored (Allison, 2012b). (See table 4.6.)

Table 4.6 Multicollinearity

Variable	Variance Inflation Factor
Gender	3.9
ASI-R Score	5.7
Quantity of Alcohol Consumed	1.0
Gender*ASI-R	11.2

Chapter 5

5 Discussion

5.1 Summary of Study Findings

FEMAP researchers collected a range of information on patients accepted into treatment covering some social and economic factors, patient-related factors, and condition-related factors. Using the literature as a guide, we selected key variables associated with engagement as potential risk-adjustment variables. Model selection revealed that female gender and anxiety sensitivity were positively associated with engagement and more than five quantity of alcohol consumed per occasion was negatively associated with engagement. We also identified a significant interaction between gender and anxiety sensitivity such that at low ASI-R scores, female patients were more likely to engage than male patients, but above an ASI-R score of 55, male patients were more likely to engage than female patients. All results reflect the effect of each variable after statistically controlling for other variables in the model.

5.1.1 Descriptive Results

We found an overall proportion of engagement of 87.4%. This is at the higher end of the proportions identified from the literature. A range of proportions from 33% to 78% have been previously reported (Baruch et al., 1998; Coletti et al., 2005; de Haan et al., 2015; DelBello et al., 2007; Fontanella et al., 2011; Ghaziuddin et al., 1999; Granboulan et al., 2001; King et al., 1997; Laurier et al., 2010; Moses, 2011; Munson et al., 2010; Pelkonen et al., 2000; Stewart & Baiden, 2013; Timlin et al., 2014). The reason for our higher proportion of engagement is unknown, though a potential explanation involves our specific definition of engagement. As noted in the literature review, engagement has been defined in a variety of ways in the literature.

Our goal was to identify factors predictive of engagement in FEMAP. It is possible that the population of FEMAP differs from those in other treatment programs, in ways that increase the likelihood of engagement. FEMAP's unique aspects, such as the

community-based setting and youth-friendly atmosphere may encourage engagement that is higher than studies in other treatment settings such as doctor's offices and hospitals.

5.1.2 Univariate Results

Univariate results revealed that only one factor, a condition-related factor, the ASI-R score was significantly associated with engagement. Other patient and condition-related factors that were not significantly associated with engagement but were notable given a p-value less than 0.1 were gender, quantity of alcohol consumed per occasion, and functioning. Females, consumers of less than five alcoholic beverages per occasion, and those with higher functioning as indicated by the SDS score were more likely to engage.

Those arriving at FEMAP via physician referral had similar levels of engagement when compared to those arriving via a non-traditional referral, indicating no association between referral and engagement. This result is consistent with Pelkonen et al. (Pelkonen et al., 2000) but contrasts the findings of other research indicating that non-traditional referral is associated with greater engagement. (Baruch et al., 1998; Osuch et al., 2015). Within the non-traditional referral group, FEMAP researchers did not record whether the patient, a parent, or another health professional made initial contact. It is possible that individuals who make the initial contact are more motivated to attend treatment and have higher engagement but we were not able to test for potential difference in engagement at this level.

5.1.3 Multivariable Results

After purposeful selection, gender, ASI-R score, and quantity of alcohol consumed per occasion were included in a logistic regression model and each was found to be a significant independent predictor of the odds of engagement. We found gender to be associated with engagement, but the majority of studies identified in the literature did not find this association (Baruch et al., 1998; DelBello et al., 2007; Fontanella et al., 2011; Granboulan et al., 2001; King et al., 1997; Moses, 2011; Munson et al., 2010; Pelkonen et al., 2000; Stewart & Baiden, 2013; Timlin et al., 2014).

We found a significant association between ASI-R score and engagement, unlike many studies that examined anxiety and its relationship to engagement (DelBello et al., 2007; Fontanella et al., 2011; Ghaziuddin et al., 1999). Inconsistent findings may be due to differing measurements of anxiety. Other studies have used a clinical diagnosis of anxiety in contrast to the ASI-R score, which measures anxiety symptom severity as a continuous variable, used in our research.

We found an association between quantity of alcohol consumed per occasion and engagement. Our measure of quantity of alcohol consumed is consistent with the definition of binge drinking (Boak et al., 2015; Public Health Agency of Canada, 2016). Few studies investigated alcohol consumption as a predictor of engagement in this patient population. Stewart et al. investigated consumption of alcohol in the two weeks preceding admission but the variable was not significant in multivariable analyses (Stewart & Baiden, 2013). The reason for lower engagement among those who drink more alcoholic beverages per occasion is unknown; however, it is possible that this type of drinking behaviour is a coping mechanism that is being used to replace therapy, consequently leading to reduced engagement.

Notably, we found a significant interaction between gender and ASI-R score. In particular, at an ASI-R score of 0, females were more likely than males to engage (OR = 5.388 95% CI [1.509, 19.237]). However, at an ASI-R score of 143, females were less likely to engage than males (OR = 0.057 95% CI [0.003, 1.159]). This result is consistent with Laurier et al. who found that anxiety predicted nonadherence in girls only (Laurier et al., 2010). The mechanism behind this finding is unclear. Anxiety may affect males and females differently, thus influencing the likelihood of engagement. It is possible that higher levels of anxiety in females leads to a greater motivation to engage in therapy and contacting several programs for treatment. Females with high anxiety may have been deterred by the increasing wait times at FEMAP and may have engaged in services elsewhere but were then designated as non-engagers at FEMAP. Studies have found that depressed females seek treatment in greater proportions than depressed males (Oliver, Pearson, Coe, & Gunnell, 2005; World Health Organization, 2001a); however, an Ontario-based study found that females were more likely to access services for mental

health reasons at ages 19 to 24 but no difference in access was found between males and females aged 15 to 18. (Cheung, Dewa, Cairney, Veldhuizen, & Schaffer, 2009).

5.2 Study Strengths

This research was strengthened by FEMAP researchers' collection of data on sequential patients enrolled into the program, including a wide range of variable available for risk adjustment. Though numerous variables were available for inclusion, the initial selection of candidate variables was grounded in the literature. A thorough, systematic approach was used for model selection followed by exhaustive testing of model assumptions and fit.

This research benefited from the low level of missing data. Redundant measures allowed for the use of logical imputation for some missing variables. Where logical imputation was not possible we used appropriate statistical imputation procedures for missing variables and missing questionnaire items so that all cases were included in analyses.

5.3 Study Limitations

Though this study had several strengths it is worth noting key limitations. This was a secondary, exploratory analysis of data so the data collection was not designed nor powered to look at factors associated with engagement. Several predictors were investigated increasing the risk of finding associations by chance; however, selection of predictors was based on a thorough literature review to minimize this risk. The limited sample size means that we may have had insufficient power to detect true associations.

The definition of engagement may result in misclassification bias due to loss to follow-up. Patients who were classified in this study to have not engaged may have actually engaged in treatment elsewhere. Four patients who moved out of London were classified as non-engaged. It is not known whether these participants would have engaged had they stayed in London, Ontario. Sensitivity analysis excluding these patients had little effect on parameter estimates, and thus this potential misclassification does not affect the main study findings.

Some of the predictor variables differed from definitions or measurements used by other studies. The gender variable presented only male and female response options thus we cannot generalize this research to a non-cisgender population. The ethno-racial background variable did not include a Black Caribbean option; however, there was a free text field in which participants could indicate a Black Caribbean background. We were not able to investigate in more detail the effect of trauma history on engagement in particular, as the Trauma History Questionnaire (THQ) did not allow for timing to be deduced. In particular, we could not investigate the effect of childhood trauma because unlike the original version, FEMAP's version of the THQ did not ask responders to indicate the specific age at which trauma occurred. When performing logical imputation for the THQ, we made assumptions about the reasons for missingness; however, we tested alternative assumptions and the impact on the THQ score was minimal.

Previous literature indicated that SES could be a predictor of engagement (de Haan et al., 2015; DelBello et al., 2007; Munson et al., 2010; Pelkonen et al., 2000). Even though parental education is likely correlated with SES, in the absence of data on family income, we may have been unable to capture an association between SES and engagement.

Previous literature found that substance use was associated with adherence; however, after investigating four variables, tobacco use, marijuana use, other illicit drug use, and quantity of alcohol consumed per occasion, only quantity of alcohol consumed was associated with engagement. It is possible that the dichotomization of the substance use variables diluted potential associations due to the heterogeneous nature of the any use ever grouping.

Though the literature suggests that a positive attitude about treatment is associated with engagement (Munson et al., 2010; Pogge et al., 2005), we did not directly measure attitude. We included satisfaction with previous mental health care as a proxy for a positive attitude about treatment assuming that those satisfied with past care are more likely to have a positive attitude about treatment. We also assumed that those who answered not applicable to the question, "The mental health care I have received has been

just about perfect”, did not previously receive mental health care. Cross-referencing with FEMAP data on receipt of previous care validated this assumption. It is also possible that participants who were included in the not satisfied group may have indicated satisfaction with previous mental health care had the question been worded more neutrally. This may have diluted any differences in engagement between the two groups, had they existed.

It was not possible to conduct stratified analysis, examining predictors by diagnosis, because the diagnosis was not determined at intake. We were able to assess symptom severity through the MADRS-S and ASI-R scores. In addition, our findings on predictors of engagement are relevant to clinical practice, before a diagnosis can be established.

We were not able to examine health system and health care team factors associated with engagement. There are aspects of the First Episode Mood and Anxiety Program that encourage engagement and reduce barriers to treatment at the system level. FEMAP is community-based, youth-friendly, allows for self-referral, and psychotherapy is provided for free whereas it can cost up to \$200 elsewhere. Because the entire cohort accessed FEMAP and were thus exposed to these factors, their effect, if any, on engagement could not be investigated in this project.

The generalizability of our results may be limited by several factors. The characteristics of the patient population in London, Ontario may differ from other settings. FEMAP treatment is provided as outpatient treatment only. Engagement in outpatient treatment may differ from engagement in inpatient care. FEMAP staff required each patient to participate in research in order to receive treatment and that may have influenced engagement.

5.4 Recommendations for Future Research

The current study defines engagement as attendance at the first clinical visit, after an extensive initial intake procedure. FEMAP patients may engage in treatment but may not remain engaged and may prematurely leave treatment. Future studies of the FEMAP population could investigate engagement in treatment over time. FEMAP continues to

collect data on all of its patients and can investigate the role of factors identified in this study on engagement in treatment over time, including gender, anxiety, and quantity of alcohol consumed per occasion.

Future studies could also investigate level of engagement rather than as a dichotomous variable. The Service Engagement Scale is a service-provider rated scale that has been used to measure engagement with community mental health services in patients diagnosed with schizophrenia (Tait, Birchwood, & Trower, 2002). There are 14 questions divided into four subscales each rated on a four-point Likert scale. The subscales: availability, collaboration, help seeking, and treatment adherence, can provide more detailed information on specific areas of engagement.

To address the limitations of a single center study, a multi-center study that compares FEMAP to other settings such as a general practitioner's office would be very informative in answering whether FEMAP has better engagement than more traditional treatments. Atwood et al. sought to investigate factors associated with dropout from community mental health treatment and found the service factors played a greater role than patient factors in predicting dropout from treatment among adults with a diagnosis of schizophrenia, MDD, bipolar disorder, paranoia, or borderline personality disorder (Atwood & Beck, 1985).

Future studies could also examine anxiety and gender, to see if our findings are generalizable to other populations. If gender and anxiety interact to affect engagement, future work could lead to a greater understanding of how anxiety influences engagement. This could lead to strategies that encourage engagement, particularly for females with high levels of anxiety.

Our study was focused on individuals who had already decided to come to FEMAP and had completed the intake procedure at FEMAP. Population-based studies can identify mood and anxiety disorders in the community, giving insight to individuals in this age group with mood and anxiety disorders who did not access FEMAP or other care options in the first place. Studies can focus on access to therapy for youth with mood

and anxiety disorders to provide insights on removing barriers to access and increasing the availability of treatment in this population.

5.5 Study Implications and Contributions

This study provided much needed Canadian data on engagement to community-based mood and anxiety disorders treatment. The study also focused on important transitional ages when services change from child to adult and responsibilities may shift to the individual rather than a parent or guardian. This research added to the literature on the link between anxiety and engagement. In particular, it added information on how gender interacts with anxiety in predicting engagement. Laurier et al. was the first to highlight low levels of engagement for female patients with high anxiety (Laurier et al., 2010). The role of substance use was investigated in greater detail highlighting the importance of the number of alcoholic drinks consumed per occasion as a predictor of engagement. This measure of binge drinking was a stronger predictor than use of illicit substances such as marijuana and cocaine.

5.6 Conclusion

We have identified gender, anxiety, and quantity of alcohol consumed per occasion as important factors for determining engagement. This information can be used by FEMAP to identify those at risk of not following through with the first clinical appointment in order to facilitate improved engagement in therapy. Our findings also highlight other areas of research that can lead to a greater understanding of engagement in treatment for youth with mood and anxiety disorders.

References

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Appendices

Appendix A Descriptive Statistics – Age

Before Categorization			After Categorization		
Age	Frequency	Percent	Age Group	Frequency	Percent
16	42	11.48	16 – 18	184	50.27
17	78	21.31	19 – 25	182	49.73
18	64	17.49	Frequency Missing = 0		
19	40	10.93			
20	30	8.20			
21	39	10.66			
22	24	6.56			
23	20	5.46			
24	11	3.01			
25	18	4.92			
Frequency Missing = 0					

Appendix B Descriptive Statistics – Ethno-racial Background

Before Categorization			After Categorization		
Ethno-racial Background	Frequency	Percent	Ethno-racial Background	Frequency	Percent
Aboriginal	5	1.38	White	279	77.07
White	279	77.07	Other	83	22.93
Black	9	2.49	Frequency Missing = 4		
Southeast/East Asian	13	3.59			
Other ethno-racial background	20	5.52			
Multiple ethno-racial backgrounds	36	9.94			
Frequency Missing = 4					

Appendix C Descriptive Statistics – Parental Education

Before Categorization			After Categorization		
Parental Education	Frequency	Percent	Parental Education	Frequency	Percent
Grade 9	2	0.56	Less than a college or university degree	88	24.58
Part of high school	8	2.23	College or University degree	270	75.42
High School Graduate	34	9.50	Frequency Missing = 8		
Part college or specialized training	44	12.29			
College or university graduate	202	56.42			
Graduate professional training	68	18.99			
Frequency Missing = 8					

Appendix D Descriptive Statistics – Parental Marital Status

Before Categorization			After Categorization		
Parental Marital Status	Frequency	Percent	Parental Marital Status	Frequency	Percent
Married	184	51.11	Married, Common law, Living together	198	55
Separated	68	18.89	Divorced, Separated, Widowed	162	45
Divorced	81	22.50	Frequency Missing = 6		
Widowed	13	3.61			
Common law/unmarried, living together	14	3.89			
Frequency Missing = 6					

Appendix E Descriptive Statistics – Marijuana Use

Before Categorization			After Categorization		
Marijuana Use	Frequency	Percent	Marijuana Use	Frequency	Percent
Never Used	125	34.25	Never	125	34.25
Tried but quit	83	22.74	Any usage ever	240	65.75
Several times a year	42	11.51	Frequency Missing = 1		
Several times a month	20	5.48			
Weekends only	17	4.66			
Several times a week	22	6.03			
Daily	33	9.04			
Several times a day	23	6.30			
Frequency Missing = 1					

Appendix F Descriptive Statistics – Other Illicit Drug Use

Before Categorization			After Categorization		
Other Illicit Drug Use	Frequency	Percent	Other Illicit Drug Use	Frequency	Percent
Never Used	248	68.13	Never	248	68.13
Tried but quit	66	18.13	Any usage ever	116	31.87
Several times a year	28	7.69	Frequency Missing = 2		
Several times a month	10	2.75			
Weekends only	3	0.82			
Several times a week	2	0.55			
Daily	7	1.92			
Several times a day	0	0			
Frequency Missing = 2					

Appendix G Descriptive Statistics – Tobacco Use

Before Categorization			After Categorization		
Tobacco Use	Frequency	Percent	Tobacco Use	Frequency	Percent
Never Used	175	48.08	Never	175	48.08
Tried but quit	77	21.15	Any usage ever	189	51.92
Several times a year	23	6.32	Frequency Missing = 2		
Several times a month	16	4.40			
Weekends only	4	1.10			
Several times a week	13	3.57			
Daily	23	6.32			
Several times a day	33	9.07			
Frequency Missing = 2					

Appendix H Descriptive Statistics – Quantity of Alcohol Consumption

Before Categorization			After Categorization		
Quantity of Alcohol	Frequency	Percent	Quantity of Alcohol	Frequency	Percent
1 drink	29	9.15	4 or fewer drinks	251	69.34
2 drinks	71	22.40	5 or more drinks	111	30.66
3-4 drinks	106	33.44	Frequency Missing = 4		
5-9 drinks	98	30.91			
10 or more drinks	13	4.10			
Frequency Missing = 49					

Appendix I Descriptive Statistics – Satisfaction with Previous Mental Health Care

Before Categorization			After Categorization		
Satisfaction	Frequency	Percent	Satisfaction	Frequency	Percent
Not applicable	56	15.43	Not applicable	56	15.43
Strongly Disagree	42	11.57	Not Satisfied	269	74.10
Disagree	107	29.48	Satisfied	38	10.47
Uncertain	120	33.06	Frequency Missing = 3		
Agree	36	9.92			
Strongly Agree	2	0.55			
Frequency Missing = 3					

Appendix J Descriptive Statistics – Trauma History

Before Categorization			After Categorization		
Types of Trauma Experienced	Frequency	Percent	Trauma History	Frequency	Percent
0	75	20.66	Low trauma	188	51.79
1	113	31.13	High trauma	175	48.21
2	104	28.65	Frequency Missing = 3		
3	71	19.56			
Frequency Missing = 3					

Appendix K Associations Among Continuous Covariates (Pearson Correlation Coefficient)

	ASI-R Score	MADRS-S Score	SDS Score	ICSRLE Score
ASI-R Score	1.00	0.39	0.31	0.39
MADRS-S Score		1.00	0.55	0.51
SDS Score			1.00	0.40
ICSRLE Score				1.00

ASI-R, Anxiety Sensitivity Index – Revised 36; SDS, Sheehan Disability Scale; ICSRLE Inventory of College Students' Recent Life Experiences; MADRS-S, Montgomery-Åsberg Depression Rating Scale – Self Report

Appendix L Chi-square Tests of Association Among Categorical Covariates (p-value)

	Age	Ethno-racial background	Parental education	Parental marital status	Quantity of Alcohol Consumed	Smoke	Marijuana	Other illicit drugs	Trauma	Satisfaction
Sex	0.7950	0.9516	0.7124	0.4862	0.1498	0.1689	0.5346	0.1321	0.2802	0.8652
Age		0.0110	0.3617	0.7454	0.0013	0.0002	0.0001	0.0019	0.0066	0.8652
Ethno-racial background			0.8680	0.6003	0.3741	0.6894	0.4201	0.1959	0.2288	0.5336
Parental education				0.0093	0.0401	0.4951	0.4985	0.0486	0.5509	0.7272
Parental marital status					0.0107	0.1515	0.4867	0.6632	0.0042	0.3777
Quantity of Alcohol Consumed						<0.0001	<0.0001	<0.0001	0.0010	0.6096
Smoke							<0.0001	<0.0001	<0.0001	0.0003
Marijuana								<0.0001*	<0.0001	0.0272
Other illicit drugs									<0.0001	0.0152
Trauma										0.4392

*Fisher's Exact Test

**Appendix M Between group differences in Continuous and Categorical Covariates
(t-tests)**

Variable	ASI-R p-value mean (SD)	SDS p-value mean (SD)	ICSRLE p-value mean (SD)	MADRS-S p-value mean (SD)
Age group	0.2292	0.1242	0.5562	0.8497
16-18	53.80 (33.52)	16.67 (7.49)	106.4 (24.06)	12.35 (4.51)
19-25	57.83 (30.26)	17.84 (6.98)	104.9 (22.76)	12.26 (4.50)
Sex	<0.0001	0.2850	0.0030	0.0455
Male	43.48 (28.36)	16.67 (7.40)	100.5 (23.06)	11.63 (4.34)
Female	61.89 (31.94)	17.54 (7.18)	108.2 (23.20)	12.63 (4.54)
Ethno-racial background	0.2344	0.4344	0.6805	0.3822
White	56.89 (32.61)	17.41 (7.33)	105.4 (23.37)	12.42 (4.38)
Other	52.16 (29.56)	16.71 (7.00)	106.6 (23.63)	11.93 (4.87)
Parental education	0.1651	0.0314*	0.4088	0.3020
College or more	54.47 (31.89)	16.83 (7.51)	105.1 (23.61)	12.16 (4.61)
Less than a college degree	59.84 (32.01)	18.56 (6.19)	107.4 (22.78)	12.73 (4.11)
Parental marital status	0.3212	0.0493	0.2461	0.9816
Married	54.30 (30.87)	16.58 (7.55)	104.4 (23.36)	12.30 (4.58)
Unmarried	57.64 (33.25)	18.07 (6.80)	107.2 (23.43)	12.31 (4.40)
Quantity of Alcohol Consumed per Occasion	0.2839	0.9297	0.0011	0.0577
4 or less	54.61 (32.45)	17.23 (7.07)	103.0 (23.18)	12.01 (4.52)
5 or more	58.50 (30.79)	17.30 (7.66)	111.6 (22.90)	12.97 (4.39)
Smoking	0.0231	0.4463	<0.0001	0.0007
Never	51.87 (32.22)	16.95 (7.41)	100.6 (23.43)	11.48 (4.59)
Any usage ever	59.45 (31.37)	17.53 (7.10)	110.3 (22.43)	13.07 (4.28)
Marijuana	0.1196	0.1414	<0.0001	0.0118
Never	52.21 (33.24)	16.48 (7.48)	98.60 (24.41)	11.49 (4.83)
Any usage ever	57.69 (31.18)	17.65 (7.10)	109.4 (22.01)	12.73 (4.26)
Other illicit drugs	0.3090	0.2376	0.0005	0.0342
Never	54.64 (32.17)	16.94 (7.26)	102.8 (23.30)	11.96 (4.58)
Any usage ever	58.29 (31.51)	17.90 (7.20)	111.8 (22.51)	13.03 (4.23)
Trauma	0.0257	0.1738	<0.0001	0.2840
Low trauma	52.24 (32.94)	16.76 (7.22)	99.81 (23.07)	12.06 (4.75)
High trauma	59.69 (30.48)	17.79 (7.27)	112.1 (22.11)	12.57 (4.20)

Variable	ASI-R p-value mean (SD)	SDS p-value mean (SD)	ICSRLE p-value mean (SD)	MADRS-S p-value mean (SD)
Satisfaction	0.0806	0.1932	0.3215	0.0002
Not applicable	49.37 (29.96)	15.74 (7.48)	103.75 (24.77)	11.60 (4.63)
Not satisfied	58.01 (32.30)	17.62 (7.12)	106.7 (23.64)	12.81 (4.32)
Satisfied	49.51 (31.79)	16.83 (7.77)	101.2 (19.06)	9.74 (4.65)

ASI-R, Anxiety Sensitivity Index – Revised 36; SDS, Sheehan Disability Scale; ICSRLE Inventory of College Students’ Recent Life Experiences; MADRS-S, Montgomery-Åsberg Depression Rating Scale – Self Report

*t-test with unequal variances

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