

Mental Illness Stigma: Experiences of Youth with a Mental Disorder

by

Sally-Anne Haug  
B.A., Douglas College, 2009

A Thesis Submitted in Partial Fulfillment  
of the Requirements for the Degree of

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## Abstract

Canadian society continues to stigmatize individuals with mental illness, despite the prevalence of mental illness in the population, decades of advocacy to combat mental illness stigma, and known negative sequelae of experiences of stigma by people affected by a mental illness. One negative impact of stigma is internalization of negative connotations attached to mental illness. Although there is extensive research on the stigma of mental illness, there is little information specifically about how youth with mental illness perceive the stigma of mental illness and how they respond to it. The current research sought to understand how youth who self-identify as having a mental illness experienced, perceived and internalized the stereotypes, prejudice and discrimination of the stigma of mental illness. A simple content categorization method was used to identify key themes in the transcribed interviews of eleven youth in Vancouver Canada who identified as having mental illness. Qualitative analysis identified that the most frequent perpetrators of public stigma included casual acquaintances, family, friends, school staff, mental health professionals and authority figures. Youths' accounts linked mental illness stigma with low mental health literacy, delayed mental health treatment and a low quality of life. The findings are considered with reference to implications for prevention of stigma, including enhanced mental health literacy for mental health professionals and the public aimed at increased understanding, sensitivity and empowerment of youth with mental illness and their families.

*Keywords: mental illness, mental health literacy, adolescence, youth, adolescent, stigma, self-stigma, medication, mental disorders, depression, disclosure.*

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Namaste

## Dedication

I dedicate this thesis to the power of music to heal, support and elate. Musicians paint their pictures on silence. After silence, that which comes nearest to expressing the inexpressible is music. Music is an explosive expression of humanity that encapsulates magic, bliss, emotion, power, myth, celebration and spirituality. Music plays an integral role in shaping cultural groups by defining their values, identities and contexts. Most cultural groups have traditions that revolve around music that connect us to memories later in life. It also provides a platform for political expression.

As well as influencing humanity, I believe music can improve mental health by reducing our stress, helping us sleep better, improving our mood and influencing us to get up and dance. Because mental illness is so prevalent, many artists are impacted by mental health challenges and the stigma of mental illness. David Bowie's original 1970 US release of *The Man Who Sold the World* album sleeve art portrayed a drawing of the now defunct Cane Hill psychiatric hospital in South London where his half-brother Terry had been admitted. He had been diagnosed with schizophrenia, one of the most highly stigmatized mental illnesses. Bowie's songs *All the Madmen*, *The Man Who Sold the World*<sup>1</sup>, *Aladdin Sane*<sup>2</sup>, *I'm Deranged*<sup>3</sup>, *Jump They Say*<sup>4</sup> and *Ziggy Stardust*<sup>5</sup> were written with themes of mental illness. David Bowie was loved and mourned by many when he passed away on January 10, 2016, two days after he released his 25<sup>th</sup> studio album, *Blackstar*<sup>6</sup>, which also coincided with his 69<sup>th</sup> birthday.

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<sup>1</sup> Bowie, D. (1970). On *The Man Who Sold the World* [Record]. London, England: Mercury.

<sup>2</sup> Bowie, D. (1973). On *Aladdin Sane* [Record]. New York: RCA.

<sup>3</sup> Bowie, D. (1995). On *Outside* [CD]. Switzerland: BMG/Arista/RCA.

<sup>4</sup> Bowie, D. (1993). On *Black Tie White Noise* [CD]. Los Angeles: Savage.

<sup>5</sup> Bowie, D. (1972). On *The Rise and Fall of Ziggy Stardust and the Spiders from Mars* [Record]. London, England: Trident.

<sup>6</sup> Bowie, D. (2015). On *Blackstar* [CD]. New York: ISO/RCA/Columbia/Sony.

I applaud the courageous artists worldwide who acknowledge their loved ones suffering with mental illness and for disclosing their mental illness to the world with their music. I believe music has the power to heal, help us understand and facilitate the much-needed change regarding the stigma of mental illness. Music never leaves.

## Chapter 1: Introduction

Mental illness is the main cause of disability in young people and has led to more life lost than any other health condition (Gore et al., 2011, Sawyer et. al, 2012; World Health Organization [WHO], 2014). In Canada, Simon Fraser University's Children's Health Policy Centre estimated 84,000 or 12.6% of youth aged 4 to 17 years experienced clinical mental illness and only 31% received treatment (Waddell et al., 2014).

The purpose of this study is to describe how the stigma of mental illness is experienced by youth living with mental health challenges. The term stigma has been widely used since the 1960's. However, it has only recently been applied to childhood and adolescent mental health challenges. Goffman (1963) explained his stance on stigma and society:

...we believe the person with a stigma is not quite human. On this assumption we exercise varieties of discrimination, through which we effectively, if often unthinkingly, reduce his life chances. We construct a stigma-theory, an ideology to explain his inferiority and account for the danger he represents, sometimes rationalizing an animosity based on other differences, such as those as social class. We use specific stigma terms such as cripple, bastard, moron in our daily discourse as a source of metaphor and imagery, typically without giving thought to the original meaning. (p. 5)

Researchers have since studied stigma components (i.e. social distance, peer rejection, global attitudes), but much less is known about emotional and behavioural responses, stereotypes, and internalized and self-stigma experienced by children and adolescents (Heary, Hennessy, Swords & Corrigan, 2017; Mukolo, 2010). These findings are surprising, given the frequently expressed concern that the majority of adolescents with emotional or behavioural disorders either do not receive treatment or do not access service (Clement et al., 2015).

A need has been identified for research evaluating mental illness stigma experiences of youth in different communities, of different socioeconomic status, in different types of treatment and diagnosed with specific disorders (Heary, Hennessy, Swords & Corrigan, 2017; Shechtman, Vogel, Strass & Heath, 2018). Findings could enable development of knowledge about the risk and protective factors for adolescent exposure to mental illness stigma and the contexts in which stigma generates harm. Furthermore, this knowledge could inform current and new interventions that support adolescents when coping with mental health challenges.

For this study, the researcher examined perceived stigmatization on the part of youth diagnosed and /or treated for various mental disorders. I interviewed youth at an urban Canadian mental health program to explore the extent to which they experience stigma and to better understand the effects of mental illness stigma on youth. Interviews focused on youths' experiences with stigma, their perceptions of their mental health, social support and experiences with treatment.

For the purpose of this study, I have taken the definition of mental health used in the 1981 WHO report on the social dimensions of mental health:

Mental health is the capacity of the individual, the group and the environment to interact with one another in ways that promote subjective well-being, the optimal development and the use of mental abilities (cognitive, affective and relational), the achievement of individual and collective goals consistent with justice and the attainment and preservation of conditions of fundamental equality. (as cited in WHO, 2000, p. 12)

This definition has several advantages in relation to adolescent mental health because it stresses the complexity of interrelationships determining mental health and that factors determining health operate on several levels. It also goes beyond the biological and the individual, acknowledges the

integral role of the ecological environment and highlights the importance of justice in determining mental wellness (WHO, 2000).

Conversely, mental illnesses are characterized by changes in thinking, mood or behaviour associated with significant distress and impaired functioning. They arise from a complex interaction of environmental, personality, biological and genetic factors and affect people of all ages, education levels, income levels and cultures. There are many types of mental illnesses and they range from single, short-lived episodes to constantly reoccurring (Public Health Agency Canada, 2015).

When the community's response to mental illness is supportive and caring, one might expect the likelihood of relapse and exacerbation of symptoms to decrease and that healthy survival would increase. Conversely, when an individual diagnosed with mental illness experiences stigma, it may leave a mark of disgrace associated with their particular circumstance (McKean, 2005) and can produce a "consequent reduction in the valuation of the individual" (Goffman, 1963, p.44). Arboleda-Florez (2003) claimed little had been done to understand why stigma develops and argued that in order for stigmatizing attitudes to happen, three major elements are required: "an original 'functional impetus' that is accentuated through 'perception' and subsequently, consolidated through 'social sharing' of information. The sharing of stigma becomes an element of a society that creates, condones, and maintains stigmatizing attitudes and behaviours" (p. 646). Therefore, stigma serves a function (possibly avoiding a threat to the self or the stigmatizer) which leads to shared beliefs that create and condone attitudes and actions against the stigmatized. Phelan, Link and Dovidio (2008) later claimed stigma facilitates power hierarchy (keeping people down) and conformity (keeping people in) and decreases exposure to contagious disease (keeping people away).

Barriers to help-seeking behaviour might include low perceived need, desire to manage

on their own, negative experiences with service providers (Andrade et al., 2014), lack of familial and social support (Petersen, Friis, Haxholm, Nielsen & Wind, 2015), substance use (Fanale, Maarhuis, Wright & Caffrey, 2017; Green, Yarborough, Polen, Janoff & Yarborough, 2015), transportation (Lingley-Pottie, McGrath & Andreou, 2013), medication dissatisfaction, staff turnover (Oruche, Downs, Holloway, Draucker & Aalsma, 2014), concerns regarding confidentiality (Gulliver, Griffiths & Christensen, 2010) and fear of mental illness stigma (Corker et al., 2016). Conversely, collaborative decision making with family (Butler, 2014), positive past treatment, mental health literacy, influence of social supports (Rickwood, Deane, Wilson & Ciarrochi, 2005) and respectful communication with service providers increased help-seeking behaviour (Gondek et al., 2017; Gulliver, Griffiths & Christensen, 2010).

### **Rationale**

When doing clinical work at an urban Canadian clinic for youth (i.e. 15-24 years of age) with concurrent disorders, I found clients capable of identifying the symptomatology of their mental illness. However, when given a label, many were reluctant to adhere to treatment. Often, referrals were made after a youth experienced a psychotic episode exacerbated by substance abuse. After meeting these youth, concern led me to question why some chose not to attend subsequent appointments. This knowledge piqued my interest in finding out why youth were not adhering to treatment and subsequently piqued my interest in the literature.

Mental health is as important as physical health. In 2011, it was estimated over 1.04 million youth were living with mental illness in Canada. This number represents 23.4% or nearly one in four young people and is expected to increase to 1.2 million in 2041 (MHCC, 2013). In 2016, more than 900,000 youth (ages 13 to 19) lived with mental health challenges in Canada (MHCC, 2017). After unintentional injuries, suicide was the second leading cause of death

among youth aged 15-34 years and third for youth aged 10-14 and adults aged 35-44 in 2012 (Statistics Canada, 2012 as cited in Skinner et al., 2016). Although suicide rates have decreased, attempts among women aged 15-19 years remain a concern because the hospitalization rate for self-harming behaviour was three and a half times that of young men in the same age category (Skinner et al., 2016). When mental illness goes untreated, it can lead to school failure (Murphy, 2014), decreased vocational success, problematic interpersonal relationships (Breslau et al., 2011) and childbearing (Jonsson, 2011), drug abuse, violence and reduced life expectancy due to increased risk of suicide, increased morbidity (Bedasso et al., 2016) and associated medical conditions (Boden, 2018; Bota, 2017; Gan et al., 2014; Smetanin, et al., 2011).

Negative effects of stigmatization occur even when symptoms and functioning are controlled, meaning that the effects of stigma originate from mental illness itself (Hinshaw, 2007; Yanos, 2018). Substantial literature reveals the integral role of supportive, stable relationships with family and peers in not only protecting at-risk youth from the stigma associated with mental illness (Warren, Jackson & Sifers, 2009) but also in reducing the level of impairment for those who already evidence mental health challenges (Meadows, Elder & Brown, 2006). Meadows et al. found mentally ill youth experience less social support than their mentally well peers, placing them at greater risk for negative life outcomes. Mental illness stigma may be the culprit behind compromised support among teens experiencing emotional and behavioural challenges.

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## **Chapter Two: Literature Review**

This chapter provides a synthesis of the literature focusing on the perceived stigmatization of people diagnosed and/or treated for various mental disorders. Although the focus on children and youth mental illness stigma is relatively new (Heary, Hennessy, Swords & Corrigan, 2017), the focus on adult mental illness stigma has been extensively documented and provides the foundation for this review. Key phrases and words such as mental illness, adolescence, youth, adolescent, young adult, stigma, medication, mental disorders, depression, disclosure, support and perception were used to locate relevant literature (i.e. books and articles) on the University of Victoria's (UVIC) databases. Reference lists in many of the articles proved helpful in securing additional resources.

### **Historical Treatment and Response to the Mentally Ill**

Throughout much of human history, in most cultures, mental illness has been associated with deviant behaviour and attributed to possession by the devil or evil spirits (Zilboorg, 1941 as cited in Hinshaw, 2005). According to Cicero and Plutarch, the mentally ill were often kept in dark cells and dungeons prior to the Christian era in Western Europe (Koenig & Larson, 2001). In Western civilization, religious organizations have provided some of the first and best care to the mentally ill in the general population. However, care provided by the church to the mentally ill was not always empathic. When an individual (often a mentally ill person) was untreatable by exorcism, religious authorities might have executed them by burning or by decapitation (Alexander & Selesnick, as cited in Koenig & Larson).

During the middle ages, mental illnesses were perceived as God's punishment and sufferers were perceived as being possessed by the devil and either burned, thrown in penitentiaries or madhouses and restricted by chains (Rossler, 2016). In Greek society, slaves, criminals and

traitors were identified with a *stizein*, a cutting or burning of their skin permanently identifying them as less valuable or immoral. Stigma, the modern derivative, is therefore understood to mean a social construction of social disgrace attached to others in order to identify and devalue them (Arboleda-Flórez, 2002; Odekon, 2015).

Fortunately, we no longer sentence the mentally ill to death when they seem untreatable or appear to be an evildoer. However, the socially constructed stigmatization of mental illness has been shown to add an unnecessary burden (i.e. decreased life opportunities and enhanced impairment) to those suffering from mental health disorders (Hinshaw, 2007; Yanos 2018).

### **Stigmas and How They Have Been Experienced**

Stigma is defined as a devalued attribute or characteristic in a social context used to reduce an individual “from a whole and usual person to a tainted discounted one” (Goffman, 1963, p. 3). Stigma entails the cognitive and behavioural constructs of stereotypes, prejudice and discrimination. Stereotypes are defined as seemingly factual structures of any given culture that typically include negative evaluation (Corrigan & Bink, 2016).

Mental illness stigma undermines help seeking, treatment adherence and participation in programs for reducing dysfunction and promoting recovery. Studies clearly show stigma is negatively correlated with lower self-esteem, lower self-efficacy, lower self-confidence, treatment adherence, quality of life, loss of hope and social support (Fung, Tsang, Corrigan, Lam & Cheng, 2007; Livingston & Boyd, 2010), internalized stigma (Lau et al., 2017), secrecy, discrimination, social avoidance and withdrawal (Sarkin et al., 2015), rejection (Perry, 2011), lower recovery orientation (Drapalski et al., 2013) and status loss (Link et al., 2001).

Substantial literature reveals the integral role of supportive, stable relationships with family and peers in not only protecting at-risk youth from the stigma associated with mental

illness (Warren, Jackson & Sifers, 2009) but also in reducing the level of impairment for those who already evidence mental health challenges (Meadows, Elder & Brown, 2006). Meadows et al. found mentally ill youth experience less social support than their mentally well peers, placing them at greater risk for negative life outcomes. Mental illness stigma may be the culprit behind compromised support among teens experiencing emotional and behavioural challenges.

Because stigma is socially constructed, I believe it is critical to examine both external and intraindividual stigma processes. In the following section, I refer to these constructs as public stigma and self-stigma respectively and discuss how each affect individuals with mental illness in different domains of their lives.

### **Definitions of Public Stigma and Self-Stigma**

The public stigma of mental illness represents the discrimination and prejudice targeted at people with mental illness by members of the public (Kranke, Floersch, Townsend & Munson, 2010) and refers to the negative attitudes about people with devalued traits (Corrigan & Rao, 2012). Researchers found public stigma plays a role in the development of self-stigma, which is the integral determinant of seeking mental health treatment (Lannin, Vogel, Brenner & Tucker, 2015; Picco et al., 2017; Vogel, Wade & Hackler, 2007; Vogel, Bitman, Hamer & Wade, 2013).

Self-stigma may begin when people with mental illness are aware of the stereotypes that describe this stigmatized group and agree with them. If they internalize the negative social responses which lead to feelings of rejection and significant reductions in their self-esteem and self-efficacy (Corrigan & Kleinlein, 2005; Corrigan, Druss, & Perlick, 2014; Link & Phelan, 2001), they are vulnerable to endorsing stereotypes about themselves (Watson, Corrigan, Larson & Sells, 2007).

## Stereotype, Prejudice and Discrimination

Table 1 displays the comparisons and contrasts between stereotype, prejudice and discrimination with these aforementioned stigmas (Corrigan & Watson, 2002; Link & Phelan, 2001; Rüsch, Angermeyer & Corrigan, 2005). These terms are referenced throughout the chapter when applicable.

Table 1

Comparisons and contrasts of self-stigma and public stigma

|                      |   |
|----------------------|---|
| <b>Public Stigma</b> |   |
| Stereotype           | Negative belief about a group (e.g. danger, incompetent, weakness)        |
| Prejudice            | Agreement with belief and/or negative emotional reaction (e.g. fear)      |
| Discrimination       | Behaviour response to prejudice (e.g. avoidance, withhold opportunity)    |
| <b>Self-Stigma</b>   |   |
| Stereotype           | Negative beliefs about the self (e.g., character weakness, incompetence)  |
| Prejudice            | Agreement with belief, negative emotional reaction (e.g. low self-esteem) |
| Discrimination       | Behaviour response to prejudice (e.g. fails to pursue opportunities)      |

This literature review will now focus on how stereotype, prejudice and discrimination have been experienced in both the public stigma and self-stigma of mental illness.

### Public Stigma

#### Family

Lieghio (2017) examined stigma within families by interviewing seven youth ages 13 to 21 years, with a brother or sister living with mental health challenges. She focused on how youth

experienced their sibling's mental illness and how those experiences affected their sense of self and family. All youth were able to name diagnoses correctly, however, most definitions were constructed as "bad" (p. 1240) behaviours or misbehaviours and their sibling's way of being was described as a character flaw. Being unable to predict recovery or count on professional treatment increased feelings of worry, stress and sense of burden. However, one participant felt relieved when his brother was diagnosed with schizophrenia (a highly stigmatized label) because he let go of the belief his brother was "not a good person" (p. 1240).

Youth also reported loss of parental income, decreased productivity and strain on family relationships. When considering disclosure, siblings reported concealment and/or hesitation to discuss the matter inside the home because it was believed talking to one another would be unhelpful. Conversely, Goodwin, Savage and Horgan (2016) found open communication with family had a positive impact on youth experiencing mental health challenges. However, some youth in Liegghio's (2017) study conveyed a desire to talk to other siblings in similar situations as they thought it may help. Family can become a stigma source and diagnosed youth can be implicated as the cause of family stigmatization. Constructions of mental illness in behavioural terms appeared to perpetuate stigma in these families because behaviours were perceived as flaws or concerns in their character or morality. Stigmatization continued to be attributed to "the other" and became a mechanism that consistently created cycles of blame and shame (Liegghio, 2017).

When studying parents of children with mental health challenges, researchers found parents experienced public stigma and self-stigma resulting in social avoidance, self-doubt, blame, judgment and criticism for their role in the causation, exacerbation or continuation of

their child's illness (Corrigan & Miller, 2004; Eaton, Ohan, Stritzke and Corrigan, 2016; Fernández & Arcia, 2004; Francis, 2012; Moses, 2010).

### **Peers**

Weitkamp, Klein and Midgley (2016) found youth experiencing mental health challenges withdrew somewhat from peers, but were able to maintain some friendships and perceived friends as a distraction and holiday from their mental health challenges. However, they were reluctant to confide in them for fear of being judged or stigmatized. This may be explained by the normalization hypothesis which posits that peer groups and friendship are their primary reference and render them sensitive to peers' negative assessment (Wolfensberger, Nirje, Olshansky, Perske & Roos, 1974).

Elkington et al. (2012) found 60 per cent of youth with mental illness believed people without mental illness would not want a partner with mental illness. Participants believed mental illness to be something they would not want to manage and that over time, would consider a partner with mental illness a burden. Some youth had internalized stigma which consequently led them to believe they had limited ability to choose a partner, did not make a good partner or were undeserving of sexual or romantic relationships. Interestingly, 25% of participants reported no stigma experience and did not seem to internalize negative beliefs or attempt to manage a stigmatized identity. Perhaps their ecological environment consisted of supportive family, school staff, friends and effective mental health care.

In their Singapore study surveying 940 youth ages 14-18 years, Pang et al. (2017) found most participants had misconceptions regarding mental illness. Almost half, 46.2%, said they would feel embarrassed if they were diagnosed with a mental illness; 44.5% held negative beliefs regarding mental illness; 22.7% said they would not want others to know if a family member had

mental illness; and 35.1% believed their friends would perceive them as weak if they had mental illness. Despite these findings, 80% would visit a mentally ill classmate in hospital; 89.6% would report someone teasing someone because they had mental illness; 87.5% would stand up for someone being teased due to illness and 52.1% were willing to volunteer for mental health related causes. Some of these findings are positive, but this study indicates the need for increased mental health literacy and decreased stigmatization.

### **Community**

When examining factors that may contribute to the development of public stigma, social proximity, or level of familiarity with mental illness or mental health services, proves important (Corrigan, Green, Lundin, Kubiak & Penn, 2001). For example, Collins, Roth, Cerully & Wong (2014) found mental illness stigma rates lower among younger (i.e. 18-29 years) versus older adults (i.e. 30 years and older). One quarter said they would not live next door to someone with mental illness and 20% considered people with mental illness to be dangerous and were unwilling to work closely with someone diagnosed with mental illness. The stigma rates of young adults were approximately 30 to 50 percent lower than older adults. Furthermore, young adults were more likely to report recent contact with someone experiencing mental health challenges, which may explain these discrepancies. On a positive note, 71% of young adults and 70% of older adults agreed or strongly agreed a person with mental illness can eventually recover.

Many studies have investigated the association between psychopathology and violence over the last twenty years. Studies have found mental illness is clearly relevant to violence risk but that its causal roles are complex and enmeshed with other significant individual, contextual and situational factors. Researchers found that most violent acts are committed by individuals

who are not mentally ill, and that substance abuse (which is more common in people with mental illness) is the cause of the increased risk of violence associated with mental illness (Fazel et al., 2015; Van Dorn, Volavka & Johnson, 2012; Van Dorn et al., 2017). Further, Van Dorn, Volavka and Johnson confirmed that childhood abuse and neglect, household antisocial behavior, binge drinking, past violence, juvenile detention and stressful life events also compounded the risk of violence.

Despite these findings, developing countries (i.e. Turkey and India) were found to have a significantly higher prevalence of belief that people who are mentally ill are dangerous or violent than developed countries (i.e. Australia, Germany, Japan and Canada). However, prevalence rates in the USA were comparable to those of developing countries where 42% of American adults perceived a depressed child likely to be violent (Jorm & Reavley, 2014).

### **School**

Thijs, Koomen, and van der Leij (2008) pointed out the significant impact of teacher behaviours and teacher-student relationships on student success and adjustment. If school staffing openly included additional mental health professionals, perhaps mental health concerns would be identified earlier, mental health literacy would be increased and the issue of mental illness stigma could be addressed. Bowers, Manion, Papadopoulos & Gauvreau, (2013) found youth either strongly disagreed or disagreed mental health resources were made available at their school if they had questions. Fortunately, 31.5% perceived their teachers to be prepared to manage and identify mental health needs.

Children who withdraw or experience difficulty participating because they are inhibited or excluded by peers can become vulnerable. These children are also at risk for mental illness (Caspi, Elder & Bem, 1988; Rudolph, Troop-Gordon, Monti & Miernicki, 2014). Another study

focusing on shyness in childhood found some outgrew shyness but recommended monitoring shyness in adolescence because they may have co-occurring mental health problems (Schmidt et al., 2017).

### **Professional Stigma**

How caregivers perceive individuals with mental illness can have significant impact on treatment outcomes and quality of life. Mental health caregivers also play the role of educator whose behaviours and attitudes influence future caregivers. A study researching therapy expectations of adolescents with depression identified four significant themes: not knowing, but being cautiously hopeful; therapy as a place to gain a better understanding of themselves; therapy as a long, challenging process and the central role of professional and interpersonal skills of the therapist (Weitkamp, Klein, Hofmann, Wiegand-Grefe & Midgley, 2017). One youth valued the idea of strengthening self-esteem and meeting peers in group therapy where they could express their mental health difficulties without fearing ostracism. Overall, participants lacked clear ideas of therapeutic processes beyond talking to a professional. However, they were optimistic about the alleviation of challenges, although some expectations were cautiously formulated to protect themselves from disappointment.

Munford and Sanders's (2016) study researching youth experiences after receiving mental health treatment found harm and adversity (i.e. exposure to abuse, violence, addictions, disengagement from school and mental health issues) had been replaced with opportunities to move forward in order to create new developmental pathways leading to better outcomes. However, youth reported confusion regarding why things were happening; where services were located and services they were involved with and therefore felt the need to develop their own explanations for why things were happening (e.g. they are too busy to offer adequate service).

Youth offered several recommendations for improvement. Common themes included wanting to be listened to and being encouraged to work alongside practitioners collaboratively as youth believed this relationship could be significant. Social workers were found to become an enduring presence as they aimed to understand their experiences and provided nurturing support. Munford and Sanders's results reinforce how supportive relationships with social workers can build on youth's capacities and create efficacious practices with youth as partners (Kumpulainen, Lipponen, Hilppo & Mikkola, 2013).

Conversely, many youth diagnosed with mental illness found it challenging to engage in collaborative treatment due to self-stigma impacting their sense of agency (Kranke, Floersch, Kranke & Munson, 2011). Further, other studies have found participants commonly reported feeling dehumanized, dismissed and devalued by health professionals. As a result, they believed poor treatment impacted their mental health negatively, creating a health issue, not just a social justice issue (Hamilton et al., 2016; Knaak, Mantler & Szeto, 2017; Sansone & Sansone, 2013).

As Link and Phelan (2001) indicated, there has been a tendency among researchers to perceive stigma as existing within the individual. As outlined in this review, most stigmas proved to be relational. Given each individual's personal and environmental perspective, the myriad of responses to mental illness appear consistent with the ecological systems perspective in that an individual's behaviour and development are unique as they interact with and are strongly affected by external influences (Bronfenbrenner, 1979).

### **Self-Stigma**

#### **Help-Seeking Behaviour**

Despite the high prevalence of mental illness across the lifespan, young people carry a significant portion of the burden of mental illness and their access to effective mental health

treatment is the lowest (McGorry, Bates & Birchwood, 2013). Often, the general public's view of mental health services and care is negative (Rüsch et al., 2014). Before a mental disorder manifests, chances are that the affected individual has heard negative aspects regarding mental illness.

Giroux (as cited in Fouts, Callan, Piasentin & Lawson, 2006) found the Walt Disney Company (WDC) to be the major world producer of full-length animated films. Of 34 WDC animated films studied by Lawson and Fouts (2004), 85% contained verbal references to mental illnesses differentiating and denigrating characters. For example, “crazy,” “mad” or “madness,” and “nut” or “nutty” (p. 312) were used by producers to segregate and illuminate the “less than” status of their character(s). A majority of families see these films which likely create a sense of familiarity and identification with the characters as the stories, emotions and potential lessons may impact young viewers (Fouts, Callan, Piasentin & Lawson, 2006). Having watched a few Walt Disney animated films, children may subsequently learn to stereotype others, thinking it is acceptable and funny (Lawson & Fouts). Further, when living in a society rampant with stigmatizing images, young people may fear accepting these notions and subsequently experience diminished self-esteem and faith in their future. The impact of stigmatizing beliefs results in avoidance and a significant loss of self-esteem (Abiri, Oakley, Hitchcock & Hall, 2016).

For children and youth experiencing mental health challenges, the persistence of stigma likely impacts many aspects of their lives including help seeking behaviours as younger adults have shown stronger critical attitudes in regards to seeking help (Bowers, Manion, Papadopoulos & Gauvreau, 2013; Corrigan, Druss & Berlick, 2014; Gronholm, Thornicroft, Laurens & Evans-Lacko, 2017; Hartman et al., 2013). In addition, researchers found one in eight high school

students experienced self-stigma and felt shameful about disclosing their mental health challenges and self-conscious about seeking help (Hartman et al., 2013). Further, a systematic review found young people feel stronger tension between their preferred social identity and negative stereotypes regarding mental health challenges, resulting in a stronger correlation between stigma and help-seeking. Disclosure concerns were the most common barrier to seeking help (Clement et al., 2015).

Another Canadian high school study (Zeifman et al. 2015) examined whether adolescents scoring high in perfectionism experienced self-stigma when seeking mental health treatment. Perfectionism was found to be associated with self-stigma among those with little to no contact with people with mental health challenges. Further, students were found to feel shame, embarrassment and have low self-acceptance and judge themselves negatively for needing treatment. Results differed when past exposure to people with mental illness was considered as perfectionism and self-stigma were significantly unrelated. Thus, contact with someone with mental illness was found to reduce self-stigma and beliefs regarding mental health treatment.

Forty-nine young people ages 13-20 years at an Ontario high school completed a survey or interview regarding their perception of stigma as a barrier to accessing school-based mental health services and their perceived extent of mental health problems. Overall, 47.8% of youth, whether they had a mental health concern or not, perceived stigma as the main barrier to accessing service and 71% reported very few or none of their friends had a mental health concern or illness (Bowers, Manion, Papadopoulos & Gauvreau, 2013). This finding contradicts the literature as researchers have found one in five experience mental health challenges and 75% of people with mental illness experience onset during childhood and adolescence (Carver et al., 2015; Kessler et al., 2012). This may reflect a lack of mental health literacy or fear of self-

disclosure, which plays a significant role in the establishment, maintenance and enhancement of intimate relationships (Bowers et al., 2013).

Thornicroft et al. (2017) examined 51,547 community surveys from 21 countries to determine if adequate treatment was delivered to people diagnosed with major depressive disorder (MDD). Out of these respondents, 4.6% met the criteria for DSM-IV MDD and of these, 56.7% reported needing treatment and 71.1% completed one visit to a service provider (this included religious advisors or traditional healers). Only 41% received treatment meeting minimal standards and 16.5% received minimally adequate care. Self-stigma and lack of knowledge may have acted as barriers to seeking help and subsequent recovery (Schnyder, Panczak, Groth & Schultze-Lutter, 2017).

Situational and environmental factors may be an explanation behind the inconsistent results on many psychological traits. For example, Kranke, Floersch, Townsend and Munson (2010) found some youth positive about adherence to medication treatment. These youth experienced supportive family and peers and a positive assessment of medication effects, which helped reduce the effect of stigma. Positive images of mental illness emerged as the youth returned to 'normal' by taking medication. These youth were accepted into their peer groups and as a result, felt their condition was normalized and no longer felt anything was wrong. Youth who endorsed stigma acted out signs of mental illness through behaviour, symptoms, suicidal thoughts and social isolation. These youth may have believed their symptoms and behaviour could not be improved by medication. Additionally, Sherman and Ali (2017) found the rate of mental health treatment utilization among youth was 66% when their mother utilized treatment compared to 45% when their mother had not accessed service. On a positive note, these findings indicate how beliefs can change and how stigma can be reduced.

In a recent systematic review and meta-analysis of 98 studies, Xu et al. (2018) found help-seeking interventions improve attitudes, intentions and behaviours to seek professional treatment for mental health challenges and mental health literacy and reduce self-stigma. Further, they claim results show long-term benefits on formal help-seeking behaviours as mental health literacy increased and self-stigma decreased. These studies are timely because Finance Canada (2017) allocated \$5 billion for provincial and territorial governments to improve access to mental health services over the next ten years. If allocated funds improve access, researchers claim the majority of the population with mental illness may be served effectively with primary care and only 1.5% will require highly specialized treatment (MHCC, 2017).

### **Disclosure and Isolation**

Individuals with a concealable stigmatized identity face disclosure decisions regularly. In every new situation, they must decide who is aware of this identity, who may suspect this identity and who has no awareness of this identity (Pachankis, 2007). Goffman (1963) claimed individuals with a concealable stigma avoid close relationships in order to cope.

The negative connotation attached to mental illness acts as a deterrent to disclosure of mental health challenges. In order to conceal mental illness, youth reported they pretend to be happy, evade questions and conversation by insisting everything is fine, make up excuses to conceal activities such as leaving school to attend mental health treatment and withdraw socially to make mental health challenges seem less problematic (Gronholm, Thornicroft, Laurens & Evans-Lacko, 2017).

There are advantages and disadvantages to disclosing or concealing a mental illness. Advantages of disclosure include increased social support, reduced isolation, stronger relationships, self-empowerment, reduced stigma (Corrigan & Rao, 2012; Karnieli-Miller et al.,

2013) and beneficial psychological effects (Rime, 2016). Additionally, increased comfort disclosing mental illness was associated with decreased levels of stigma related stress and anticipated discrimination (Rüsch, Brohan, Gabbidon, Thornicroft & Clement, 2014).

Disadvantages of disclosure might involve rejection, discrimination, public stigma (Goodwin, Savage & Horgan, 2016; Switaj, Chrostek, Grygiel, Wciorka & Anczewska, 2016). Researchers also found frequently concealing stigmatized identities has harmful effects on physical and psychological health (Quinn, Weisz & Lawner, 2017). Despite these potential benefits of disclosure and harmful effects of concealment, some people with mental health challenges chose to conceal their stigmatized identity with peers (Gronholm, Thornicroft, Laurens & Evans-Lacko, 2017), family (Liegghio, 2017) and when they are employed (Yoshimura, Bakolis & Henderson, 2018). After many years of concealing his struggle with clinical depression, Railton (2015) explained how depression symptoms affected him and his thought processes that prevented his disclosure:

I couldn't *say* it. I couldn't say, "Look I'm dying inside. I need help." Because that's what depression is-it isn't sadness or moodiness, it is above all a logic that undermines from within, that brings to bear all the mind's mighty resources in convincing you that you're worthless, incapable, unloveable, and everyone would be better off without you. Not a steely-eyed, careful critique from which one might learn, but an incessant bludgeoning that exaggerates past errors while ignoring new information, eroding even the ability to form memories.....We are captive audiences to our own minds, and it can become intolerable. So why should *I* contribute to making it harder for others to acknowledge their depression and seek help? I know what has held me back all these years. Would people think less of me? Would I seem to be tainted, reduced in their eyes,

someone with an inner failing whom no one would want to hire or with whom no one would want to marry or have children? Would even friends start tip-toeing around my psyche? Would colleagues trust me with responsibility? (pp. 14-15)

Similarly, Corrigan (2018) disclosed his diagnoses of major depression, anxiety disorder and bipolar disorder 15 years ago and has extensively researched the stigma of mental illness since. Corrigan claims his mental illnesses caused the greatest harm on his educational career and although his parents encouraged post-secondary education, they believed “people like us” (p. 1) could never make it in medical school. Corrigan believes he became someone with a mental illness when he started medical school. He recalls:

I was panicked by my failures. I remember sitting in a lecture while feeling overwhelmed by anxiety.... I felt alone, as if I were yelling in the crowd and no one could hear me. I experienced dissociative feelings of being apart from everyone and failing badly. I became depressed. (p. 1)

Through these experiences, Corrigan now questions what would have helped him 40 years ago and how he can contribute to the expansion of best practices for people with psychiatric illnesses struggling with higher educational goals. Interestingly, both these reputable academics concealed their illnesses and like wounded healers, personal struggles led them to help others suffering the challenges of mental illness. One may wonder how the stigma of mental illness affected their choices and question why they did not disclose sooner.

In efforts aimed at understanding illness concealment, Kranke, Floersch, Kranke and Munson (2011) developed the Adolescent Mental Health Self-Stigma model entailing three steps: stereotype, differentiate, and protect. Essentially, the adolescent gains awareness regarding mental illness labels (i.e. psycho, crazy, bizarre) and personalizes it, next they differentiate (e.g. I

do not feel normal due to medication) because they have a mental illness and finally, they protect themselves by hiding their illness in order to maintain social capital and future opportunities and avoid being humiliated or ostracized.

Loneliness can result in a two-fold stigma for people living with mental illness. Loneliness carries a social stigma as a lack of social connections and friendship are undesirable and social perceptions of lonely people are usually negative (Lindgren, Sundbaum, Eriksson & Graneheim, 2014; Rokach, 2012). Loneliness is highly prevalent among with those with psychotic illness. Stain et al. (2012) found almost 70% of study participants with psychosis chose not to participate in social activities in the previous year due to past experience, fear of stigma, social anxiety and their mental illness symptoms. In an additional study exploring the impact of psychosis, 80% indicated experiencing loneliness and trained interviewers claimed 63% had severe social skill deficits (Morgan et al., 2012).

Gronholm, Thornicroft, Laurens and Evans-Lacko (2017) found conditional disclosure significant when researching young people's coping preferences when they were at risk for psychosis. They defined conditional disclosure as "a concept reflecting the rules and prerequisites that influenced how/whether the participants sought help" (p. 1842). Researchers identified four main themes that reflected the conditions for disclosure: why is disclosure conditional; who to disclose to; how is conditional disclosure maintained and what is the impact of conditional disclosure on pathways to treatment. Specifically, participants considered risks regarding contextual and interpersonal factors and whether reactions would be helpful, understanding, negative or unsupportive. Most participants reported feeling scared and/or worried as they anticipated negative judgment, malicious rumours and loss of friendships.

### **Stigma Resistance**

Stigma resistance is the ability to resist or remain unaffected by the harmful effects of stigmatizing attitudes (Ritsher, Otilingam & Grajales, 2003). Lien et al. (2015) studied 160 adults living with psychosis in China and found over two-thirds reported high stigma resistance to be associated with increased self-esteem and self-efficacy and decreased depression and hopelessness. Conversely, Bifftu, Dachew and Tiruneh (2014) found little resistance to mental illness stigma in Ethiopia. Contributing factors included rural residence, living arrangement, challenges adhering to antipsychotic medication, challenges adhering to treatment follow up, stereotype endorsement, high internalized stigma, social withdrawal and alienation. Interestingly, Bifftu et al. found patients who experienced difficulties adhering to medication were approximately seventeen times less likely to develop high stigma resistance than those who took their medication. Almost half of patients non-adhering to medication attributed this choice to fear of stigma and discrimination (Assefa, Shibre, Asher & Fekadu, 2012).

### **Summary**

The literature review demonstrates several ways the stigma of mental illness continues being formed and sustained through communication and social interaction. Stigma affects disclosure, help-seeking, treatment, goal achievement, education, relationships and recovery. Research focusing on the stigma of mental illness with youth has increased in the last ten years and has shown some adolescents feel inferior and that stigma can affect the attainment of developmental milestones. Research needs to continue to recognize the effects mental illness stigma has on adolescents in order to develop interventions that will facilitate their socio-emotional development, help them develop confidence, resilience and efficacy and promote their health and well-being.

The focus on youths' perspectives of mental illness stigma is relatively new; therefore, we are left to speculate about their experiences, perceptions and recommendations to youth experiencing the onset of mental health challenges. This study will address part of this gap evident in the current mental illness stigma research. Further, this study will indicate the need for a different age appropriate approach in order to promote mental health at a younger age.

Given this gap, I utilized a qualitative methodology because it allowed me to delve into a complex research phenomenon to solicit the perceptions of participants experiences and processes. Thus, I interviewed key informants that self-identify as having mental illness, have experienced mental illness stigma and received mental health treatment (i.e. one to one or group counselling, medication, appointments with a psychiatrist). The questions I developed were dynamic (i.e. they were guided and redirected by me) as the interview progressed and responses identified what it meant for the key informants to live with a stigmatized illness. I was able to observe and document behaviours, patterns, needs and upsetting points without fully understanding what data would prove meaningful. As a researcher, this required me to be comfortable with ambiguity. The qualitative data provided by the youth living with mental health challenges can illuminate helpful information for policy makers and mental health care providers so they can deliver collaborative youth-focused service for age-appropriate developmental needs (Leavey, 2005).

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### **Chapter Three: Methodology**

This chapter focuses on the purpose of the study, the qualitative methodology underpinning this research, participant recruitment, informed consent and confidentiality, data collection, thematic analysis, ethical considerations and study limitations. This study is a descriptive, non-random, qualitative investigation of youth perceptions of the stigma of mental illness.

#### **Purpose of the Study**

When I was doing clinical work with youth (i.e. 15-24 years of age) at an urban Canadian clinic for with concurrent disorders, I found them capable of identifying their mental health challenges. However, when given a label, many were reluctant to accept and/or attend treatment. This led me to question what the possible barriers to mental health treatment were and subsequently piqued my interest in the literature. For this study, I interviewed youth at Covenant House, an urban Canadian mental health program in Vancouver, B.C. to explore the extent to which they experienced the stigma mental illness and better understand the effects. More specifically, questions focused on youths' experiences with the stigma of mental illness, their perceptions of their mental illness, social supports and experiences with mental health treatment.

#### **Qualitative Research**

I chose qualitative methodology because it aims to yield insights by gathering and analyzing the self-reported experience of individuals involved in the phenomenon of inquiry. In the current study, a qualitative methodology comprising key informant interviews and thematic analysis enabled an intimate exploration of youths' perspective through relatively in-depth interviewing of those directly involved in the phenomenon under study. Guba and Lincoln (2003) resonates with why this approach fits this type of study:

Qualitative researchers stress the socially constructed nature of reality, the intimate relationship between the researcher and what is studied, and the situational constraints that shape inquiry. Such researchers emphasize the value-laden nature of inquiry. They seek answers to questions that stress *how* social experience is created and given meaning. (p. 10)

Qualitative research is a broad term encompassing a wide range of methodologies influenced by several philosophical traditions (Patton, 1990). Creswell (1994) defines a qualitative study as “an inquiry process of understanding a social or human problem, based on building a complex, holistic picture, formed with words, reporting detailed views of informants, and conducted in a natural setting” (pp. 1-2). Conversely, in a quantitative study, hypotheses are formed and variables are controlled to test theories. Quantitative research creates a context that is artificially created and removed from daily social reality (Patton, 1990). A naturalistic study therefore enhances the ecological validity of the results. Furthermore, a qualitative design places this research with the body of past and current literature on the stigma of mental illness which predominantly uses qualitative methodologies.

Qualitative methodology allows the complexities of individual experience to emerge. Uncovering subjective meanings in the data will reflect the diversity within youth’s perceptions of mental illness stigma. A myriad of experience is honoured and sought in order to elaborate theory and deepen understanding (Flick, 2002). Meeting in person was integral to this study as it required me to engage with participants in order to gain an understanding of their experience. Patton (1990) claimed “...qualitative evaluators question the necessity of distance and detachment, assuming that without empathy and sympathetic introspection derived from personal encounters the observer cannot fully understand human behavior” (p. 47).

Merriam (1988) claims the qualitative researcher is the primary instrument for data collection and analysis. Data are processed through this human instrument rather than through machines, questionnaires or inventories. The qualitative researcher is interested in the process, meaning and understanding gained through words, and this methodology is inductive as the researcher builds concepts, theories, hypotheses, abstractions from detail. These aspects informed my decision to utilize qualitative methodology as I aimed to understand what kinds of stigma youth receiving mental health services experience and how youth narratives regarding stigma are constructed.

Qualitative researchers reflect on data, data collection and analysis in a cyclical manner. Due to this methodology's interpretive nature, qualitative researchers' subjectivities are explicitly stated (Creswell, 1994) and are considered data as they are woven into interpretation (Flick, 2002). Further, these data enable the reader to evaluate the permeability of the researcher's interpretations. Within the context of qualitative research, Stiles (1999) believes "the concept of objectivity is replaced with the concept of permeability, the capacity of understanding to be changed by encounters with observations" (p. 99). More specifically, close proximity to participants, settings and data change the researcher's interpretation.

### **Key Informant**

I chose to utilize a key informant methodology which has been utilized since the 1970's (Kumar, Stern & Anderson, 1993; Phillips & Bagozzi, 1986) and has a history of use with anthropology (Metraux, 1953). Seidler (as cited in Tsai & Bagozzi, 2014) claimed this technique depends on a "small number of knowledgeable participants, who observe and articulate social relationships for the researcher" (p. 151). A key informant is an expert source of information (Marshall, 1996) and when several informants report similarity, these reports can be attributable

to an underlying concept (Phillips & Bagozzi, 1986). Tremblay (1957, p. 692) delineated the criteria of an ideal key informant in order to obtain required data:

*Role in community.* His formal role should expose him continuously to the kind of information being sought.

*Knowledge.* In addition to having direct access to the information desired, the informants should have absorbed the information meaningfully.

*Willingness.* The informant should be willing to communicate his knowledge to the interviewer, and to co-operate with him as fully as possible.

*Communicability.* He should be able to communicate his knowledge in a manner that is intelligible to the social scientist.

*Impartiality.* As an ideal, personal bias should be at a minimum, and such biases as do exist should be known to the research worker....

In the current study, participants fulfilled most of Tremblay's ideals as they played a role exposing them to stigma and were likely to possess knowledge about the way the stigma of mental illness is constructed. As Krannich and Humphrey (1986) indicate, key informants' views are influenced by the positions they play in their ecological environment and inevitably, know more about some issues than they know about others. Key informants in this study had specific knowledge related to the sensitive issue of the stigma of mental illness and interviews allowed follow up questions when youth said something leading to other ideas or questions. Data derived were used to obtain a more comprehensive viewpoint of what the needs of youth living with mental illness are and possible barriers to treatment.

Advantages to utilizing key informants include the provision of high quality information in a short period and inexpensive data collection (Marshall, 1996). However, informants are

unlikely to represent views held by the majority of community individuals and any status difference between the researcher and informant could prove uncomfortable (Marshall, 1996). Further, Spradley (1979) advised researchers to respect informants' interests, sensitivities and community position in order to prevent exploitation.

In the current study, questions (see Appendix C) administered to key informants successfully elicited information needed to identify youth's perceptions. Questions entailed: 1) the key informant's perceptions of treatment by people (i.e. family, peers, school staff, mental health professionals); 2) the key informant's perceptions of their mental health and how their illness affects their life; 3) how the key informant came to understand their illness; 4) who and what the key informant has perceived as helpful; and 5) advice the key informant would give youth experiencing signs and symptoms of early-onset mental illness.

## **Research Design**

This section outlines how the current study progressed and includes participant recruitment, informed consent and confidentiality, data collection methods, thematic analysis and considers validity and reflexivity.

**Participant recruitment.** I approached Vancouver's Covenant House mental health program to recruit potential key informants. Participants were recruited through purposive sampling and they each attended a single interview with the author. Purposive sampling is a non-random technique that does not require a set number of participants or underlying theory. Instead, it is a deliberate choice of participants meeting specific criteria (Tongco, 2007). Covenant House staff was provided with study information leaflets (see Appendix A) and agreed to hang recruitment posters (see Appendix B) in prominent locations at both Covenant House locations. These documents included my contact information (i.e. phone number and email

address) and each participant contacted the researcher to arrange a date and time to conduct the interview. In order to participate, youth must have been between the ages of 18 and 24 years and mentally stable at the time of the interview, self-identify as having mental illness, receiving mental health treatment, be fluent in English and able to communicate and give informed consent (see Appendix D). The research sample consisted of eleven youth aged 18-24 years who self-identified as living with mental illness.

**Informed Consent and Confidentiality.** Before each interview, I guided key informants through the informed consent form (see Appendix D) to ensure they made an informed, voluntary and rational decision to participate. My aim was to ensure participants understood:

- the purpose, objectives and benefits of the research
- that participation was voluntary
- why they had been invited to be a key informant
- that they could request a break during the interview
- that they could withdraw from the study at any time
- that the interview was going to be audio recorded and later transcribed verbatim
- how their anonymity, confidentiality and data would be protected
- that there may be risks involved and how those risks would be managed
- that confidentiality may be breached where the law required it or there was a reasonable expectation of harm
- how to contact me or my thesis supervisor if they had questions after the interview
- that study results would be shared during my thesis defense and published on the UVIC website

Aside from the key informant coming to meet for the interview at Covenant House, confidentiality was maintained. Key informant names and identifying features were not disseminated and each informant provided a pseudonym during data collection. Study results excluded personal features of study participants.

**Data Collection.** Semi-structured life world interviews were conducted by the author at a private office at Covenant House in Vancouver, B.C. This type of interview was “an interview whose purpose is to obtain descriptions of the life world of the interviewee with respect to interpreting the meaning of the described phenomena” (Kvale, 1996, p. 6). Rapport was built with each key informant as I aimed to ensure each participant was comfortable throughout the interview process.

Each key informant was interviewed in person for approximately an hour to an hour and a half. The semi-structured interview guide (see Appendix C) focused on the same questions for each informant and was structured around the public stigma and self-stigma of mental illness. As advised by Creswell (1994), the interviews were recorded so I could concentrate on asking questions, listening to participants’ responses and taking notes. My attention focused on the youth as I engaged in appropriate eye contact and body language. If a youth felt anxious and/or uncomfortable sharing information during the interview, I assured them the recording would be kept confidential and destroyed when the study concluded.

**Thematic Analysis.** I recorded interviews on an iPad mini using the application SpeakEasy (Zarboo Software, LLC, 2010) and transcribed them using Dragon Dictate and Microsoft Word for Mac. Upon completion of each interview, I transcribed the recording verbatim and subsequently deleted the audio file. After transcribing the audio recordings, I

uploaded the transcription files to the online qualitative analysis tool Saturate (<http://saturateapp.com>).

Saturate (Sillito & de Alwis, 2010) provides a secure, online working environment accessed by a Twitter user name and password. This application is a clean and easy to use qualitative data analysis internet application that works with internet browsers Firefox, Safari and Chrome. After creating a free Notebook for my study in Saturate, I uploaded each transcript to a Notebook page and allocated a page title ensuring anonymity. The interface displayed my interview transcripts by sentences and paragraphs and I coded them by clicking on the sentences or paragraphs. When I clicked on a section of text, Saturate would then display the allocated codes. If I chose to rename a code, I deleted the previous code and renamed it.

Once coded, the data was integrated and categories were allocated. As I read through the coded transcripts, I applied a category in front of the code followed by a back slash. Saturate then divided the categories and codes. After reading through the codes and categories thoroughly, I created a comma-separated value (CSV) spreadsheet and downloaded it to my computer. I then imported that spreadsheet to a Microsoft Excel spreadsheet so I could create an individual page for each category.

Thematic analysis was used to examine key informants' responses to identify common themes and proved integral to understanding the role of the stigma of mental illness in their lives. In this analysis, the researcher used a six-phase analysis delineated by Braun and Clarke (2006) to locate patterned responses within the data:

1. Familiarization with the data. I transcribed the interviews before conducting the next interview. I then repeatedly read the responses to search for meaning and patterns.

2. Generation of initial codes. I then extracted and gave phrases, sentences and paragraphs codes. Codes referred to “the most basic segment, or element, of the raw data or information that can be assessed in a meaningful way regarding the phenomenon” (Boyatzis, 1998, p. 63).
3. Theme Search. Next, I searched for relationships between codes, themes and different levels of themes. I sorted the different codes into potential themes and collated relevant coded extracts within the identified themes.
4. Revision of themes. Having devised a set of candidate themes, I then refined them. Coherent patterns included internal homogeneity (i.e. codes link together meaningfully in each theme) and external heterogeneity (i.e. there are clear distinctions between themes) (Patton, 1990). Braun and Clark advise against becoming over-enthusiastic during this phase as “coding data and generating themes could go on ad infinitum” (p. 21).
5. Definition and naming of themes. I identified the essence of each theme and determined what aspect of the data each theme captured. Each theme captured a specific aspect of the stigma of mental illness and a detailed analysis was written.
6. Report production. I utilized fully-developed themes and wrote a concise, coherent, logical, non-repetitive report.

A description of the findings follows and includes an analysis of data in relation to my research questions and the broader study of the stigma of mental illness. I remain keen to hear youths’ stories and discovering how they experience mental illness stigma, as I believe it is time to hear more from those who may be experiencing these conditions. The underlying intent of this inquiry was to enhance an understanding of the perspectives of youths, caregivers and

professionals working with youth diagnosed with mental illness, focusing on their experiences with stigma.

**Validity.** As the researcher for this study, I was committed to considering how feelings and emotions regularly came into decision making (Artz, 1994), which can have a significant influence on how people construct meaning. Feeling as a way of knowing also allows marginalized voices to become clear in research studies. As such, feeling can help clarify concepts that seem unknown (Manning & Kunkel, 2014). I believe I have laid out clear criteria, increasing the opportunity for the reader to evaluate the trustworthiness of this research. I ensured a clear basis was set for the evaluation of data collected and conducted member checks with each participant to ensure I understood their viewpoints, thoughts, intentions and experiences correctly.

**Reflexivity.** Reflexivity (i.e. self-awareness and critical self-reflection) on my potential biases and predispositions increased trustworthiness as they could have affected the process and study outcomes (Pillow, 2003). My gender, race, sexuality, age, geography, class, physical ability and mental ability shape my fluid identity, social location and knowledge. As this study progressed, I paid attention to these social constructs and how they may be influencing the process. As the study progressed, I recorded my thoughts, observations, challenges, assumptions, oversights, feelings and questions to increase reflexivity.

### **Ethical Considerations**

I read UVIC's regulations, policies and procedures governing the ethical conduct of human research because my signature indicated my agreement to abide by the University's guidelines. Prior to having my supervisor and the Chair/Director or Dean sign documentation, I ensured

approval had been granted at the departmental level. The name of the study and research questions were provided to UVIC's ethics review board.

The research protocol was reviewed and approved by UVIC's Human Research Ethics Board and I provided Covenant House with UVIC's ethics approval prior to data collection. My ethics plan strived to respect the youths' dignity as I ensured to protect their multiple and interdependent interests. I respected the youth by conveying my belief they had the capacity and right to make free and informed decisions. I respected them by securing their written consent (see Appendix D). Youth are considered vulnerable persons and I ensured I protected their interests. The youth were neither exploited for the advancement of knowledge nor were they subjected to unnecessary risk of harm. High standards of confidentiality, anonymity and privacy protected the access, control and dissemination of the data collected (UVIC, 2016).

Before each interview, I informed each key informant of the purpose of my study, type of activity they would be involved in, nature of the study (e.g. interviews) and the amount of time required. I ensured them their identity would remain anonymous and that the raw data collected would be kept confidential. I ensured them the data would be for this study only and locked away until the study was complete. Upon completion of the study, the data (e.g. audiotapes and transcripts) will be destroyed (e.g. shredded or deleted).

I informed the youth I was the principal investigator and would independently transcribe and analyze the raw data. If any investigators had been added, I would have notified the participants and the Human Research Ethics Board by sending a Request for Amendment form to indicate the name and role of the person(s) (UVIC, 2016).

I considered power over the key informants as I strived to provide an environment where the youth would not perceive me as an adult who would coerce or harm them in any way. There

were potential risks to youth including possible emotional or psychological stress. I informed participants that if they became upset, a break would be offered. If youth were unable to speak to request a break or end the interview, they were provided with a stop sign (see Appendix E) to push toward the researcher. If the youth remained upset, they would have been offered access to a Covenant House clinician or psychiatrist. If these professionals were unavailable, youth would have been provided counselling without any cost from Susie Lang Gould, Registered Clinical Counsellor. Prior to the study, I informed participants of their right to withdraw at any time throughout the study.

I ensured that data collection and analysis were sensitive to clients regardless of ethnicity, national origin and ancestry, age, gender and socio-economic status. Participants were neither burdened by the research nor were they unfairly excluded from the benefits of research participation. There was one study participant who self-identified as Indigenous and I ensured I respected their culture, traditions and knowledge of their Indigenous group. Indigenous Peoples have not been treated with respect in some research studies, and inaccurate or insensitive research has led to stigmatization (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, Social Sciences and Humanities Research Council of Canada, 2014). I strived to prevent this from occurring for the duration of my study.

### **Study Limitations**

The researcher worked specifically with staff from the *Inner City Youth Mental Health Project (ICYMHP)* in Vancouver, B.C. to recruit study participants. *ICYMHP* provides youth with access to immediate on-site treatment for mental illness and is coordinated by three in-house mental health clinicians from Covenant House and delivered by a team of six psychiatrists from St. Paul's Hospital. Therefore, most participants had been or were receiving mental health

services. Stigma deters some youth from seeking professional services when they are suffering mental illness and my sample consisted of youth diagnosed with mental illness; therefore, I may not have accessed youth refusing service. Further, if youth agreed to treatment (i.e. counselling and/or medication), they may have accepted their condition and may not be experiencing stigma anymore, as experience with mental illness stigma may shift and emerge. In order to manage this, I questioned youths' retrospective experiences with mental illness stigma.

Findings from my study pertain to a small sample of youth living in the downtown core of Vancouver, B.C. and interviews were conducted in years 2013 and 2014. The time lapse between data collection and analysis and the current reporting on the research project was unfortunate. Although there is no reason to believe that this affects the reliability and validity of the data, it is likely that the time elapsed between the interviews and the current report represents a limitation of the study. Conditions for young people living with a mental illness may have changed between 2013 and 2018. No doubt, the study does not represent all youth living in Vancouver, B.C. or Canada when the data was originally collected or at this present time. Essentially, this is an aged exploratory study of perceptions of the stigma of mental illness of a group of youth ages 18-24 years. Data collection entailed individual interviews and did not consider perspectives of informants' parents, siblings, employers, health care providers or school staff. As the sole researcher for this study, my personal experience of being a woman of British descent living in Vancouver, B.C. may have influenced key informants and interpretation of study data.

Creswell (1994) points out several limitations to using interviews for data collection: they provide indirect information filtered through the perceptions of the participants, researcher's presence may influence participants' responses, and not all participants are equally articulate

and/or perceptive. These limitations may have affected my study, but not necessarily. If youth had experienced any kind of difficulty expressing themselves verbally, I would have offered an alternate medium (i.e. a journal or a sketchbook).

Although many promising stigma reduction programs have been identified since data collection, few have been thoroughly evaluated or implemented enough to assess broad public health effects (Stuart, 2016). Conversely, research is starting to indicate some well-meaning anti-stigma interventions can do significant harm (Pescosolido et al., 2010). Stuart claimed negative societal responses to people with mental health challenges may remain the greatest barrier to the development of mental health programs worldwide.

### **Summary**

The methodology for this study was a qualitative research approach entailing key informant interviews as the primary research instrument and thematic analysis of the interview transcripts. Purposive sampling for the interviews focused on recruiting key informants self-identifying as having mental illness and receiving mental health treatment. Interviews were conducted in person and questions were designed to supplement the findings from the main questions that were the subject of thematic analysis. The methodology enabled an intimate exploration of youth's perspective of the stigma of mental illness.

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## Chapter 4: Results

Interviews conducted with youth self-identifying as having mental illness explored first hand experiences and perspectives of the stigma of mental illness. In this chapter, I report on data collected from 11 key informant interviews. Thematic analysis allowed key concepts to be elaborated drawing on participants' self-reports with reference to two phenomena: self-stigma and public stigma. These two over-arching categories of experience are discussed in the sections of this chapter. Themes that emerged in regard to public stigma included mental health literacy, consequences within relationships and professional stigma. Themes of self-stigma included mental health literacy, consequences of psychiatric labelling and treatment, self-concept, disclosure and concealment and anticipating stigma in interaction. The analysis also enabled selection of the interview content about what was helpful from the key informants' perspectives and what they would advise regarding a youth experiencing the onset of mental illness. Direct quotes from interview responses are provided in order to emphasize personal experiences. The chapter concludes with a brief summary of findings. In the chapter that follows, the perspectives of the key informants in relation to the stigma of mental illness are discussed.

### Sample Characteristics

The research sample consisted of 11 participants self-identifying with diagnosed mental illness. Figure 1 shows the key themes that were discerned in the qualitative analysis of the interview data. Attention was paid to interview content that pertained to the primary focus of this study on stigma. The concept map shows the main headings and sub-headings in the order they

are presented in this chapter.

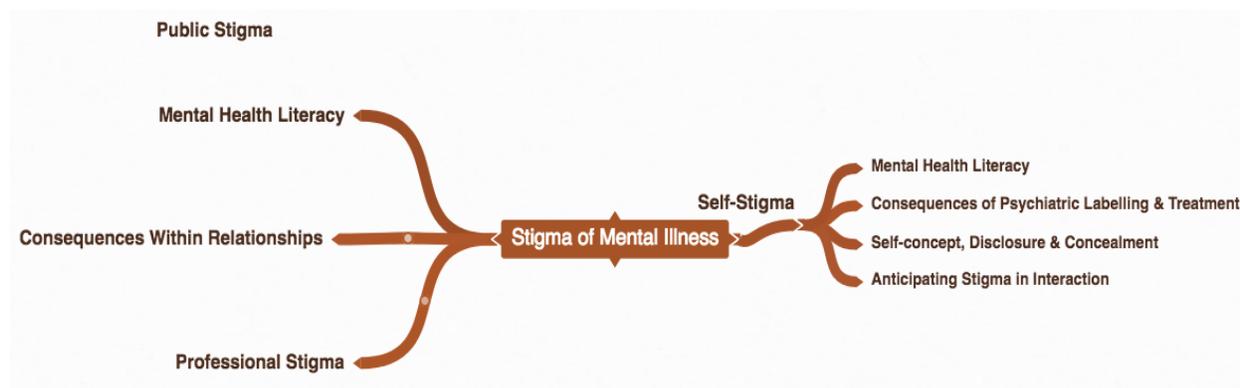


Figure 1. Key themes representing interviewee experiences.

## Public Stigma

### Mental Health Literacy

Joe indicated low levels of MHL when he explained friends' attempts to support him, "I'm always stressed...worrying about small things." Friends believed he could change or control his "priorities" and he wished they could understand how his illness affected his behaviour. When participants were asked about how understanding their family members were, most said their family members either did not understand or were suffering from their own mental illnesses. Johnny reported that the "conversation went nowhere" when he attempted to explain his diagnoses to his father. Kate also felt misunderstood, totalized and frustrated when people attributed her schizophrenia as the cause of all of her behaviours.

...people [say], she's crazy or that's because she's crazy or you're doing that because of your schizophrenia...it's just who I am. They don't really understand it.

Ahmed also struggled because he believed his family blamed him for his behaviours and thus, he concealed his symptoms.

...huge misunderstanding...they don't know what's going on...blame[d] me...I think of them as the enemy.

The remainder of this section is divided into seven public domains of the participants' lives and their considerations regarding the stereotypes, discrimination and prejudice they experienced as a result of having mental illness. These seven public domains are family, peers, school, employment, treatment, institutions and emergency services.

### **Consequences within Relationships**

**Family.** Mental illness had negative effects on all of the participants' family of origin and several participants reported tenuous relationships with their parents. Robert began to experience tension with his mom when he disclosed to her that he thought he was gay. His parents were more concerned with his sexuality and paid minimal attention to his diagnoses. When his mom did recognize his mental illness symptoms, Robert believed that she "was just afraid of me." He believed that they responded to his behaviour change in an unhelpful manner. Robert was asked to leave home and he admittedly "started doing really sh\*\*\*y things."

John reported a disconnect from his mother at a young age because "my mom didn't have time for me, didn't know how to handle me." He described his subsequent experience of being apprehended and placed in foster care.

I was 5 to 6 years old...battling [with] my mom...trying to get me back. I was always in care. She didn't have time for me...could do anything I wanted. It's not like she taught me from a young age...I was mostly on my own.

Violet Rose also indicated that her mother "didn't set up a good environment growing up." By 14 years of age, Violet Rose had experienced many abusive, physical altercations with her mother. She recalled a time when she lost control and acted in "self-defense." The police

came and Violet Rose was admitted to the hospital. Having had negative experiences with treatment and increased independence, she was better able to assert her needs and boundaries to her mother.

***Leaving the family home.*** Several participants were either asked to leave their family home or had chosen to leave themselves during adolescence. Some believed this transition worsened their symptoms and/or led to increased substance abuse. For example, after trying to explain to her mother why she had stopped taking her medication, Dorian Gray found herself homeless. She explained how this transition affected her choices, symptoms and relationships.

...my depression was bad, my mom [and I] were fighting after I stopped taking the medication and I was kicked out...homeless...it really affected my depression. I lost a lot of friends. There'd be days when I'd be so horrible...I'd be really down.

***Extended family.*** Three participants recalled receiving positive support from extended family whilst two others reported tenuous relationships with relatives. For example, Violet Rose conveyed that relatives blamed her for the challenges they observed when she interacted with her mother.

...when I see them, me and my mom bicker...Violet Rose, don't tease your mother...you're irritating to her, can't change something in your concept about them see she's upset.

Carol also recalled being upset when her aunt spoke to her grandmother about her mental illness. She felt her aunt was “burdening” her grandmother who lived too far away and would worry. She asserted herself by saying:

...what the hell, why are you burdening a crazy 90-year-old with this sh\*\*?...she doesn't need stuff that she'll worry about...if she was more in my life, then it would be fine.

On the other hand, John believed he was supported by some of his relatives when his mom was busy.

...my grandmother took care of me...uncle always helped, but overall my uncles and my aunts, they've been pretty cool with me.

Dorian Gray reported that her cousin helped her by listening, understanding that she was experiencing difficulty and not stigmatizing her.

...she was understanding...didn't tell me I was crazy...understood I was suffering...I didn't like the pills. I took her advice because I felt she understood.

***Out of home placement.*** Violet Rose was in care from ages 14 to 17. During this time, she experienced four hospitalizations. She reported the group home workers were directed by her social worker to treat her differently than the other youth in the home.

I was doing the same thing as the guys and it was, Violet Rose's going crazy again and we were told to call [the police mental health car] if Violet Rose does anything.

***Experiences with mental illness within the family.*** Several participants experienced family members having mental illness symptoms and they reported that they did not understand. For example, when John was 13 years old, his 24-year-old sister was diagnosed with schizophrenia and he believed that “she went crazy” and that her condition “messed up the whole family.”

...my sister...was nuts. She was hearing voices...I didn't understand. I remember her being normal and the next thing I know God was talking to her...she went nuts from one day to another. I was confused and scared.

Similarly, Carol reported that her mother suffered from depression and was unable to parent her effectively.

...she was crazy and unhelpful...clinically depressed and not working...in bed all day, blinds closed...just withdrawn and she would go into bits of anger...when she wasn't checked out, she was really aggressive.

Carol reported that she was “really, really resistant to medication” and explained her experience witnessing her mother take medication.

...the cycle, she would be taking 5 medications and one of them would give her high blood pressure so she would have to change the medication...she would have to go off all her meds for a month to get them out of her system and she'd be crazy during that month and I just wanted to try and deal with it without meds.

Violet Rose's also witnessed her mother suffer with mental illness. She reported feeling “embarrassed” when her mom exhibited PTSD symptoms and was frustrated because others did not believe how her mom treated her when they were alone.

**Peers.** This section is divided into two sections, youth and young adult, because the experiences reported regarding peers differed significantly as participants aged. However, disclosing and exhibiting their mental illness symptoms sometimes resulted in bullying, isolation and social distancing during both life phases.

**Youth.** In elementary school, Dorian Gray reported being “crippling shy.” She recalled feeling sad because boys would “make me cry.” She reported that she had a best friend because he was “different.”

...he had ADD and had to take Ritalin. I thought he was from outer space because he had to take this pill at lunchtime...I started to understand why he had to take his pill. I didn't see him as crazy, I thought he has to take this because he has some disorder, like genetically, like a medical condition, not a mental illness.

Reflecting on this childhood experience enabled her to understand that being diagnosed with a mental illness and taking medication does not equate with being “crazy.”

Similarly, Violet Rose reported being “shunned” in alternative school after being hospitalized for three months and that she “tried to talk to her classmates.” She recalled a classmate’s response, “OH, you have bipolar?”

**Young adult.** As a young adult, Robert believed that “not everybody's that concerned about it [mental illness] and that he had several good friends that “really stood by” and did not stop seeing him because of his mental health.

Although Johnny was comfortable talking to his friends about his diagnoses, he preferred confiding in female friends after failed communication with male friends. He found some male friends judged him, put him down or did not want to hear about his “hardship.” However, Johnny did find one male friend who was able to listen and support him in the manner he was seeking.

I can really spill my heart out with this one friend, and...he'll listen and nod...ask questions...give me a pat on the back...a hug or phone call, or just listening.

This type of support offered by close friends enabled some participants to maintain hope and “survive from one day to the next.”

As young adults, Artemis reported that they had been able to establish and maintain healthy friendships. When she experienced mental illness symptoms, Artemis was able to tell her friends that she wanted “to be left alone” and would tell them that she was “in a bad mood, I'm grumpy, I'm a little overwhelmed and want to be left alone.” Some friends would leave and tell her that they would see her later and others said, “let's talk about [it].” Artemis also reported that her friends supported her.

### **Professional Stigma**

**School staff.** Joe's behaviour changed in elementary school when his OCD symptoms resulted in his apathy for being on time. He realized teachers and peers began noticing his compulsive behaviour.

...being late for school, being late for class...having a locker and you have to beat the bell. I would get [a] detention...my compulsions started, the locker doors got to be done right...they were calling me crazy...this guy has no sense, is he stupid, what's wrong.

As time progressed, several of his teachers noticed that “something's up” and referred him to the school counsellor. He reported that he did not fit in, was “antisocial” and that he could not get along with people because the world was “out to get me.”

Two participants, Artemis and Robert reported being bullied in elementary school. When Artemis was bullied, she indicated that she “didn't want to talk to anyone,” but the school staff were trying to talk to her. She reported that she “felt they never did anything.”

Robert recalled taking the initiative in grade six to go to his school counsellor when he experienced suicidal ideation.

I remember...saying I need a book on depression and suicide...the counsellor looked wide-eyed [and said], want to talk, have a seat and when I got home...[my mom] was sobbing.

Following his disclosure, Robert recalled seeing the counsellor frequently and that “it was nice...she was nice.” Robert's mother was a “mess” afterward, but paid more attention to him in a “positive way.”

When Saliann began missing classes due to her mental health challenges, she reported that the school staff did not check in to see how she was. She believed “nobody [at school] knew” that her behaviour had changed.

...in grade 8, I would not skip, I would do as much as I could, then in grade 9, I'd skip a day, in grade 10 I'd skip a week, grade 11 I'd skip months and then grade 12, I just completely, totally went downhill. I'd go once a month maybe.

She recalled that the principal offered “anything” and suggested “a counsellor [and] a tutor,” but she declined these opportunities and instead indicated that she would “come more often.”

Similarly, Dorian Gray recalled that her “teachers were nice, but I wouldn't say helpful, [or] went out of their way to reach out to me.” By the time she “was sixteen I wasn't going to school very much...dropping out of my classes and skipping all the time.” She also indicated that she began drinking and smoking at this age and reported that was caused by her depression. She reported that none of her teachers were curious about why she dropped their class when they came to talk to her and that they did not do anything. Additionally, Dorian Gray believed she was “crazy” and that people didn't know what to do because they were “a little scared...and would stay away from me because they didn't know if I was going to freak out.”

Kate did not find the staff at her school “very accepting” and perceived herself as a “disruption.” After grade 8, she gave up and it went “downhill.”

Another participant recalled being “a little sh\*\*” at school and that staff gave her lots of chances. Carol explained how she had worked with a one to one worker for “learning disabilities” and met with a counsellor when she was in grade 4 or 5. They had a “meeting with my mom, teacher, a social worker when I would get in trouble.” She explained how her school experience was good until high school.

...I got in lots of trouble at school, lots of fights and lighting fires, but in high school they were good until grade 9, I went to [this high school] for a while and they basically told me to leave because I ended up at [the Child and Psychiatric Emergency Unit].

Carol reported that the school did not help her find another program. Carol got into a lot of trouble while she was not attending school and eventually registered in a small program. She said the staff there displayed respect by “giving people space.”

Violet Rose was hospitalized for nine months and had “no friends” talk to her for a year after she was discharged. Although she wanted a fresh start, she experienced a loss of friendship. Despite these challenges, Violet Rose continued with post-secondary school and found it very stressful. She reported feeling “exasperated” and being advised by the staff during the first semester to inform the teachers if they had any health issues so they could accommodate them. Thus, she recalled telling the head person about her mental health challenges and they responded with “that's not really my problem unless it's going to affect you, I don't really see how it's related to anything we do here.” Thus, she recalled thinking “maybe I'm just complaining and...trying to take an easy way out of doing hard work.” She explained further, “it's also not something I feel comfortable telling everyone because there's so much stigma and people don't understand it and they think you're an idiot.”

Ahmed reported that one of his high school teachers “noticed something wrong with me” and how she connected him to resources that could help him with his mental health challenges.

...my marks kept dropping and I was pushing myself really hard. I was...depressed, tired, worst ever...my mind was not there to follow. Fortunately, this teacher noticed something was wrong and asked me what was going on...I tell her [about] my issue, I

said my family kept losing their patience with me and [I] kept losing faith in me...so upset.

This teacher's observation was the first step of many that Ahmed needed in order increase his MHL and secure effective mental health treatment.

**Employment.** Most participants reported that their mental illness either prevented them from looking for work or that it interfered. Saliann reported that she could secure work easily and preferred jobs that kept her busy. One job was fast paced and required her to memorize recipes. Initially, this drove her "nuts" and caused a lot of anxiety. Over time, she became competent at her job, gained the respect of her co-workers and did not believe her employer would fire her because she has mental illness.

John was deterred by his moods when he considered employment. He experienced anxiety and nervousness when he looked for work and irritability when he was working. He smoked a lot of "weed" and was unable to smoke marijuana at work. Thus, he experienced mood swings, had a temper and become irritable.

**Employers.** John believed that his past employers had given him a good chance at his job. His last supervisor "had to let me go" because he "pretty much snapped." John reported that having mood swings made it hard for him to keep a job and that these experiences brought him "lower." Joe's symptoms also interfered. He recalled working at a restaurant where he was told that he was using the washroom "way too much" and that they couldn't keep him there.

Dorian Gray recalled having a panic attack at a job and how the lack of communication with her boss and her feelings of embarrassment prevented her from returning.

I was a hostess in a restaurant once and had a panic attack then and it was really...I was so embarrassed...they're all staring at me like I'm insane. The waitress, (asked) are you

okay...no, I'm freaking out, and my boss sent me home. I wouldn't return ever...I think if he had talked to me and said it's okay, I would have come back.

Conversely, Violet Rose reported a positive response from an employer when she disclosed that she had mental illness. She was working as a security guard and conveyed to her employer that she had a health issue that prevented her from getting up early in the morning. The employer did not ask her to elaborate and subsequently scheduled later shifts for her.

**Medical professionals.** Several participants reported negative experiences when they received mental health treatment from medical professionals. For example, Violet Rose wished her doctors “could have waited to see” and “would have seen what I acted like in a different environment before diagnosing...they should have, researched it better.”

Over the duration of her hospitalizations, Violet Rose recalled how she felt patronized by the doctors and how she perceived them.

...doctors see you as a specimen, you're not even a person, they think of themselves as bigger and better...[my] current doctor interrupts me when I am talking and says, that must be really hard for you, but in a really patronizing voice, not interested in what I say, not listening and then she stops me and asks me an unrelated question to stop me from talking. So, I think that's pretty screwed up.

Robert reported that he “liked it” when he was hospitalized after attempting suicide at age 12 years.

...they treated me like a regular patient...I was getting support...they had me on a suicide watch and somebody was sitting there the whole time and it felt nice being able to talk to...having a friend and so when they took it away, I reacted negatively and tried to kill myself again.

Several years later, Robert reported that he went to the hospital again and hated it. He explained how the staff were “not very nice” and that the “doctor was awful...I needed a psychiatrist but, [the doctor said] I don't follow drug addicts.” Further, he reported that there was “no follow-up” after he was discharged. Further, he indicated that his parents did not like it either because the doctor chose to focus on his “addiction.” He reported that there was “no question of depression or anything.”

Joe believed his symptoms were hard to explain and that the doctor was unaware of everything he was experiencing. He found this frustrating because the doctor would listen “a little bit, talk a lot” and then “jump to a conclusion” regarding treatment.

Similarly, Dorian Gray reported an experience when she went to the doctor with her mother. She had experienced the onset of her anxiety disorder when she was 13 years of age and her “mom wanted to medicate me.” Dorian Gray recalled disclosing her symptoms during her first appointment with her doctor.

...telling him how I'd get really depressed and sad and I would lock myself in my room, I'd be really mean to my brothers...just do really horrible things and get into fights with my mom because I was feeling so sh\*\*\*y all the time.

Following her disclosure, Dorian Gray indicated that the doctor turned toward her mother and “started talking about...EMO kids, she was...an EMO kid.” The doctor “pretty much labelled me as an EMO kid” and “that the depression was an attention seeking thing, which was wrong.” She had chosen to attend the appointment hopeful, but instead left angrily. Dorian Gray took “some pill for anxiety” briefly, but stopped because she “just didn't feel like me.” She reported that this “doctor in high school...gave me this outlook that all doctors, that they're all like that, so I kind of didn't really care for doctors.”

As a young adult, Dorian Gray recalled having a panic attack and calling 911 herself and landing at the hospital. She explained, “when I had a panic attack and the doctor was telling me that I must be on drugs that he was like, just don't do meth.”

...they didn't even admit me, they...made me wait in the waiting room for a long time while I'm hyperventilating, and then after an hour and a half, finally I got to see a doctor and he just gave me a pill [Ativan] and told me to go away and told me not to do drugs.

Similarly, Artemis reported feeling hopeful when a mental health worker “understood her” and asked if she would like to see someone about her anxiety. However, she reported difficulty seeking mental health treatment “and felt every time I tried to[explain], it just went over [the doctor's] head.”

...he misdiagnosed me, he said everything was related to my mom's death, I asked to be here for my anxiety, not to deal with depression. Two different things. It felt awful...you're depressed because of your mom's death, not you have anxiety because of this.

Artemis reported that, “like anyone, I was upset” when her “mom passed away...but I got over it and believed she was going to a good place.” Artemis valued the mental health worker because they were listening to her. With the doctor, she indicated that he was not listening and believed her mother's passing was the cause for what he diagnosed as depression.

Carol reported that the medical professionals “usually respond well and a lot of them ask how long has it been happening,” “do you feel like it's depression or do you think you're just having a bad day or maybe we should try medication?” She reported that her psychiatrist was “a really nice guy, but tries to convince me that his choice is better than mine.” She explained a situation that led her to believe she was not being heard.

...if I wanna go off my meds, he's like, okay well let's just give it another week and see how it is and that'll go on for months. Or maybe we could look at other options or we could taper it down a little bit, but let's talk about it next week.

She reported that she felt “frustrated” and stopped taking her medication because her doctor’s procrastination “kept going.” She explained her withdrawal symptoms and the next appointment with her doctor.

[I was] super anxious, couldn't eat, couldn't sleep, sweaty hands, clenched jaw, it was gross...my psychiatrist was really disappointed...he told me that that was really disrespectful, told me I should have talked to him first about it then I said I told you over and over I didn't want to be on them and then we agreed he would try and listen.

At the time of his interview, Robert was living in a single room occupancy (SRO) when a visiting doctor noticed that he “wasn't feeling right, so he talked to me.” Robert recalled that he “was done, I pretty much felt like I had given up on everything.” He explained his interaction with the doctor and finding a new place to stay.

...he suggested methadone, because I kept going back to heroin...why don't we take you to [the homeless shelter], it was supposed to be for three or four days while I got used to the methadone, but I stayed for a while.

Robert reported receiving the same positive support at the homeless shelter that he found when he was hospitalized at 12 years of age.

Saliann also reported positive interactions with her doctor. She sought mental health treatment confidently because she entered the medical clinic with intention.

I knew how to work the doctor, so I'm really depressed, I just knew how to act well and knew what to say for the doctor to give me the pills and the doctor said, are you sure you want this because it might screw, screw with your emotions and your body.

Despite the doctor's efforts to inform her, she chose not to listen and took the antidepressants. She chose to stop taking them after two months because she believed she was "better." However, when the doctor followed up, she asked him if she could go back on her medication. They worked collaboratively this time and he informed her she had "to stay on them this time" and to talk to him "before you want to stop taking them." This time she reported she began to "start and...stop" taking them and came to believe the medication was "screwing" with her.

Kate reported having a "conflict" with her "psyc." She indicated that this was a result of having schizophrenia and that it was difficult for her to get out of the house. She would miss scheduled appointments and her psychiatrist conveyed, "if you're not going to come, I don't want to see you anymore...next time you schedule an appointment, if you don't come, I don't want to see you."

**Counsellors.** Kate and Johnny spoke about their experiences with one to one counselling outside of a school setting. Kate reported that she felt "pissed off" about counselling and thought it was "pointless" because "they would always ask the same thing."

...every single counsellor I saw would say the same thing, why are you here?...you know why I'm here...then I would have trouble cause I didn't really know why I was there, because I was unsure about what was going on...I need help...I would have to repeat my life story and then at the end, they would go how do you want to deal with it?...I don't know! That's why I'm here. I don't know. So, it was pointless.

Johnny also reported having several counsellors. He found one of them helpful because they were able to “pinpoint the problem” and worked collaboratively with him to resolve it.

Conversely, he reported another counsellor gave him “pep talks” instead of the advice he “really need[ed].”

**Detoxification and rehabilitation programs.** Most of the participants reported that they experienced some form of substance abuse treatment. Johnny reported being in treatment where he witnessed staff discuss traumatic disclosures made in confidence. He felt “irked” by this because he believed they found others traumas “entertaining,” including his own.

I may have a moment that's entertaining to you but that's traumatic to me...I'm at my worse when I'm coming into detox. It irks me to think that a life or death situation is entertaining... when it's happened half an hour ago and this person's run to detox to save their life...to hear a nurse say they find that funny...some things shouldn't be expressed. [It] sends people back out to do drugs again because they know, my addiction is a laughing stock to you, so what's the point of even looking for help.

Johnny continued to explain how this treatment approach also reminded him of being excluded in high school and that he began using drugs because he “never fit in.” To sum, he reported that there were counterproductive settings in recovery that people have to maneuver.

**Social workers.** Ahmed reported that his ministry worker understood that he was going through difficulties and needed help. His social worker put him on a youth agreement so he could stop working and attend school. Ahmed explained how his condition worsened over time and how he worried about having to support himself because he was breaching the youth agreement terms.

I kept suffering, I got weaker and weaker and I started missing school days. I would get up and I wouldn't have even slept at night... devastated tired...going through depression, too many thoughts, anxiety. I would go outside, alone, myself, think, cry, but how [do] I support myself, ...to the point where maybe I would lose absolute control of myself or do something stupid. I would read Karan and it brings me back to peace. I moved on my own, it's just me who's deciding to go to school, but I got weaker, weaker, weaker. The school told the social worker that I had missed many days and I still couldn't explain it [my mental illness], but I remember her giving me a psychologist.

**Psychiatric hospital.** While in the hospital, Violet Rose reported she “was trying to escape because it was a really boring, depressing place.” She reported feeling “claustrophobic,” “caged” and being around other people that “aren't healthy and feeling like, I am nothing.” She also reported that the doctors told her that her behaviour was unacceptable and “that's why you're bipolar.” She indicated that some of the staff were “nice” because they took her on walks and “asked me what things I liked.” Initially, Violet Rose indicated that she “really liked” the doctor as “he understood” her, but he was keeping her in hospital. Violet Rose reported that she was able to establish and maintain a good rapport with this doctor and saw him for several years.

**Ambulance.** Dorian Gray reported that her symptoms were minimized by paramedics after she called 911. She experienced one of “those panic attacks where you feel like you're having a heart attack,” and the paramedics were not very nice about it. She indicated that they said, “it's just anxiety, calm down,” whereas she believed, “I'm dying here, I'm fu\*\*ing dying and they just make me sit around for...an hour.” She believed this treatment “worsened and prolonged it [her symptoms] because they weren't doing anything, not caring, not compassionate about it.”

**Police.** Following a serious physical altercation with her mother, Violet Rose reported that her mother had run onto their balcony and that she had locked her out. She explained how the police came because her mother “was screaming on the balcony” and that the police sent me to hospital and “they thought I was a psychopath [and believed I] actually wanted to stab her.” She explained why she thought she went unheard.

They weren't listening to me at all because, she just played that card so much, she emphasized it so much...they thought every time, me getting a little bit, angry or something, oh Violet Rose might go crazy and stab someone, let's call [the police mental health car]. She has bipolar.

Further, Violet Rose reported that she had not yet received her bipolar diagnosis when this occurred. She reported feeling unheard often and had become increasingly frustrated when people believed what her mother said and dismissed her perception of their unsafe, dysfunctional interactions.

### **Self-Stigma**

#### **Mental Health Literacy**

Participants found recognizing mental health challenges a lengthy process due to low levels of mental health literacy (MHL). Some reported earliest symptoms made them question who they were and why they were behaving as they were; yet were oblivious an illness was the cause.

Several participants mentioned knowing something was “different” or “wrong,” blamed themselves for their symptoms and believed they were the only ones suffering with mental health challenges.

John: I've always been different...nobody else in the family was like that.

Ahmed: I had no idea what mental illness was. I felt like crap at first...like it was my fault. I did not believe it (that there was mental illness), I was raised in my country (Somalia), people who have mental illness are not treated well there, people blame them as something they have caused and as dumb. Treat them as lower.

Dorian Gray: It's confusing...you feel like you're dying, you're in pain, you feel impending doom and something bad is going to happen, and you don't know why and you can't help it.

Johnny: I didn't know it...no clue that a) that it's a mental illness and b) it's a mental illness caused by drugs.

Kate: When I was younger...something wrong with me, I'm a burden on society.

### **Consequences of Psychiatric Labelling and Treatment**

**Diagnosis.** Receiving a psychiatric diagnosis and being prescribed medication was received and understood differently by the participants. Carol and Dorian Gray believed their label confirmed they were “crazy;” Carol felt a sense of commonality; and Robert felt relieved as he gained insight regarding his symptoms.

Being labelled with depression was problematic for Carol because as a child, she witnessed her mother take medication to treat her depression.

Oh my God, I'm crazy like my mom. I was really, really resistant to medication...they've tried to put me on meds and the thought of being my mother.

This led Carol to resist treatment. Dorian Gray also believed her diagnoses of anxiety and depression confirmed that she was “crazy.”

...when no one can explain what the anxiety was from...that means I'm crazy, crazy people experience crazy things because it's unexplainable. This impending doom feeling and panicking.

Similarly, Robert reported that his diagnosis afforded him relief as he gained insight regarding his symptoms. Further, he sought, accepted and adhered to treatment recommendations.

...now I know the real reason why, I have bipolar disorder, so that's probably when it was starting to show its face. I mean like it's just my brain chemistry is a bit different than other people and to be normal I have to take this medication.

Kate disagreed with her diagnosis of schizophrenia because endorsed a negative stereotype of schizophrenia.

I didn't think that's what I had, because that's not what my symptoms are. It's not a Jekyll and Hyde thing, lose consciousness and become somebody else, it's not true.

Although some participants struggled with the acceptance of a diagnostic label, Violet Rose claimed her bipolar disorder diagnosis provided a sense of identity and pride within an online journaling community.

...people on that website would brag about being bipolar, everyone wanted to have bipolar, it was like an identity...when they told me, I was glad...told people that I was proud and they were like, why are you proud of that?

**Medication.** As a young adult, Carol reported that she had a “bit of willingness” to take medication and why she stopped.

...my first thoughts were not again, being in a deep dark hole....there's no hope...not going to be able to achieve anything...all I can think about is the negative. So, I can do that [take

medication], but it's gonna suck. I'll try it and the side effects seemed too much for me and I stopped.

Carol reported being on “all sorts of things,” but while she was taking medication(s), she did not feel like herself and thus did not “want to take it anymore.” This led to a “giant power struggle” that she would “always win because they [the medical professionals] can't shove it down my throat.”

Saliann agreed to take antidepressants when her mother “first kicked me out.” However, she indicated that she was reluctant to take pills because she believed it was an “excuse to do something” and that she should instead, “self-regulate” her emotions and “handle it.” At the time of her interview, Saliann indicated that she was postponing a reassessment with her doctor because she was scared to go on medication and think that she was “not normal.” Similarly, Violet Rose did not believe it was a good thing for people to be on medications and did not want to “think I depend on it.” She reported that she had stopped taking her medication in high school and that she would “feel fine.” She chose against sharing this with anyone because she believed “they probably would have sent me to hospital.” However, as a young adult, she realized that “if I don't take my medication, I feel really depressed.”

Dorian Gray reported that she was willing to take medication to treat her symptoms. However, she believed that she “must be crazy” because she “had to go on pills because I was having these attacks on myself from somewhere in my mind.” She tried them “for [a] little bit, but didn't like how they made me feel” and stopped. Similarly, Ahmed reported that “medication established my mood” previously, but he stopped taking it after he learned to utilize “acceptance and faith to [deal] with myself.”

Robert reported mixed thoughts about the medication he was prescribed. He had been taking Paxil since he was eleven or twelve years old and “just trusted that it would help” him. However, he also believed that Paxil caused him to be “suicidal” and was ineffective. At the time of the interview, he was still taking Paxil and reported that he’s been on it for so long now, “it’s just like breathing.”

**Perception of diagnosis and medication.** Participants were asked how they came to understand their diagnosis and prescription(s). Carol explained how hard it became to cope and how she felt apathetic.

...like waking up underwater...everything takes 10 times more effort...feeling really hopeless, don't want to do anything,...I don't care. I get really depressed...hate everything, my friends, don't want to go to work, don't want to go to school, don't really want to do anything.

When Violet Rose was diagnosed, she reported that she was told “you have ups and downs and you have manic stages of happiness but then the low stages of psychosis and depression.” She recalled believing this because she “did feel that way.” Dorian Gray reported that “it's a very confusing thing to feel and experience because you feel like you're dying, like you're in pain...impending doom and something bad is going to happen and you can't help it.” She asserted that “people tell you it's all in your head, calm down” and that “doesn't help because, I understand, it's just anxiety, it's not really happening, but I can still feel it really happening.”

Johnny was diagnosed when he was “seriously drunk” at the hospital. He reported that he “didn't get it at the time” and was saying yes to his doctor’s questions because he wanted the conversation to end.

They didn't really explain it. I don't remember [being] in the psych ward. The professionals used verbose, wordy, scientific terms that I [didn't] understand...I was saying yes to end the conversation and I can't leave the psych ward, because I'm certified under the mental health act because I hear voices, which tell me kill people which isn't true at all because I said yes to psychosis.

Six months later, Johnny received an explanation of what psychosis was and that it was caused by his drug use.

When Joe was diagnosed, he thought the doctors were wrong and that he was fine. He reported that both his parents and doctors referred to him as “abnormal,” which he thought was “a lot better than crazy.” Further, he believed his condition “was too hard to explain.” He indicated that there are “a lot of clueless people” and that he believed a lot of them thought he was “acting...they think I am making it up.” He indicated that his condition was bad and that it was “his real life.”

### **Self-concept, Disclosure and Concealment**

This section includes the beliefs some of the participants had about themselves and explains how some participants became increasingly comfortable disclosing their illness. More specifically, their self-concept embodies their answers to the question “Who am I?” now that they were living with mental illness and how their symptoms had played a role in their beliefs about themselves.

Recognizing he had an illness was a delayed process for Joe because he did not perceive his earliest symptoms as problematic because no one else did.

I just brushed it off because nobody said anything to me, I felt something was wrong, but because nobody said nothing to me, I just ignored it.

However, after naming his illness and receiving treatment, manifestations of self-stigma increased. Joe conveyed frustration as he explained how his health challenges affected his daily routine and how he wished “there was one day I could live normally.”

Although he accepted having a severe mental illness, Joe sometimes felt “trapped” or “paralyzed.” John noticed that he was “different” and lacked motivation.

Saliann experienced “life with more challenges” and angrily conveyed how she needed “someone to talk to.”

I...put a smile on my face, it might be fake, sometimes it's genuine...leaving the house is hard...I don't want fake conversation...I want to...say I'm feeling like crap.

Kate also “separated” herself from people, but felt “the need to tell what’s going on.” When she chose to disclose her illness, she added “don't be scared of me.”

John also shared that he “preferred to keep personal things secret most of the time.” John explained that he chose not to communicate when he felt “irritated” and became “pretty secret.” Both John and Artemis were able to ask their friends for space but chose against talking to their friends about their illness.

The remainder of this section is divided into four domains of the participants’ lives and their considerations regarding self-concept, disclosure and concealment in context. These four domains are family, peers, intimate relationships and employment.

**Family.** Kate conveyed how her beliefs about mental illness prevented her from sharing with her younger siblings: “I try not to tell “the little ones, because I’m scared it’s going to affect them.” Kate was “scared” to ask her family for support with her mental illness because she felt a sense of “pride” and believed it was an “issue” she “didn’t want to bother” her family with.

Although Artemis was “pretty open” she did not always, “want to talk about it.” However, when it came to her father, she avoided any conversations by telling him he was in a bad mood and he would subsequently leave her alone.

Dorian Gray reported she “was never really too close” to her brothers and did not “think we could...share personal sh\*\* with each other.” Carol attributed her resistance to family support to her independence and past disappointment with them. She reported that “I don’t really have anybody” therefore, “we talk about it once in a while but...it feels uncomfortable.” Johnny also chose against disclosing to his father because his dad had repeatedly told him Johnny had “traumatized” him.

**Peers.** Carol attended an outpatient hospital program aimed at reducing anxiety. Although “they treated us well,” she “definitely didn’t tell anyone” where she was going. She chose not to tell her friends she was receiving treatment because she “didn’t want them to think differently of me.”

Similarly, Johnny feared he may be thought of the “crazy one” if he disclosed his mental illnesses to his friends, but he felt comfortable disclosing at twelve-step meetings. Johnny reported that he was not “being judged” and he believed that the “information” he shared at a meeting would be kept in confidence.

**Intimate relationships.** Participants considered how open they could be about their thoughts, feelings and behaviours. Johnny, Robert and Dorian Gray that they would conceal their mental health challenges when they met someone they were interested in dating.

Johnny: If there's a girl, I'm not gonna share my...psychosis.

Robert: I tell them about being in recovery, but, not the mental health...they would run.

Dorian Gray: I wouldn't tell them until they seen it...craziness might scare them away.

**Employment.** Joe, Carol and Robert expressed the desire to work but did not believe they could hold a job. Despite being proficient at securing employment, Joe discussed how his OCD symptoms "slowed" him down. Similarly, John reported he was "out of work (because) I don't think I can handle it. If I do, I don't know how long."

### **Anticipating Stigma in Interaction**

Kate's beliefs, doubts and subsequent fears about mental illness led to constant worries as she interacted, "It's always in the back of my mind, like is this person taking me seriously, is this person scared of me...angry with me...confused with me?"

As a young adult, Saliann worried that she would lose the significant relationships that she had longed for.

...people are actually paying attention to me now...showing me love and if I have something...I actually have friends...relationships with family...pressure on me...I found this out and they'd be like, okay, really cool and they'd just brush it off and these guys would probably do the same thing.

Although she believed they would "not change their thoughts on me," and that they would love her "the same," she indicated that her anxiety "goes worst-case scenario."

### What Was Helpful

Several participants reported programs and/or approaches that they perceived as helpful. I have explained how the participants found them effective and have removed any identifying features of these programs.

#### Health Centres

**Medical services for street entrenched youth.** Dorian Gray reported that she found a medical program for street entrenched youth helpful. She reported that a street nurse and a street doctor were “both pretty good.” She recalled having a panic attack when she was with them. Although, Dorian Gray believed that the staff member “didn't know what to do,” they “sat and waited until I calmed down, gave me a cigarette and talk[ed] a bit...sometimes it helped...she gave suggestions, breathe slowly, count your breath.”

**Concurrent disorders outpatient programs.** One participant found knowledge provided by medical professionals to be helpful. Johnny reported that the concurrent disorder program he attended had an outpatient day program that was “led by an addictions doctor...who [provided him with] useful information...a nurse [taught a class on] nutrition and mental go hand in hand and another on the neurobiological side of things.”

Violet Rose also reported that she “liked” the “concurrent disorders place,” but that she could not wake up early enough for their programs. She found the staff were “really nice and were different from the mental health team, they were not as judgmental.” She explained why she perceived a conversation with a psychiatry student as helpful.

...what are some problems you're dealing with now, I might be able to help you...I'm dealing with relationship problems and she told me about cognitive therapy to have

higher self-esteem and...genuinely help me with a problem and she was not talking in a judgmental or a condescending way. She sounded like she was my friend.

**Concurrent disorders inpatient programs.** Robert reported that he spent nine days at the dual diagnosis ward at the local hospital and “was angry” that he had been committed. He explained how he displayed resistance to treatment.

...not taking the meds that they wanted, I was coming off heroin and they said do you want methadone...nope, and the groups [therapy], nope, not going, give me the cigarettes, but I’m not doing anything else.

Although “he was totally resistant,” Robert explained why he found this experience to be positive.

...because you can be treated for both mental health and addiction at the same time without people judging you. It's more of a treatment centre and a lot more helpful, even though I was totally resistant to any, any kind of help, they tried.

At this time in his life, Robert reported that he “was tired of using...tired of being sick.” He recalled “threatening to kill myself and the police and ambulance came and took me away...to [the] hospital.” The medical professionals there realized there was more than drugs involved and sent him to dual diagnosis ward at the hospital. In addition, the medical professionals at the dual diagnosis ward referred him to a counsellor at a homeless shelter.

### **Programs for Street Entrenched Youth**

**Homeless shelter.** Carol reported that she learned about the homeless shelter on their website when she was growing up. She “kinda knew where it was” and decided to do an intake when she was “really sick...[with] mono for 3 months...homeless and using every day.” Prior to this, she had been staying with a friend and subsequently had nowhere to go. Dorian Gray also

reported staying at the shelter for one night when she was homeless. She thought there were too many rules and thus, chose to access their hot meal program instead.

Violet Rose also reported that she had eaten at the shelter “a lot and like[d] the food and the youth workers. They’re really nice.” These staff had helped her hang a mirror in her apartment and helped her “cook soup...they just seem like they want to help.” Additionally, Artemis valued seeing a counsellor at this shelter every two months who had given her “a journal...to write because I used to write all the time, she actually listened...you used to write, here is a very nice journal, start writing again.” Carol also spoke highly of the staff who were running a coming of age program at the shelter. She reported that she was “close with the staff at the shelter...and I have my psychiatrist there and I’ve got a worker from a legal education association. Those are positive connections.”

When asked where his resilience came from to change his thinking and behaviour surrounding his substance abuse, Robert reported that it came from the opportunities at the shelter.

I made the real decision when I relapsed because I was [at the shelter]...I was going to use again, and I remember being high and having a bit of money...instead of going to buy drugs, I just said, what am I going to do after this, and I just thought about it and I opened my door and my social worker was coming down the hall and I said, get me back in the shelter.

Saliann also utilized the services offered by the homeless shelter. She attended meals, stayed in the shelter and took clothes so she didn’t “have to wear the same clothes over and over” as she did as a child. She reported that she found the staff to be “really, really friendly” and that

you could tell that they enjoyed doing their job. Unfortunately, she did not access the mental health services the homeless shelter offered because her “anxiety” stops her.

### **Semi-Independent Living Program**

Violet Rose reported that her semi-independent living (SIL) worker helped her find housing online. She attended the interview with her worker and together they secured an apartment. She was receiving disability because she was enrolled in school, and therefore had a SIL worker assigned. Further, she explained she did not like being on disability, but her doctor deemed it necessary in order for her to manage her mental health while attending school.

### **Treatment for Substance Use**

Few participants elaborated on their experience with substance abuse treatment because most of their treatment experiences were intertwined with their mental illness. However, Carol reported being at a substance treatment program at the hospital for six weeks and that it was “okay.” She also had counsellors at a community substance treatment program.

Johnny reported that he benefitted from the factual knowledge he gained during treatment regarding illegal substances, mental illness symptoms and neuroplasticity. Further, he conveyed that he is transparent with his experiences and has posted information on social media and subsequently, people have approached him when they have been struggling and are seeking help.

### **Twelve-Step Programs**

Violet Rose reported that she recommended twelve-step programs because they provided members with contacts that are open to hearing anything. She indicated that members inform other members with what is bothering them and that they can help because a some of them “also have mental illnesses, but they're doing really well, so they are well suited to provide hope and connection in order to feel better about it.”

## **Connecting with the Right Counsellor**

Johnny reported that he had “at least a dozen” counsellors since he was in grade two and that he found them unhelpful. He had attended a Jewish school in Jamaica and had “never felt acceptance.” He recalled being bullied at this school because he was “too dark and different to hang out with.” He indicated that people continued to remind him “constantly” that he was “dark” and “different” at the time of his interview because “people aren't accustomed to being around black people.” He referred to himself as a “novelty” and that this came with “a lot of insecurity.” Fortunately, Johnny had found a counsellor who he believed was “precise” because he could be “one hundred percent honest with her.” This counsellor enabled him to address the anxiety he had experienced since childhood and “work through all these different things I've been experiencing my whole life and I walk away feeling like changing.”

Johnny explained how this counsellor enabled him to perceive “issues” in a new way.

Life isn't about what's next, it's about enjoying the moment and that was a big thing with her, in embracing the moment and not thinking about what I'm going to be doing after it, my anxiety easily slipped. So, in one session a large part of my addiction, my trauma, my issues, my anxiety, all of those things I've been experiencing dropped dramatically with one session.

Carol also valued having a counsellor that she trusted and thus, was able to establish a positive relationship with. She preferred being able to ask her counsellors questions because their role required them to ask her many questions. She reported that she found it “helpful” if she was able to learn about their life, where they grew up, what their parents did, if they had used drugs and why they became a counsellor. She indicated that she had been able to “really connect with [some counsellors]...because they had been honest,” while others had told her it was a “conflict

of interest” to answer her questions. When a counsellor answered her questions honestly, she thought their working relationship was “balanced” and this ensured that they were “the right people” for her. Similarly, Saliann valued her counsellor’s honesty and referred to her as a “close friend” as they had maintained a working relationship for “four to five years.”

### **Faith-based Programs**

Saliann reported that she was raised “knowing who Jesus” was and that she “lost” her faith when she began using substances. As a young adult, she “started really questioning” if Jesus was real and made “fun of God and people who believe in God.” However, when someone she admired asked her to attend a Christ based recovery group, although reluctant, she chose to attend because she valued their connection. She “really loved” the woman who invited her and reported that the recovery group “actually helped” her “realize” who she was and that she was “broken” and that this was “okay.” Saliann valued the “unconditional love” and acceptance that she felt. She reported that she stopped attending for a while and “got into heavier drugs” and that when she returned, the members conveyed that they were happy to see her and not to worry about missing.

### **Housing**

Although John believed that the staff at his SRO and his mental health program tried to support him, he reported that it was not working. They came to see him “every now and then, but it's mostly I've got to tell them what I want.” For example, he told them that he wanted to “move out” and was waiting for another place. He reported that instead of helping him secure a new home, “they were trying to push” him “to work...to school...to meetings every week and they give us goals we have to do.”

### **Advice Regarding Youth Experiencing Mental Illness**

The interviewees often proffered advice for other youth experiencing the onset of a mental illness and those they interacted with. They reported on five domains: youth experiencing the onset of mental illness, family, mental health professionals, employers and school staff. These are enumerated and explained briefly in this section.

#### **Advice for Youth Experiencing the Onset of Mental Illness**

1. **Become passionate and stay busy.** John recommended to youth that they “get into something and keep your mind busy” with something they are passionate about, that would help keep them “on the line.” He reported he “was hanging out there, doing not much during my days” and that getting “into sports or something probably would’ve helped me stay in school.”
2. **Speak to a counsellor.** Carol recommended youth get a counsellor themselves if they did not want to “go through their parents.”
3. **Increase your MHL.** Kate recommended youth accept their mental illness and “research a lot” in order to secure accurate information about common psychiatric diagnoses, effective treatments and psychopharmacologic medication. She also advised that mental illness is something “that a lot of people deal with.” Ahmed also reported the importance of increasing MHL as it would enable youth to “become a better person.”
4. **Give back.** Robert suggested youth enroll in a mental health program training and work with other youth experiencing mental health challenges. He believed this type of work helped him become a “good role model.”
5. **Make informed decisions regarding marijuana.** After experiencing several suicide attempts, homelessness, dependence on welfare, drug induced psychosis, opiate

addiction, “rehab and detox,” Johnny recommended learning about the effects of marijuana before using it. He reported with disbelief that he “would've never guessed it [marijuana] would have taken him” to the “rough spot” he had been in over the “last five years.”

6. **Have faith.** Kate recommended taking “it day by day” and Robert recommended that youth believe “they can get better” and to “hold on and be true to yourself.”
7. **Seek mental health treatment early.** Joe reported the importance of seeking help early because mental health will “deteriorate...and progress” if it remains untreated. Further, he recommended listening to people when they witness mental health symptoms and convey genuine concern. He suggested “going to somebody that believes in you” and “doesn’t call you crazy.”
8. **Disclose your symptoms.** Ahmed reported that youth would benefit from sharing their difficulties with people they are close with and to increase their MHL levels together. Artemis also reported that youth “should not feel afraid to talk to someone” and Saliann indicated that it was important to accept that “not everybody is...going to be understanding, but...find one person [and] let stuff out.”

### **Advice for Family**

1. **Accept.** Robert believed youth would benefit from family members “admitting they don’t understand, but they want to.” He wished that he had “parents that accepted me before.” Joe also wished his parents had been supportive by doing “whatever they can to make me feel more comfortable” instead of being “argumentative or giving up hope.” He believed that he would have been “a different person today if they had encourage[d] me to get help [in order to] get better.”

2. **Empathize and understand.** Kate reported feeling sad when asked for advice because she believed the youth would have “a long way to come.” Thus, she recommended family members show empathy and understanding towards youth experiencing mental health challenges.

### **Advice for Mental Health Professionals**

1. **Listen to and acknowledge your clients or patients.** Artemis recommended that professionals respond to what their patients say and to acknowledge and validate their experience. She also believed it was important for professionals to be mindful of their body language and to maintain eye contact.
2. **Show your patients respect.** When she began receiving mental health treatment, Violet Rose reported feeling “lesser than” her doctor. She reported that medical professionals “have to respect people with mental illnesses [in order to] be someone the patient... wants to talk to.”
3. **Diagnose people correctly.** Artemis recommended that medical professionals “take the big picture into account” before making a mental illness diagnosis. She then referred to the importance of considering of learning about a patient in their ecological environment and how this could provide additional information regarding their symptomatology.

### **Advice for Employers**

1. **Be curious and ask questions.** Carol’s employers were aware she was diagnosed with mental illness and that she had a drug and alcohol counsellor. Although she believed they acted sensitively toward her, she thought they treated her “like a kid” and acted “awkwardly” towards her because they were unsure about her illness. She believed that

her employers were unable to ask her questions and recommended that they would just ask “the friggin’ question.”

### **Advice for School Staff**

1. **Intervene at elementary and high school levels.** Dorian Gray recommended that teachers talk to their students about mental illnesses in order to increase awareness and MHL levels. She also recommended that teachers assure youth “that they are not crazy” and that “what they are experiencing is real.”
2. **Develop curriculum aimed at improving success for multiple learning styles.** Dorian Gray recommended one to one teaching and discovering the “best way [students] can learn, especially the ones with mental illnesses, like ADHD.” She believed that individuals have “different ways...they learn” and that she saw many “struggle” with the curriculum when she was in high school.

### **Summary**

When participants experienced the onset of their mental illness, many were unable to recognize their changes in mood, personality, thinking, personal habits and/or behaviour as symptoms of mental illness. This could be attributed to lower levels of MHL. As a result, some blamed themselves for their differences and were unable to communicate what has happening or help themselves. All eleven participants reported experiences with both public and self-stigma and how they impacted several domains of their lives and their motivation to seek and adhere to mental health treatment. As emerging young adults, their maturity, mental health treatment and knowledge led to increased acceptance, insight and improved coping techniques. This enabled them to offer advice regarding youth experiencing the onset of mental illness and what services

they found helpful. The following chapter will be a discussion of the significance of the relevant themes in light of the literature review and implications for practice.

## **Chapter 5: Discussion**

This chapter will begin with a summary of the themes related to the stigma of mental illness found in the previous chapter. This discussion highlights the overarching themes; thus, less significant themes noted in the results chapter have been omitted. The themes are then considered with reference to relevant literature and their significance is discussed. Finally, implications of the study as they pertain to clinical and counselling practice are discussed.

### **Summary of Findings**

Participants' accounts offered a view of their experience of stigma as being comprised of two aspects: poor understanding and the endorsement of negative stereotypes of mental illness. Participants perceived that societal conceptualizations of mental illness were either uninformed or misinformed. From their perspectives, this lack of knowledge has led to their confusion and their family members' confusion regarding the cause of their symptoms, fear of the unknown, distrust, lack of acceptance, tenuous relationships and delayed mental health treatment.

Upon the onset of their mental illness, participants questioned why they were thinking, feeling and behaving as they were. As a result, several feelings (e.g., inferiority, tainted, worried, hopeless, scared, blamed, guilty, angry, confusion and frustration) were elicited and participants stigmatized themselves by concealing their experience. Participants and their family members did not attribute illness as the cause of their symptoms because they had low levels of mental health literacy (MHL). All of the participants reported experiences of low self-esteem, childhood bullying, dysfunctional relationships, homelessness, substance abuse, poor academic achievement, decreased employment opportunities, abandonment and isolation.

Mental illness stigma undermined help seeking, treatment adherence and participation in programs for reducing dysfunction and promoting recovery. After receiving effective mental

health treatment, most of the participants became capable of discussing their experience with those that were either close to them or experienced common symptomatology. Maturity, treatment and increased MHL levels resulted in increased acceptance, insight, improved coping and healthier familial and social relationships. The following section, public stigma, is divided into three essential themes and relates the participants' experiences with the stigma of mental illness to previous research. These three themes are mental health literacy, consequences within relationships and self-concept, disclosure and concealment.

### **Public Stigma**

At the lowest level of severity of stigmatizing behaviour, but probably the highest level of frequency, participants experienced subtle behaviours called microaggressions. These are common slights used to denigrate or demean individuals in marginalized groups (Gonzales, Davidoff, Nadal & Yanos, 2015). Participants in this study experienced microaggressions in the forms of assumptions of inferiority, patronization, overt discrimination and subtle behaviours indicating fear of mental illness. Perpetrators included acquaintances, family, friends, school staff and professionals.

The findings of this study mirror previous research regarding the negative consequences of public stigmatization experiences for lower self-esteem, lower self-efficacy, lower self-confidence, poor treatment adherence, quality of life, loss of hope, and social support (Fung, Tsang, Corrigan, Lam & Cheng, 2007; Livingston & Boyd, 2010), internalized stigma (Lau et al., 2017), social avoidance (Abiri, Oakley, Hitchcock & Hall, 2016), secrecy, discrimination and withdrawal (Sarkin et al., 2015), less social support (Meadows, Elder & Brown, 2006), rejection (Perry, 2011), lower recovery orientation (Drapalski et al., 2013) and status loss (Link et al.,

2001). The remainder of this section is divided into the three essential themes of public stigma mentioned above.

### **Mental Health Literacy**

Mental health literacy “is the knowledge and beliefs about mental disorders, which aid their recognition, management or prevention” (Jorm et al., 1997, p.182). A higher level of MHL enables an individual to differentiate a mental illness from general stress, recognize mental illness symptoms and access correct information and seek professional help (Jorm, 2000). MHL has been researched extensively since the 1990’s and several studies have concluded that the level of MHL needed to be raised in order to recognize mental illness early in the community and ensure an appropriate intervention was sought (Coles & Coleman, 2010; Jorm et al., 1997; Tay, Tay & Klainin-Yobas, 2018; Wong, Lam, Poon & Chow, 2011).

Parents, caregivers and guardians are most likely to observe mental health challenges in youth and their MHL is integral for identifying symptoms and seeking effective treatment. Jorm and Wright (2007) found that adolescents are more likely to access informal sources of support and subsequently access mental health treatment after these informal sources recommended it (Rickwood, Deane, Wilson & Ciarrochi, 2005). This study’s findings mirror previous findings that lower levels of MHL in parents had negative consequences for youths’ mental health including missed or delayed diagnosis, delayed treatment and increased levels of stigma (Mendenhall & Frauenholtz, 2015). Participants in this study reported that their caregivers were unable to recognize their mental illness symptoms or a need for mental health treatment. As a result, parents perceived youths’ symptomatology incorrectly, rendering them incapable of supporting them in an effective manner.

## **Consequences within Relationships**

**Family.** Studies have confirmed the integral role of supportive, stable relationships with family and peers for reducing the level of impairment for those who already evidence mental health challenges (Bygstad-Landro & Giske, 2017; Meadows, Elder & Brown, 2006) and for protecting at-risk youth from the stigma associated with mental illness (Warren, Jackson & Sifers, 2009). Research has found that youth suffering from stigma experience family members as less judgmental than other (Mikelson, 2001) and consider them a primary source of support (Jorm & Wright, 2007). However, Meadows et al. (2006) found mentally ill youth experience less social support than their mentally well peers, placing them at greater risk for negative life outcomes.

All participants reported tension and a lack of familial support when they experienced the onset of their mental illness. Constructions of mental illness in behavioural terms appeared to perpetuate stigma in these families because their behaviours were perceived negatively and participants often found themselves in trouble. These findings support previous results that family can become a stigma source and diagnosed youth can be implicated as the cause of family stigmatization. Stigmatization was attributed to “the other” and became a mechanism that consistently created cycles of disconnect, blame and shame (Liegghio, 2017).

***Experiences with mental illness in the family.*** Three of the participants reported that their single parent (i.e. their biological mother) was diagnosed with mental illness and another witnessed their sister exhibit symptoms of schizophrenia. Participants reported a limited understanding of their family member’s mental illness, stigmatized them and were able to identify the strain on family relationships. They felt embarrassed when their family member exhibited symptoms, were concerned when they began experiencing mental health symptoms

themselves and were reluctant to seek mental health treatment because it would confirm they were crazy.

**Peers.** The normalization hypothesis posits that peer groups and friendship are youths' primary reference and render them sensitive to peers' negative assessment (Wolfensberger, Nirje, Olshansky, Perske & Roos, 1974). During adolescence and childhood, peer exclusion and rejection affected the participants' basic needs for belonging and acceptance and had negative implications for their mental health, academic engagement and social withdrawal. As emerging adults, they indicated that they were capable of establishing meaningful connections with trustworthy, caring people. Some peers chose to support them unconditionally and others distanced themselves after spending time with them. These findings reflect results from Weitkamp, Klein and Midgley's (2016) study.

### **Professional Stigma**

**School staff.** The majority of study participants perceived school staff unhelpful and uncaring when they missed or dropped out of school as a result of their mental health challenges. This finding is consistent with the results from the research of Bowers, Manion, Papadopoulos and Gauvreau (2013). However, a teacher recognized the behavioural changes of one participant which resulted in referrals to effective mental health treatment and a supportive home environment. This disconnect from school staff is unfortunate because Thijs, Koomen, and van der Leij (2008) pointed out the significant impact of teacher behaviours and teacher student relationships on student success and adjustment.

**Employers.** Participants did not indicate that their past or present employers stigmatized them. Despite knowing how to secure employment, some participants stigmatized themselves and were reluctant to seek employment because they believed their symptoms would interfere.

They also expressed difficulty maintaining employment as a result of mental illness, but believed their employer understood why they could no longer work. Few of the participants were employed at the time of their interview. One participant reported finding work via her drug and alcohol counsellor and indicated that her employers were awkward around her. She believed that they were aware of her mental illness and addiction and felt uncomfortable talking about them. She found this frustrating and wished they had been forthright.

**Medical professionals.** Stigma from doctors as identified by the participants was seen in treatment as stereotyping, indifference, disrespect, devaluation and judgment. Another aspect of professional stigma was their overdependence on medication and limited usage of individual or group therapy recommendations. Several participants also reported complications with diagnosis and recommended treatment as a result of their substance abuse. When three participants went to the emergency ward for their mental illness, they reported that their doctor indicated that they were abusing too many illegal drugs despite their expressed concern for their mental illness symptomology. This professional stigmatization also frustrated one of the participant's parents because they were hopeful they would secure effective mental health treatment for their son. However, during a subsequent emergency ward visit, this same participant received effective mental health treatment because the doctor referred him to a co-occurring disorders clinic because they recognized his mental illness symptoms and his drug addiction.

For some participants, this professional stigma resulted in lack of treatment adherence and decreased motivation to seek mental health treatment in the future. These findings support previous studies that found that youth believed poor treatment impacted their mental health negatively, creating a health issue, not just a social justice issue (Hamilton et al., 2016; Knaak, Mantler & Szeto, 2017; Sansone & Sansone, 2013). Conversely, one participant had the same

doctor for many years and this led to increased motivation to get better, treatment adherence and collaboration.

Youth offered several recommendations for improvement. Common themes included wanting to be listened to and being encouraged to work alongside practitioners collaboratively as youth believed this relationship could be significant. These recommendations echo findings from the study of Munford and Sanders (2016).

**Counsellors.** The majority of participants reported that they had experienced a counsellor who listened actively, responded in an honest, respectful manner and provided them with helpful resources and coping techniques. However, some reported that they tired of communicating their experiences repeatedly to multiple counsellors.

**Social workers.** Several participants reported experiences with social workers because they were removed from their familial home. One participant reported that her social worker totalized her with her schizophrenia diagnosis by blaming all of her inappropriate behaviours on her illness and by responding accordingly (i.e. admitting her to the psychiatric ward for lengthy periods of time). Another participant reported that his social worker provided helpful information, helpful referrals to medical professionals, financial support and safe housing. This latter finding is consistent with previous results indicating that social workers were an enduring presence as they aimed to understand participants' experiences, provide nurturing support (Munford & Sanders, 2016), build on youth's capacities and created efficacious practices with youth as partners (Kumpulainen, Lipponen, Hilppo & Mikkola, 2013).

### **Self-Stigma**

The current findings are consistent with previous studies finding that youth experience significant reductions in their self-esteem and self-efficacy and feelings of rejection after they

internalize negative social responses (Corrigan & Kleinlein, 2005; Corrigan, Druss & Perlick, 2014; Link & Phelan, 2001). This left them vulnerable to endorsing negative stereotypes about themselves (Watson, Corrigan, Larson & Sells, 2007). This section provides a brief summary of how three components of some participants' lives were affected by self-stigma. These concepts are mental health literacy, consequences of psychiatric labelling, self-concept, disclosure and concealment.

### **Mental Health Literacy**

For this study, the youths' early conceptualizations and descriptions of their mental illness symptoms were consistent with the majority of the literature (Bowers, Manion, Papadopoulos & Gauvreau, 2013; Pang et al., 2017). As a result of lower levels of MHL, participants blamed themselves for their illness, thought they were crazy and their treatment was delayed as they suffered in silence or coped by abusing substances. This is concerning because unrecognized and untreated mental illnesses can lead to higher risk for numerous physical illnesses and substance abuse, poorer academic and work achievement, criminal activity, relationship problems, poor social functioning and early mortality (Rosenberg, 2015).

### **Consequences of Psychiatric Labelling and Treatment**

**Diagnosis.** When an individual is diagnosed with a mental illness, the possibility of devaluation become personally relevant if they endorse the negative connotation of their diagnosis. The findings in this study reinforce an understanding that receiving a psychiatric diagnosis can be experienced as a relief, as youth gain a way to understand their challenges. Yet, some youth may experience receiving a diagnosis as a confirmation that they are 'crazy.'

**Perception of diagnosis and medication.** Earlier studies found that individuals respond to receiving a mental illness diagnosis in different ways. Corrigan and Watson (2006) believed

there were three primary responses to being diagnosed with a mental illness: indifference, righteous anger and self-stigma. For the current study, some participants responded with indifference because they eventually recognized that they had a mental illness, wanted to recover and were provided with effective mental health treatment. This indifference has been found to occur when individuals do not identify with a certain group or do not believe in the legitimacy of negative stereotypes.

Conversely, Link, Cullen, Struening, Shrout and Dohrenwend (1989) developed the “modified labelling theory” (p. 400) after finding that people were socialized to accept negative stereotypes about those with mental illness and that labelled individuals are subjected to differential treatment. This finding is also consistent with the current study because the participants were concerned that their social networks might be affected if they disclosed they illness and they wondered how they would manage their stigmatized identity. Participants in this study appeared to waver between internalizing negative stereotypes and stigmatizing themselves, being angry and accepting their diagnoses.

### **Self-concept, Disclosure and Concealment**

Public stigma can erode young people’s experiences of self-worth, causing them to feel angry, frustrated, inferior and hopeless. This led many of the participants to withdraw socially because they internalized stigma and believed they were excluded and rejected by those around them. Individuals with mental illness have been found to expect social rejection (Corrigan & Kleinlein, 2005; Corrigan, Druss, & Perlick, 2014; Link & Phelan, 2001).

**Family.** All of the participants’ chose to conceal their mental illness from their family. They were unaware what was happening, were unconvinced their family members would understand and their confusing behaviour appeared to perpetuate stigma because their behaviours

were perceived negatively and participants often found themselves in trouble. These findings mirror the study of Richardson, McDermott, Cobham and Murray (2013).

**Peers.** Expectations of social exclusion and the negative connotation attached to mental illness acted as a deterrent to disclose their mental illness to their peers for all of the participants. In order to conceal their mental illness, youth masked their feelings and pretended to be happy, evaded questions and conversation by insisting everything was fine and withdrew socially to make their mental health challenges seem less problematic. These findings are consistent with findings from a study by Gronholm, Thornicroft, Laurens and Evans-Lacko's (2017) study.

**Intimate Relationships.** A majority of participants who endorsed societal experiences of stigma had internalized those messages and believed they were not desirable as partners. These participants' self-reports echoes those of youth in an earlier study which found that 60 percent of youth with mental illness believed that people without mental illness would not want a partner with mental illness (Elkington et al., 2012).

### **Implications for Practice**

A reflection on the accounts of youth in the current study yields several implications for clinical and counselling practice with youth with mental illness. Enhancing the general public's mental health literacy could result in prevention, early recognition and intervention and reduction of the stigma associated with mental illness. The capacity to label a mental health challenge correctly could improve communications with mental health professionals and improve the likelihood of an early diagnosis and effective mental health treatment.

In order to support youth with mental health challenges and their families, mental health professionals must assess the youth broadly by using the bio-psycho-social model as a guide. Multiple domains of an individual's life need to be considered. Most mental health challenges

are influenced by biological, psychological, social, cultural and spiritual impacts. Regardless of the illness, the individual will likely exhibit physical, psychological and social symptoms. Thus, recommended treatment might effectively include prescribed physical activity and psychopharmacological medication, psychotherapy and social activity. Mental health care professionals may benefit from additional education in order to enhance their knowledge, understanding, awareness and sensitivity. Their approach should promote transparency in order to reduce the stigma of mental illness. Lastly, a collaborative, respectful approach to youth affected by mental illness and their families would contribute to their empowerment, supporting them to accept and competently manage their mental health challenges with dignity.

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## **Appendices**

**Appendix A.** Study Information Leaflet for Covenant House Staff

**Appendix B.** Research Posters

**Appendix C.** Interview Guide

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## Appendix A

### Study Information Leaflet for Covenant House Staff



University  
of Victoria | School of Child  
and Youth Care

*Study Information Leaflet for Covenant  
House Staff*

**Title of Study:** “Mental Illness Stigma: Using Key Informant Methodology to Explore Youths’ Perspective.”

#### **What is the study about?**

I am a Child and Youth Care Masters student at the University of Victoria. The purpose of this study is to explore how youth experience the stigma of mental illness. According to the World Health Organization, mental disorders are the single most common cause of disability in young people. In North America, approximately 15%–20% of adolescents suffer from some form of mental disorder. Furthermore, 70% of mental disorders onset prior to the age of 25, making the adolescent years a critical window in which mental health can be promoted, and mental health challenges can be addressed. If left untreated, mental disorders can impede all aspects of health, including emotional well-being and social development, leaving young people feeling socially isolated, stigmatized, and unable to optimize their social, vocational, and interpersonal contributions to society. Mental illness stigma represents a significant public health concern because it is a major barrier to care seeking or ongoing treatment adherence. I believe study outcomes may provide important information about the mechanisms by which stigma affects the mental health and well-being of youth. The results may also illuminate how professionals and society can intervene to prevent or decrease stigma and its harmful consequences.

#### **What will the participants be asked to do?**

Participants will be asked open-ended questions regarding their experiences living with mental illness and their experience of the stigma of mental illness. Participants who voluntarily agree to be involved in the study will be interviewed once for up to two hours-this will allow for introductions, informed consent and the interview. The interview will be tape recorded and transcribed later. To prevent or manage risks, the following steps will be taken: 1) the youth will have the right to have a break or withdraw from the study at any time and 2) every attempt to maintain sensitivity (i.e. by respecting what the youth says, accepting their truth and remaining non-judgmental) will be made during the course of the interviews. In the event of significant emotional upset or concern during the interviews, the interview will be terminated and the youth will be provided access to a counsellor at Covenant House. If there is no one available at Covenant House, youth will be able to access counselling from Susie Lang-Gould, R.C.C. free of charge (<http://www.susielanggould.ca/>).

**How can you help?**

As Covenant House staff, I would be grateful if you could post the enclosed recruitment posters in prominent locations (i.e. areas the youth gather) at the two Covenant House locations. The poster outlines the study, inclusion criteria and includes my contact information for the youth.

**Where will the study take place?**

The interviews will take place in a private meeting room at Covenant House. This space will be one where confidentiality can be assured for the participants.

**What will happen to the information?**

All information provided by the youth will be confidential. Using a pseudonym in the data analysis will protect their confidentiality and the confidentiality of the data. Any unique identifying aspects of their identity will be altered when reporting data in an attempt to foster confidentiality. In terms of protecting anonymity, names will not be documented during collection of the data and will not be used in the analysis. I personally ensure that secure placement and storage of the research data will occur during the research project. Only the minimal amount of relevant data will be utilized, and a restricted number of people (i.e. my research supervisory committee) will assist with data analysis and interpretation.

Participants will be informed that if they disclose information that causes concern regarding their safety or the safety of others, appropriate professionals will be informed.

It is anticipated that the results of this study will be shared with others during my thesis defense, submitted to UVIC website and presentations at scholarly meetings.

Thank you for taking the time to read this information. If you have any questions, please do not hesitate to contact me. I am also willing to attend meetings to explain the research further.

Sally-Anne Haug, University of Victoria Child & Youth Care Masters Student  
shaug@uvic.ca

Master's Thesis Supervisor-Dr. Jessica Ball  
jball@uvic.ca  
250-472-4128

## Appendix B

### Research Posters



University of Victoria | School of Child and Youth Care

School of Child & Youth Care  
University of Victoria  
P.O. Box 1700, STN CSC  
Victoria, BC V8W 2Y2

## YOUTH RESEARCH PARTICIPANTS NEEDED

**Are you a youth living with mental illness who has experienced the stigma of mental illness?**

### What is Stigma?

*Mental Illness Stigma* refers to negative attitudes or beliefs (prejudice) and negative behaviour (discrimination) toward people who are perceived as different. This research is important because of the need to hear and honour the voice of youth living with mental illness.

**As a volunteer in this study, you would be asked to meet for a one-hour confidential interview to express your experience with the stigma of mental illness.....**

**You are eligible to participate if:**

- ✓ You are between the ages of 18-24 years
- ✓ You are living with mental health challenges (anxiety, psychosis, depression, high and low moods, etc.)
- ✓ You have experienced and been affected by mental illness stigma
- ✓ You are currently receiving mental health treatment
- ✓ You are currently mentally stable
- ✓ You are able to communicate in English in an interview setting
- ✓ You are willing to provide up to 2 hours of your time for an interview

I, Sally-Anne Haug, am a UVIC Master of Child and Youth Care student and I am conducting a study called "Mental Illness Stigma: Using Key Informant Methodology to Explore Youths' Perspective." Please contact me if you are interested and want to learn more. All participants will receive a \$25 vendor gift card.

[shaug@uvic.ca](mailto:shaug@uvic.ca)

This study is being supervised by Dr. Jessica Ball, Professor, UVIC Child and Youth Care, tel: 250-472-4128 email: [jball@uvic.ca](mailto:jball@uvic.ca)

# Stigma



University  
of Victoria

## **Youth Participants needed for Mental Illness Stigma Research**

### **What is Mental Illness Stigma?**

*Mental Illness Stigma* refers to negative attitudes or beliefs (prejudice) and negative behaviour (discrimination) toward people who are perceived as different. This research is important because of the need to hear and honour the voice of youth living with mental illness.

**As a volunteer in this study, you would be asked to meet for a confidential interview to express your experience with the stigma of mental illness.....**

**Contact me if you are interested in volunteering and are able to answer yes to the following questions:**

- ✓ Are you between the ages of 18-24 years?
- ✓ Are you living with mental health challenges (anxiety, psychosis, depression, schizophrenia, high and low moods, etc.)?
- ✓ Have you experienced the stigma of mental health?
- ✓ Are you currently receiving mental health treatment?
- ✓ Are you currently mentally stable?
- ✓ Are you able to communicate in English in an interview setting?

Contact Sally-Anne Haug, student researcher, to learn more about the study. Your participation will not affect services you receive at Covenant House, health care providers, schools, employers or social service agencies. All participants will receive a \$25 vendor gift card.

[shaug@uvic.ca](mailto:shaug@uvic.ca)

This study is being supervised by Dr. Jessica Ball, Professor, UVIC Child and Youth Care, tel: 250-472-4128 email: [jball@uvic.ca](mailto:jball@uvic.ca)

## Appendix C

### Interview Guide

#### Interview Guide

Prior to each audio taped interview, the author will have a casual conversation with the youth to establish rapport in order to help them feel comfortable. A drink and a snack will be offered. The use of the tape recorder will be explained and the researcher will confirm the youth gives for audiotaping. The youth will have the opportunity to ask questions and be reminded they do not have to answer any questions they are not comfortable with and can stop the interview at any time. The author will explain that strong feelings may surface when the youth talks about their experiences and convey how this risk will be managed with the following steps:

1. the researcher will make every attempt to maintain sensitivity (i.e. by respecting what the youth says, accepting their truth and remaining non-judgmental) towards your experience will be made during the course of the interviews
2. the youth will be provided with privacy
3. the youth can request a break or end the interview if they are feeling uncomfortable
4. the interview will be kept at two hours-this will allow time for introductions, the informed consent process and the interview
5. the youth will have the right to withdraw from the study at any time

In the event of significant emotional upset or concern during or following the interview, the interview will be terminated and the youth will be provided access to a counsellor or psychiatrist at Covenant House. If Covenant House counsellors are unavailable, Susie Lang-Gould, RCC, will provide counselling at no cost to the youth or Covenant House. (<http://www.susielanggould.ca/>).

Participants will be reminded that the researcher will maintain confidentiality except in the event that they share information about a) unreported sexual or physical abuse b) risk of self-harm or suicide or c) risk of seriously harming someone else.

#### **QUANTITATIVE QUESTIONS**-Sample demographic and clinical characteristics

Gender  
Race/Ethnicity  
Age at first treatment

#### **QUALITATIVE QUESTIONS**

#### **PUBLIC STIGMA**

- Ask youth to specifically comment on any perception(s) of treatment by family, peers and friends, and teachers/school staff since they have experienced mental health challenges.
- Do you think people (family, peers, school staff, etc.) treat you differently than they used to before you experiencing symptoms? How do they treat you differently?
- Do you think people treat you differently in comparison to (a) your siblings (in the family), (b) other youth?
- Why and how do you think they treat you?
- Is there anyone in your life that you would not want to know about your mental health challenges?
- What do you recall being told by others (e.g., psychiatrist/doctor, clinician, teacher, family member....) about the diagnosis? (name the diagnosis, e.g., bipolar, if one was given).
- Do you recall conversations with others (e.g., siblings, grandparents, teachers, doctors, friends) about your first time accessing mental health services and treatment/ medication?
- How would people in your life who do not know about your concerns react if they found out about it?
- Has anyone been particularly helpful in regards to your having emotional or behaviour issues?
- What did they do that was helpful?
- How did they offer support and encouragement?

#### **SELF-STIGMA**

- Before you went for help, what did you think/feel about what was happening to you? Where do you think those thoughts come from?
- What went through your mind when treatment was first suggested?
- How does having mental health challenges affect how you think or feel about yourself? Does it affect how you make choices day to day?
- If you tried to explain to a friend who does not have a mental illness what the experience is like for you, what would you tell them?
- What do you tell people about your concerns (i.e. regarding their mental health challenges) that we have been talking about? (probe for what do you say, to whom have you told, what was their response, probe for examples)
- Are there things you keep secret about your concerns? Or your treatment?
- [If yes to above] You are quiet about some concerns, how do you keep it a secret?
- Stepping back from your personal situation, what do you think about youth that have mental health

problems?

- Can you share any new understandings that you have about yourself since being affected by mental illness?
- Can you tell me of a time or times when you handled stigma well? How did you and feel/think then?
- Do you think some of your beliefs/experiences have affected or changed the way that you see yourself?
- What do you think having a mental health challenges means about your future

#### **GENERAL**

- What advice would you give to a youth that was beginning to experience the symptoms of mental illness?

#### **SENSITIVITY TO CUES AND THE USE OF PROBES**

The researcher will follow the youth's verbal and nonverbal cues throughout the interview/conversation and at times may attempt to elicit more detailed responses about topics that seem to be of importance to the youth or to clarify meanings using probes, for example:

1. · Can you say something more about that?
2. · What did you think about that?
3. · How did you feel about that?
4. · What did that mean for you?
5. · Could you give me an example of that?
6. · Thinking about that now...

Can you give a more detailed description of what happened?

What was it about ... (that experience) ... that affected the way that you see yourself?

Are you saying that ... (summary of participant's statement about their experience)?

#### **CLOSING THE INTERVIEW**

At the end of the audio taping the participant will be asked if there is anything else they would like to share about their experiences. The researcher will express appreciation and provide positive feedback about their participation.

## Appendix D

### Participant Consent Form



University of Victoria | School of Child and Youth Care

### *Participant Consent Form*

#### Mental Illness Stigma: Using Key Informant Methodology to Explore Youths' Perspective

You are being invited to participate in a study entitled "Mental Illness Stigma: Using Key Informant Methodology to Explore Youths' Perspective" being conducted by Sally-Anne Haug.

I, (Sally-Anne Haug) am a graduate student in the department of Child & Youth Care at the University of Victoria and you may contact me if you have further questions by emailing me at [shaug@uvic.ca](mailto:shaug@uvic.ca).

As a graduate student, I am required to conduct research as part of the requirements for a Master's degree in Child & Youth Care. It is being conducted under the supervision of Jessica Ball who can be reached at 250-472-4128 or [jball@uvic.ca](mailto:jball@uvic.ca)

If you participate, we will have an initial chat for you to ask any questions you have about your involvement. Following that conversation, an interview of up to two hours will occur at in a private meeting room at Covenant House where you will have an opportunity to share some of your experiences with mental illness and mental illness stigma. Approximately five youth will participate and after each interview, the data will be analyzed, interpreted and used as a key part of research required for my Masters in Child and Youth Care credential. The purpose of this research is to explore how youth experience the stigma of mental illness. You have been asked to participate because you identify as a youth living with mental illness. Whether you choose to participate or not, will have no effect on how you are treated by the researcher. These interviews will be audio recorded and your responses will be typed and printed out. This will help me remember all the things we talked about and ensure I understand your responses. There are no wrong or right answers, the aim is to discover what you think about your experiences.

Participation in this study may cause some inconvenience to you, including the time commitment for the interview. It is possible that some strong feelings may surface when you are talking about your experiences. To prevent or manage this risk, the following steps will be taken:

1. every attempt to maintain sensitivity towards your experience will be made during the course of the interviews
2. you can request a break or end the interview if you are feeling uncomfortable
3. you will have the right to withdraw from the study at any time

If you are unable to say you need a break, you can stop the interview by touching a card with a red "stop" sign provided by me.

In the event of significant emotional upset or concern during the interviews, the interview will be terminated and you will be provided access to either a counsellor at Covenant House. If a counsellor at Covenant House is unavailable, counselling will be provided to you at no charge by Susie Lang-Gould, R.C.C.

The potential benefits of your participation include the possibility of giving you an opportunity to express your thoughts and feelings about some of your experiences with mental illness. Potential outcomes include provision of information about how stigma can affect the mental health and well-being of youth. Sharing results will contribute

to knowledge and possibly highlight how professionals and society can intervene to prevent or decrease mental illness stigma and its harmful consequences.

As a way to compensate you for any inconvenience related to your participation, you will be given a \$25 gift card from a vendor of your choice. If you agree to participate in this study, this form of compensation to you must not be coercive. It is unethical to provide undue compensation or inducements to research participants. If you would not participate if the compensation were not offered, then you should not participate.

Your participation in this research must be completely voluntary. If you decide to participate, you may withdraw at any time without any consequences or explanation. If you do withdraw from the study your data will be destroyed and will not be used for analysis.

Using a pseudonym (a fictitious name) in the data analysis will protect your confidentiality and the confidentiality of the data. Any unique identifying aspects of your identity will be altered when reporting data in an attempt to foster confidentiality. With your permission, anonymous quotes of what you have said may be used. In terms of protecting your anonymity, your name will not be documented during collection of the data and will not be used in the analysis. I will ensure secure placement and storage of the research data will occur during the research project. Only the minimal amount of relevant data will be utilized, and a restricted number of people (such as my research supervisors) will assist with data analysis and interpretation.

Confidentiality may be breached where either the law requires it or where there is a reasonable expectation of harm occurring to either you or others (i.e. disclosure of plans to commit suicide or murder).

It is anticipated that the results of this study will be shared with others during my thesis defense, presentations at scholarly meetings and the UVIC website.

Data from this study will be disposed of by destroying the audiotapes, computer files, transcripts and notes. Data released will not contain names, initials or any other identifying information.

There will be no names or initials of identifying information publicized.

Individuals that may be contacted regarding this study include the researcher and supervisor indicated above. In addition, you may confirm the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria at 250-472-4545 or ethics@uvic.ca.

Your signature below indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered by the researcher.

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*Name of Participant*

---

*Signature*

---

*Date*

*A copy of this consent form will be left with you and a copy will be taken by the researcher.*

**Appendix E**

Stop Sign to Indicate Need for a Break or End Interview

