Perceptions of Stigma and Care Receipt Among Youth who Self-Harm and Have Received Mental Health Treatment in a Hospital Setting

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ABSTRACT

PERCEPTIONS OF STIGMA AND CARE RECEIPT AMONG YOUTH WHO SELF-HARM AND HAVE RECEIVED MENTAL HEALTH TREATMENT IN A HOSPITAL SETTING

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This thesis is an investigation of youths’ experiences with stigma and care receipt. Stigma within the context of mental illness, which has been conceptualized as negative attitudes held against someone with mental illness (Stuart, Arboleda-Florez, & Sartorius, 2012) and care receipt have been explored in adult clinical populations; however, these experiences have not been widely explored with adolescent clinical populations who self-harm from the point of view of the youth. Using a cross-sectional design, open-ended interviews were conducted with 12 adolescents (14-19 years, 83% female) and examined using a content analysis. Results indicated that youth have experiences of both positive and negative care receipt, and of stigma from both clinicians and other patients. Youth were able to provide an enriching perspective on the functions of self-harm, the characteristics that make a good and bad care provider and details on common stigmatizing reactions. Future goals of researchers could include the reduction of negative care experiences and stigma in healthcare settings to provide the best chance of success for youth engaging in self-harm.
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Introduction

Stigma is generally understood to be a harmful practice that results in a host of negative outcomes and reduces the successfulness of treatment practices (Schulze, 2007). Within the context of mental illness, stigma is defined by Stuart, Arboleda-Florez, and Sartorius (2012) as both negative and prejudicial attitudes that an individual holds against someone with mental illness, and a complex social process that may marginalize people with mental illness. Adolescents who have self-harmed are at risk of experiencing stigma as a result of their self-harming behaviours. Furthermore, adolescents who are seeking care at a mental health treatment facility are in a position to potentially experience stigma from the people who are providing care. The purpose of this project was to explore the perceptions of adolescents who have self-harmed and have received mental health care in a psychiatric hospital setting. Specifically, the researcher examined adolescents’ perceptions of care receipt and stigma as they related to self-harming behaviours.

What is Self-Harm?

For the purpose of this study, the definition of self-harm provided by Hawton, Rodham and Evans (2006) was employed; here self-harm is defined as:

An act with a non-fatal outcome in which an individual deliberately did one or more of the following: initiated behaviour which they intended to cause self-harm, ingested a substance in excess of the prescribed or generally recognized therapeutic dose, ingested a recreational or illicit drug that was an act the person regarded as self-harm, ingested a non-ingestible substance or object. (p. 29)

This definition was selected for use in this project because it is purposefully broad, includes many different methods, varying severity, duration and frequencies of harming behaviour, and includes harming behaviour regardless of suicidal intent. Given that researchers aimed to use engagement of self-harm as a context for stigma, rather than for
the focus of the project, and given that the research is exploratory, it seemed important to select a comprehensive definition to allow for a wider range of self-harming behaviours and a varied participant perspective.

Researchers acknowledge that there are a variety of terms that have been frequently used to describe self-harming behaviours (D’Onofino, 2007). One of the most commonly employed terms and corresponding definition is that of non-suicidal self-injury (NSSI), which involves the purposeful manipulation of body tissue without suicidal intent (Nock & Favazza, 2009). The definition of this term is more specific than that for self-harm, as it specifies intent and does not include acts such as ingesting substances and other non-fatal acts of self-harm. Indeed, NSSI can be considered a form of self-harm. Due to its specificity, NSSI was not selected to operationalize this behaviour for the purposes of this project, however, ‘NSSI’ and ‘self-injury’ are commonly employed terms in the literature. In order to be transparent in the presentation of previous literature, researchers have used the terms originally employed by the referenced researchers when discussing their studies.

**Self-harm as maladaptive.** Self-harm results in physical harm, although the severity of injuries endured often varies across individuals (Nock, 2010). Those who self-harm are also more likely to have psychiatric difficulties, including depression, anxiety, substance abuse, and some personality disorders (Klonsky & Olino, 2008; Serras et al., 2010; Whitlock et al., 2006). People who engage in self-harm are also more likely to experience feelings of shame and guilt for engaging in a generally socially unaccepted practice (Gratz, 2003; Klonsky, 2009). In addition, self-harm is related to negative interpersonal outcomes, including social isolation, which could be a result of the stigma
concerning self-harm (Gratz, 2003).

Engagement in self-harming behaviours without the intent to die is also associated with suicidality. For example, engagement in NSSI behaviours is correlated with increased suicidal thoughts (Klonsky & Olino, 2008), and Nock et al. (2006) suggested that engagement in self-injury increases a person’s capability for committing suicide. Furthermore, Hawton, Rodham and Evans (2006) identified that 45% of the adolescents in their sample who engaged in deliberate self-harm reported wanting to die at the time of self-harming. Because self-harm is considered a maladaptive behaviour, it is important to contribute to the body of research on self-harm that may inform prevention and treatment practices with the hope of reducing self-harm in our population (Gratz, 2003).

**The functions of self-harm.** Researchers have documented a variety of functions associated with self-harm and these can generally be grouped in two main categories: intrapersonal and social (Klonsky & Glenn, 2009; Nock & Prinstein, 2004), although intrapersonal functions are most often reported by people who self-harm. The most commonly empirically supported reason for self-harm is to regulate emotion (Klonsky, 2007). In this case, self-harm is used to alleviate negative emotions and to cope with emotional difficulty. In addition to people endorsing self-harm as a tool for emotion regulation, people who are engaging in self-harm have higher scores on depression and anxiety scales both generally (Andover, Pepper, Ryabchenki, Orrico, & Gibb, 2005) and before an episode of self-harm, and are likely to experience a cessation of negative feelings after engaging in self-harm (Klonsky, 2009; Nock & Prinstein, 2004). These findings, although with varied samples and definitions of self-harm, all suggest that youth
may engage in self-harm due to poor coping skills because self-harm helps to regulate their emotions.

Another intrapersonal function of self-harm is self-punishment. Linehan (1993) proposed that self-harm is sometimes used as an expression of anger or derogation against oneself. People use self-harm in order to punish themselves because they are experiencing self-anger, self-criticism, or self-loathing. Klonsky (2007) found that self-punishment was strongly endorsed as a function of self-injury in ten of the 18 studies he analyzed, and it was identified as the fourth most supported function in his (2011) random digit dialing study of 439 adults in the United States. In addition, Nixon, Cloutier and Aggarwal (2002) reported that half of the clinical population of adolescents in their study agreed that they were self-harming to punish themselves for bad behaviour and thoughts.

There are also many social functions associated with self-harm. Nock (2010) identified two sub-categories under the category of interpersonal, or social, functions of self-injury. Interpersonal positive reinforcement occurs when people engage in self-harm to experience an increase in a desired social event after engaging in self-harm. In this case, a person who engages in self-harm does so to experience positive social effects, like increased communication, attention or to seek out a sense of belonging. In contrast, interpersonal negative reinforcement occurs when a person who is self-harming engages in self-harm to decrease the frequency of a social event or to avoid a negative social outcome, such as when someone self-harms to stop bullying or to avoid taking responsibility (Nock & Prinstein, 2005). These less empirically supported social
functions, combined with the intrapersonal functions discussed above, represent only a selection of the functions of self-harm discussed in the literature.

**Who engages in self-harm?** Overall, the average age of onset for self-harm has been reported as between 12 and 16 years of age (see Klonsky, Muehlenkamp, Lewis and Walsh (2011) for a review). However, some researchers have found that self-harming behaviours are evident among children (Harris, 2000; Preyde et al., 2012; Spandler, 1996). Research that attempts to delineate gender statistics on people who self-harm is varied based on the setting of the research, and the employed definition of self-harm. Some suggest that males and females engage in self-injuring behaviours at the same rate in community samples (Gratz, 2003; Lloyd-Richardson, Perrine, Dierker & Kelley, 2007), while other research conducted in clinical samples, specifically emergency room attendees, found that females are more likely to engage in self-harm than males (Hawton & Harriss, 2008). Preyde and colleagues (2012) have reported that, on a clinician rated scale at admission, more males than females were identified as self-harming, though the differential was not statistically different than the overall sample (i.e., 75% of the overall sample and 75% of this subgroup of youth who self-harm were male). Furthermore, gender differences seem to vary by age, notably in adolescence, such that adolescent and young adult females engage in self-harm more frequently than males, though there are no reported differences between genders in adulthood (Klonsky, 2011). Researchers suggest that adolescent and young adult females engage in self-harm more frequently than males in this age range (for a review see Klonsky, Muehlenkamp, Lewis & Walsh (2011). As a result of the varied reports on the relation between self-harm and gender, it is difficult to make generalizations about these prevalence rates.
There are a range of prevalence rates cited in the literature due to varied populations and methods of measurement. For example, the prevalence rates of self-harming behaviours are high among adolescents with rates ranging from 13-45% in community samples (Lloyd-Richardson, Perrine, Dierker & Kelley, 2007; Nock, 2010; Polk & Liss, 2007; Ross & Heath, 2002). In this case, the greater rate (45%) was obtained by including instances where a person engaged in self-injury only once rather than on a regular basis (Lloyd-Richardson, Perrine, Dierker & Kelley, 2007). Rates are even higher among clinical mental health samples with estimates around 40-60% (Cloutier, Martin, Kennedy, Nixon & Muehlenkamp, 2010; Nock, 2010; Nock & Prinstein, 2004). For the purposes of this study, researchers focused on a clinical population because incidents of self-harm are likely to be more common, severe, and ongoing than in a community population (Klonsky & Olino, 2008). In addition, males and females between the ages of 14-18 were included in the project because although self-harm can begin at any age, the most common age of onset is middle adolescence and self-harming behaviours are common in adolescence, thus we can access experiences of this behaviour at an age during which it is most likely to occur.

**Treatment of self-harm.** Given the varied functions, definitions and demographic characteristics of self-harm, developing a treatment plan is especially difficult and there are no empirically supported treatments for self-harm. Nock (2010) discussed the need for evidence-based interventions and prevention programs, as most presently used treatments are research-informed, but not directly research-supported. Generally, clinicians use a variety of treatment approaches (e.g., cognitive behavioural,
psychodynamic, and pharmacological interventions) that they have adapted, but were not initially developed for the treatment of self-harm specifically.

Dialectical Behavioural Therapy (DBT) is a therapeutic technique that shows research-informed promise for the treatment of self-harm (Klonsky & Glenn, 2008). DBT focuses on increasing mindfulness, interpersonal effectiveness, distress tolerance, and emotion regulation using cognitive behavioural techniques and was initially used to treat Borderline Personality Disorder (Linehan, 1993; Linehan et al., 2006). Given that people who self-harm are likely to have difficulties with emotion regulation, and given that self-harm is a symptom of Borderline Personality Disorder, DBT may be an effective treatment for self-harm. Other researchers suggest that Cognitive Behavioural Therapy (CBT) could be a helpful treatment approach (Walsh, 2006). When applied to self-harm, CBT focuses on changing the patients’ thoughts, assumptions and core beliefs that support self-harming behaviours. Given that CBT has been shown to be effective in treating suicidality, depression, anxiety, and other mental illnesses, researchers suggest that it too could be effective with self-harming behaviours (Walsh, 2006).

Another research-informed treatment that has been employed to help with self-harming behaviours is Motivational Interviewing (MI). MI is a method of counseling aimed at developing behavioural changes by enabling clients to become agents of their own change through discussion of the benefits and drawbacks of the behaviours with the intention of creating the desire to change (Miller & Rollnick, 2002). MI has been shown to work well with addictive behaviours and researchers suggest that it could also be successful with self-harming behaviours (Klonsky, Muehlenkamp, Lewis & Walsh, 2011; Kress & Hoffman, 2008).
There are certain recommendations for engaging in treatment with patients who are self-harming. Researchers warn against appearing as negative towards or, conversely, too eager with a heightened interest in self-harming behaviours as patients might feel uncomfortable with that and clinicians will not develop rapport (Klonsky & Lewis, in press). Instead, Walsh (2006) suggested that therapists ought to take on a low-key, dispassionate demeanor, which is a middle ground between appearing too supportive of and conversely too negative toward self-harm. Walsh (2006) also recommended that clinicians maintain a respectful curiosity and use nonjudgmental compassion while interacting with clients. This demeanor can be used to develop a rapport with clients in order to ensure that therapy has the potential to be successful.

**Self-Harm in a Clinical Population**

Youth with a history of self-harm may receive treatment through a variety of avenues, including hospital, mental health clinic or residential settings. Researchers have investigated a variety of topics as they relate to a clinical population of adolescents who self-harm. For example, there is a body of research on the relation between self-harm and emotion regulation. Nock and Prinstein (2005) identified that most episodes of self-injury reported by the psychiatric inpatients were not premeditated and were used for either social reinforcement or to remove negative feelings. As with the general population, many of the children and youth in a clinical setting experienced negative automatic thoughts, depressed mood, and hopelessness before engaging in self-injury (Nock & Kazdin, 2002). In addition, there is consensus that adolescents in a clinical population engage in self-harm to reduce and regulate their negative emotions as they experience
difficulty with emotion regulation (Adrian, Zeman, Erdley, Lisa, & Sim, 2011; Sim Adrian, Zeman, Cassano, & Friedrich, 2009).

When comparing children to adolescents in a clinical population, Sarkar and colleagues (2010) found that more males than females self-harmed in the younger group than in the older group. Also, children under 12 were more likely to have a family history of depression than the older youth who self-harmed. They also identified that the children who presented to clinical treatment were engaging in self-harm methods that were similar to adolescents, such as hanging and strangulation.

When looking at a clinical population of adolescents who self-injure and comparing those who have or have not attempted suicide, Dougherty et al. (2009) found that youth who engaged in both were more likely to report depression, hopelessness, impulsivity and suicide ideation than those who did not attempt suicide. Furthermore, young people who engage in both behaviours may be more likely to have higher levels of psychopathology and depression compared to adolescents who either self-harmed or engaged in suicide attempts (Claes, et al., 2010).

Within a Canadian clinical population of youth who have a self-harm history, research is sparse; only three studies could be located. In one study, Nixon, Cloutier, and Aggarwal (2002) examined the addictive and impulsive nature of self-injury and found that 97% of adolescents who were had self-injured in a clinical population reported three or more addictive features of self-injury. These included: increased frequency and severity of self-harm over time, continued self-harm despite recognizing the consequences, experiences of social problems as a result of the behaviour, and the behaviour being time-consuming. The majority of their participants experienced urges to
self-harm on a daily basis.

More recently, Cloutier et al., (2010) explored a clinical population of adolescents presenting to emergency crisis services. They concluded the following: half of the participants engaged in self-injury within 24 hours of admission to the hospital and an additional 4% engaged in both self-injury and a suicide attempt; females were more likely than males to have engaged in self-injury; youth who engaged in self-injury were more likely to also have self-reported symptoms of depression, compared to those attending crisis services who did not self-injure; and 40% of the young people who had engaged in self-injury also reported suicide ideation. Adolescents who self-injured were also less likely to show aggression towards objects (on the Childhood Acuity of Psychiatric Illness scale (Lyons, 1998)) than those who did not self-harm, but they were more likely to experience internalized aggression.

Finally, Preyde and colleagues (2012) explored clinician ratings of children and youth attending a residential treatment or an intensive home-based program and found that those adolescents who were identified by clinicians as people who self-injure upon admission were rated higher on symptom severity by caregivers. They also found that clinician and caregiver ratings of the youths’ self-injuring behaviors were reasonably consistent. While these three studies present as a relatively small group of research that is focused on a clinical population of Canadian adolescents who self-harm and who receive treatment for mental illness, there are even fewer studies focused on this population from the perspective of the adolescent and fewer still that focus on how it is for adolescents who are self-harming to receive care in a clinical setting. Thus, researchers do not presently have a good understanding of how youth feel about the care they receive, which
is a gap in the knowledge on mental health treatment for youth.

**Self-harm in a clinical population from the perspective of the adolescent.**

Comparatively few research studies have been focused on a clinical population of people engaging in self-harm from their perspective through in-depth interviewing. Both Crouch and Wright (2004) and Spandler (1996) completed interviews with the population of interest in this study: adolescents with a self-harm history who participated in residential mental health treatment. Crouch and Wright (2004) completed interpretive phenomenological analyses on in-depth interviews with six adolescents at a residential mental health treatment unit. They found that most were engaging in self-harm in response to conflict or negative feelings (intrapersonal negative reinforcement); however, some who engaged in self-harm found that their harming behaviour resulted in negative feelings. They also identified that youth were engaging in competition to be *genuine* versus attention seeking with their self-harm. As a result, the adolescents were prone to keeping their self-harm a secret in order to seem more genuine in their behaviours. The adolescents who were engaged in self-harm found help-seeking difficult, as they reported attempting to keep their self-harm secretive in order to compete with other patients, resulting in reduced care receipt. Interestingly, the second study also addressed receipt of care and the authors reported that adolescents were having issues with receipt of care.

Spandler (1996) completed a study that was focused on adolescents’ experiences of self-harm as accessed through in-depth interviewing and qualitative data analysis. Her report, which is based on interviews with 15 young adults, outlines the functions of self-harm, the distinctions between self-harm and suicide, information on frequency, severity and age of onset, and overall experiences with self-harm. Her findings are consistent with
the literature discussed above, but in addition, she focused a portion of her interviews on
the adolescent’s receipt of care and explored the negative aspects of care receipt in detail.

While Spandler focused on the adolescents’ negative experiences with types of
treatment and with tools and techniques used by clinicians, her participants also discussed
negative experiences with the behaviour of clinicians themselves. Her participants spoke
of clinicians making assumptions about the causes and the functions of their self-harm,
clinicians worrying about cross-infection, which occurs when one patient might
encourage another and thus they were kept separate from one another, clinicians wanting
to teach the people who self-harm ‘a lesson’ and clinicians pathologizing resistance to
change. These negative reactions from clinicians resulted in a number of negative
outcomes for the youth including feeling guilty for engaging in a ‘bad behaviour,’ having
an increased desire to self-harm upon leaving the unit, and an increased sense of
marginalization and isolation.

Both of the above studies revealed some previously unidentified issues with
receipt of care from the unique perspective of an adolescent population. Unfortunately,
neither study was focused on care receipt but rather the overall experience of self-harm;
moreover, in both studies the authors identified themes around care receipt as an
unexpected result of exploratory research. Consequently, the authors’ discussion and
depth may be limited by the scope of their projects. It is important to better understand
how adolescents are experiencing the receipt of care for self-harm in an attempt to
develop knowledge that may lead to initiatives that will impact treatment of self-harm. As
the patients, adolescents ought to have their perspective on care receipt included in the
development of best practices, as they are the people most affected by these
developments.

Furthermore, given that the most recent in-depth interview study with this population was completed almost ten years ago, it is also important to explore this research in a present-day context. Presumably, youth today are facing a very different set of rules, expectations and societal factors than those ten years ago and these factors may affect self-harming behaviours and treatment. For example, youth are heavily influenced by mass-media, and the internet seems to have a direct influence on the way that some youth experience and share about their self-harming behaviours (Lewis, Heath, St. Dennis & Noble, 2011; Whitlock, Powers, & Eckenrode, 2006). In addition, with the proliferation of research on self-harm over the last 30 years, there has been a dramatic increase in overall knowledge about self-harming behaviour. In order to effectively develop treatment practices for present-day youth, it is valuable to base recommendations on recent data. In addition, given that so little research on self-harm has been completed from the perspective of the person who is self-harming via interviewing, it is important to address this exploratory issue from this perspective to both broaden research in this area, and give voice to the adolescents who may have unique insight and knowledge into their experiences. Finally, it is also prudent to explore these issues in Canada since the two studies discussed above were conducted in the United States and Europe, where the mental health care systems can be considered to be very different than in Canada. The researchers of the current study aimed to provide information from Canadian youth to add their valuable perspective to the research that could be informing best treatment practices. Thus, the first research question explored by researchers on this project is: how do Canadian adolescents in a clinical setting experience the receipt of care for their self-
harm behaviour?

For the purposes of this study, receipt of care was defined as how the adolescents feel they have received care from all caregivers who work or volunteer in the clinical setting. Receipt of care, in this case, refers to the behaviour of and relationships formed with the caregivers in the institution. The term caregivers includes all people whose job it is to provide care to the adolescents in the hospital, which includes but is not limited to nurses, doctors, counsellors, youth workers, social workers and clinical volunteers.

**Stigmatization**

There is a large body of literature concerning the receipt of care from the perspective of adults that identifies how some care receipt issues can be linked to the stigmatization of self-harm by clinicians; this research may have relevance for youth. Stigma, in the context of mental illness is defined by Corrigan et al., (2005) as behaviours or thoughts that imply that a person has the following conceptions: that people with mental illness are more responsible for and in control of their illness than those with physical illness, that he or she is less willing to help people with mental illness than those with physical illness, that people with a mental illness are more dangerous, and that he or she wants to avoid people with a mental illness. In the literature presented below, researchers included a variety of behaviours to denote stigma, all of which imply a generally negative and prejudiced disposition towards those with mental illness, specifically self-harming behaviours.

Stigma affects a large portion of the population of people experiencing mental illness. While rates are varied based on research methodology, definition of stigma, and type of mental illness, researchers estimate that roughly 40-70% of people face
discrimination and stigmatizing attitudes and behaviours on a consistent basis (for a review, see Stuart, Arboleda-Florez & Sartorius, 2012). Stigma may result in a host of negative outcomes for people who are suffering from mental illness. As a result of mental illness stigma, families of people with mental illness experience fear, shame, secrecy, distrust, low family esteem, hopelessness, among other negative experiences (Gullekson, 1992). Those with mental illness experience guilt, shame, inferiority and the desire for isolation (Goffman, 1963). They may also experience a reduction in positive social and familial relationships as a result of the stigma of mental illness (Link, Strunning, Nesse-Todd, Asmussen, & Phelan, 2001). Additionally, people with mental illness may experience a reduced quality of life, difficulties accessing treatment and overall social disadvantage as a result of the stigma associated with mental illness (Stuart et al., 2012). Taken together, stigma represents a major barrier to help-seeking, treatment, and recovery (Stuart et al., 2012).

Mental illness has been historically and is presently associated with shame, guilt and fear (Stuart et al., 2012). It is generally understood that the most common reason people have for engaging in stigmatizing behaviour is related to social differencing and distancing (Stuart et al., 2012). By labeling and degrading those with mental illness, people maintain a separation, and protect themselves, imagining that mental illness cannot happen to them. Furthermore, this labeling and stigmatization is maintained and dependent on social structures that allow powerful social groups to oppress less powerful social groups (Stuart et al., 2012). In summary, stigma is an ongoing and persistent problem that has affected millions of people over thousands of years.
The stigma of mental illness is also a very important topic in the Canadian community. For example, the Mental Health Commission of Canada launched “Opening Minds” in 2009, which is an ongoing, systematic program aimed at reducing stigma around mental illness in Canada. They are partnered with health care providers, youth, employers, and the media to educate people and reduce stigma associated with mental illness. In conjunction with this project, the Globe and Mail has initiated “Breaking Through,” an ongoing series of articles through which they shed light on various mental illnesses and attempt to break down stigma through education and widespread acknowledgement of the impact of mental illness in the lives of many Canadians. Both of these examples of initiatives highlight the importance of studying the stigma in a current, Canadian context.

Who holds stigmatizing beliefs? There is a wealth of research on the cumulative stigmatizing attitudes and behaviours of the general public towards mental illness. Researchers have concluded that many individuals in the general public view those with mental illness to be dangerous (Link, Phelan, Bresnahan, Stueve & Pescosolido, 1999), embarrassing (Huxley, 1993) violent, and as having difficulty managing money (Pescosolido, Monahan, Link, Stueve, & Kikuzawa, 1999). Researchers also found that many people in the general public have the desire to avoid those with mental illness and a willingness to coerce individuals into treatment (Corrigan, Markowitz, Watson, Rowan, and Kubiak, 2003; Link et al., 1999). The general public also has misconceptions about the recognition and causes of mental illness (mental illness is seen as a social issue, rather than biological), as well as misconceptions about help and information-seeking, such that the general public mistakenly believes that self-help is the most effective (Jorm, 2000).
Stigma does not only come from other people, but can also come from within. Self-stigma is a form of internalizing mental illness stigma from others, such that the person experiencing the mental illness also possesses stigmatizing thoughts about his or her mental illness (Watson, Corrigan, Lawson, & Sells, 2007). Self-stigma results in diminished self-esteem and self-efficacy, loss of self, diminished social functioning, increased symptom severity and poor recovery (Stuart et al., 2012). Thus, stigma from others is not only initially harmful, but those perceptions are also internalized and become persistent contributors to negative wellbeing.

**Stigma and mental health treatment.** Not only do people experience stigma from the general public and from themselves, but they also experience stigma within the context of care receipt. Schulze (2007) discussed how stigma is a serious obstacle for people accessing mental health treatment they experience stigma from mental health professionals. In his summary of recent research in this area, Schulze (2007) identified that many people experiencing mental illness have experienced stigma in contact with mental health professionals. More specifically, he reported that some health professionals engaged in a variety of stigmatizing behaviours and held a variety of prejudiced attitudes including: having negative opinions on treatment processes and outcomes for patients (Caldwell & Jorm, 2001; Rettenbacher, Burns, Kemmler, & Fleischhacker, 2004); acceptance of negative stereotypes (Jorm, Korten, Jacomb, Christensen & Henderson, 1999; Lauber, Anthony, Ajdacic-Gross, & Rossler, 2004), including dangerousness, individual responsibility for illness (Kingdon, Sharma, & Hart, 2004), unpredictability (Magliano Fiorillo, De Rosa, & Malangone, 2004), and the desire to maintain a social distance from those with mental illness (Üçok, Polat, Sartorius,
In addition, Gagnon and Hasking (2012) found that younger psychologists felt more comfortable and confident working with people who were self-harming or who had attempted suicide compared to older psychologists. Finally, Timson, Priest and Clark-Carter (2012) found that 95% of their sample of mental health professionals, emergency department professionals and teachers felt that they could use more training relating to self-harming behaviours, with mental health professionals reporting less need and more previous training than the other professionals. Schulze (2007) concluded that mental health professionals should simultaneously be aware of the way that they may be producing and reinforcing stigma while making an effort to reduce stigma from mental health professionals.

Many mental health organizations are developing training for clinicians to reduce the stigma of mental illness in health care settings. For example, the Mood Disorders Society of Canada held a news release about the development of a web-based training course developed to reduce stigma in the medical health profession. This initiative, which has been developed by a large group of collaborators, including the Mental Health Commission of Canada and the Canadian Medical Association, employs the use of education to increase awareness about stigma and its effects so that health care providers can understand the issue and provide better quality support for their patients (Mood Disorder Society of Canada, 2011). This is just one example among a variety of initiatives and training programs aimed at combating stigma from clinicians.

There are many studies about how adults with mental illness experience stigma while receiving care, although most were not conducted in Canada. Lindgren, Wilstrand, Gilje and Olofsson (2004) studied a sample of women who received clinical care for self-
harm, in addition to other mental health issues, and also found that the women had issues with their receipt of care. Through in-depth interviewing, women shared their stories of care receipt. They discussed the importance of feeling confirmed, validated, understood, and believed by clinicians and staff while being treated for self-harm. Researchers reported that the women felt treated as objects, were labeled with negative values, were insulted by the staff, and experienced a lack of respect. Researchers classified all the above behaviours as stigmatization, and concluded that this type of stigmatization resulted in reduced treatment success and stifled hopefulness for the women.

Other researchers have also reported that stigmatization is an issue amongst clinicians who are treating self-harm. Harrison (1995), who was studying nursing behaviour, indicated that women who attended clinical settings for self-harm behaviour reported feeling stigmatized by staff, while those treated for other injuries did not experience the same stigmatization. This finding is consistent with Goldney and Bottrill’s (1980) report that patients felt more hostility when presenting with self-harm injuries compared to any other injuries. In fact, they identified that next to alcoholic liver disease, self-harming behaviour received the most hostility (Goldney & Bottrill, 1980).

Harris (2000) completed a study in which she corresponded with a group of six women who had attended an emergency department to receive care for self-harm. The women told stories of receiving hostile care from clinicians in the emergency department, including displaying a lack of sympathy, infantilizing, and attempts at embarrassment, belittlement and humiliation. The participants reported that they received little or no help in these situations and left having had no success with treatment.

Within the adult populations discussed above, stigmatization was identified as an
important component to the negative experiences of receipt of care for the people engaging in self-harm when accessing treatment. While the adolescents in the in-depth interviewing studies (Crouch and Wright, 2004; Spandler, 1996) did not speak directly about the stigmatization of their behaviour by clinicians, they did discuss negative treatment that seems to mirror the behaviour that the adults experienced when working with clinicians in attempt to treat their self-harm. As described next, it will be important to consider if adolescents have similar experiences of stigma.

**Adolescents and stigma.** Although stigma has not been directly studied in adolescent populations who self-harm, stigma is understood by adolescents, as evidenced by research conducted about stigma in populations of adolescents who experience mental illness. For example, Moses (2010) studied the stigma experienced by adolescents dealing with various mental illnesses from their family, peers, and school staff. Through mixed method interviewing, Moses concluded that adolescents experienced the greatest amount of stigma from peers (social isolation and avoidance), followed by family members (pity, gossip and avoidance), and finally school staff (fear, dislike under-estimation of the adolescents’ abilities). Many other researchers have examined adolescent populations and stigma in schools (Chandra & Minkovitz, 2007; Mickelson, 2001), self-stigma (Corrigan & Watson, 2002), and stigma in families (Hinshaw, 2005). All of these studies have been focused on the perceived stigma experienced by adolescents who have mental illness and show that adolescents are able to identify and talk about stigma as it relates to mental illness.

Some researchers have examined stigma and self-harm in adolescents. For example, Muehlenkamp, Walsh, and McDade (2010) piloted the Signs of Self-Harm
Program, which attempted to address barriers (specifically stigma) to help-seeking among adolescents who self-harm. One of the goals of this program was to reduce stigmatization by reducing judgment and by providing education about self-harm to teachers, peers, and parents. They concluded that effective education and anti-stigma campaigning could increase help-seeking for adolescents engaging in self-harm behaviours. While informative and novel, the study was not intended to explore perceptions of stigma, or stigma outside of a school setting. More research is needed on how adolescents who were self-harming experienced stigma, especially in a clinical setting, which is the focus of the present study. Given that these adolescents are feeling stigma from so many other groups of people in their lives (Moses, 2010), it is prudent to determine if they are also experiencing stigma from clinicians. It will be important to consider this possibility, since this information could identify a need to change certain practices that may be perceived as stigmatizing by youth, resulting in better outcomes in treatment.

One group of researchers did explore stigma in a clinical setting against adolescents who were self-harming, although their focus was on the perceptions of health care students who were learning how to interact with those adolescents. In this study by Law, Rostill-Brookes, and Goodman (2008), healthcare (medical, nursing, and clinical psychology) students were surveyed about their perceptions of adolescents who self-harm and about how these perceptions impacted their care delivery. They found that if the students had the opinion that the adolescents were responsible for their self-harm, they felt anger towards them, identified them as manipulative, and were less willing to help. They also identified that male health-care students and medical students had more negative attitudes than women and other healthcare students respectively. This study
revealed important information about the subject of stigmatization and self-harm, and is
directed at a clinical population of youth who self-harm, but does not focus on the
perceptions of the adolescents who are experiencing stigmatization from the clinicians.

Walsh (2006) also recognized that adolescents accessing treatment for self-harm
are likely to experience negative reactions from clinicians. He suggested that
professionals should manage their reactions when interacting with people who are self-
injuring in order to avoid stigmatization. He provided many helpful tips for professionals
to manage emotions, expectations and behaviours, and for intervening with clients when
appropriate. His recognition of this important issue and endeavor to provide suggestions
for clinicians highlights the likelihood that clinicians are engaging in negative behaviours
towards adolescents and the importance of understanding this issue in greater detail.
Moving forward, it will be important to understand this issue from the perspectives of the
adolescents who are experiencing this negative behaviour rather than from the
perspectives of clinicians. In order to provide a better understanding of adolescents’
experiences of stigma from clinicians, it is important to access the youth perspective,
especially because research in this area is ultimately aimed at benefitting those youth.

While there are many studies on stigma in adolescent populations, they either
focus generally on mental health without looking at self-harm specifically, or focus the
perceptions of people surrounding the adolescents who self-harm rather than the
perceptions of the adolescents themselves. None of these studies were directly focused on
stigma in a clinical setting as perceived by an adolescent who is self-harming. It will be
important to determine if the phenomenon of experiencing stigma for mental health
issues by mental health professionals carries over to adolescents engaging in self-harm in
a clinical setting. There appears to be scant research on this topic to date, thus it would seem timely to explore these topics in attempt to improve treatment by adding to the body of knowledge on treatment practices for youth who self-harm. In addition, it will be important to consider this question from the adolescents’ perspectives via one-to-one interviewing, as this is a methodology that has not yet been used in this target population. Qualitative interviewing is helpful to explore an issue from the participants’ perspective and allows researchers to avoid imposing their own structures and meaning on the topics (Britten, 1995). Therefore, it would be important to address how adolescents in a clinical population experience the receipt of care, and to attempt to understand if stigma is as relevant to their receipt of care as it seems to be in the other populations discussed above. Thus the second set of research questions: if the adolescents are experiencing stigma in a clinical setting, what does this look like and mean to them?

**The Present Study**

The purpose of this study was to explore how Canadian adolescents who have been in a clinical psychiatric setting experienced the receipt of care for their self-injuring behaviours and furthermore, to explore their perceptions of stigma in care receipt. Researchers used a cross-sectional interview design to capture youths’ perceptions with a semi-structured and open-ended interview. This research was exploratory in nature and as a result, there were no specific hypotheses. This study was designed to address the following research questions:

How do Canadian adolescents who have received intensive mental health treatment and have engaged in self-harming behaviour, experience the receipt of care?

How do these adolescents understand stigma as it relates to mental illness and self-harm?
Do these adolescents experience stigma associated with self-harming behaviours?
Do they experience stigma when receiving mental health services? If yes, in what ways?

**Methods**

This research was part of a larger project on self-harm completed by a group of clinicians and one researcher who was conducting an anonymous survey in a psychiatric hospital setting. Participants in the original study included youth accessing in-patient services. Upon completion of the original study, participants were asked if they would like to be contacted in the future to participate in interviews, and if so, they provided their contact information and preferred means of first contact (for example: phone, email).

**Setting**

The setting of the original study was the Child and Adolescent In-patient Psychiatric Unit (CAIP) at a local hospital. The unit is a nine-bed inpatient child and adolescent unit for people 18 years old and younger. The 24-hour hospital setting has treatment teams that include child and youth workers, teachers, psychologists, psychiatrists, nurses and social workers. They focus on short-term stabilization and crisis intervention through individual and group programming for both the individuals and their families. Children and youth stay at the CAIP for approximately 5 days. Children and youth are admitted to the unit in crisis situations through emergency services.

All children and adolescents admitted to the CAIP unit and their caregivers were asked to participate in the original study, upon being determined by medical staff to be capable of providing appropriate consent or assent and complete the survey. Children and adolescents were excluded if they have an unstable psychiatric condition or pervasive developmental disability/cognitive disability.
Recruitment

For the present study, participants were contacted via the telephone or email contact information they provided in the first study. At the point of contact for the present study, participants were already discharged from the CAIP unit. The researcher contacted the youth who were between 14 and 19 years of age and obtained their consent to participate by providing detailed information about the study. Participants were screened for the presence of self-harm over the telephone. The researcher defined self-harm for the participants (as defined above), and asked if they had engaged in this behaviour more than once. When they reported that they engaged in self-harming behaviours, they were asked if they would like to participate in this study. Upon consenting to take part in the study, the researcher arranged to meet individually with the adolescents in locations preferable to them (either in the family home, at the university in a private meeting room or in another place of comfort at the adolescents’ choosing).

Sample

Green and Thorogood (2009) suggested that 20 is an appropriate number of people to interview in applied health qualitative research, because after this point, researchers are unlikely to find any new information within a category.

Procedure

Upon meeting, the student researcher fully explained the study to the participant. The participant was asked to provide informed consent (See Appendix A) and upon giving consent, the researcher proceeded to the interview. The student researcher engaged the participant in a one-on-one interview. All interviews were audiotaped and transcribed. The student researcher also took notes on behavioural observations. Upon completion of
the interview, the interviewer reviewed the debriefing form (See Appendix B) with participants, including providing details on how they could contact support should they experience any negative feelings as a result of participation in the interview. The student researcher also detailed the process of member checking, which involves sharing a summary of the results with participants and asking them to provide comments and detail if the summary represents their perspectives consistently. The student researcher asked each participant if they would like to be involved in the member checking process. If participants agreed, they were asked to provide the researcher with their preferred means of contact (e.g., e-mail, mail address). Researchers emailed or mailed a copy of the results and discussion section of the final thesis document to each participant who consented to member checking, requesting feedback if required.

**Interview guide.** The interview guide included demographic questions and open-ended questions on self-harming behaviours, receipt of care and stigma. The open-ended questions included questions from Crouch and Wright (2004), Spandler (1996) and Lindgren et al. (2004). Questions and prompts regarding self-harm were abbreviated from those used by Crouch and Wright (2004). Participants were asked “Tell me about your self-harm” and “What does it look like to you?” Questions on receipt of care and experience in clinical settings were abbreviated from those used in the interview guide created and employed by Spandler (1996). In addition, all four questions used by Lindgren et al. (2004) to collect data about participants’ experiences of ‘received care’ and ‘desired care’ were included in the interview guide used for this study. Participants were asked questions like “Tell me how you were treated by staff.” Finally, researchers developed questions on stigma with the goal of maintaining the tone of the interview and
the format of questions. Participants were asked: “Tell me what stigma means to you” and “what does stigma look like in your life?” See Appendix C to review the interview guide.

Data analysis. Demographic data were analyzed with descriptive statistics. The qualitative data were analyzed using conventional content analysis as outlined by Hsieh and Shannon (2005). This is a method for categorizing the context of data by systematically classifying, coding and identifying themes in text. Conventional content analysis is used when researchers are attempting to describe a phenomenon and is best used when existing research on the topic is limited, as is the case with the present study. Hsieh and Shannon (2005) describe that researchers should avoid using preconceived notions and allow themes and categories to flow from the data through an inductive process. Effort was taken to allow for the emergence of themes, however researchers did focus on four main topic areas, which guided the theme development. Researchers of the present study focused on categorizing the manifest content, which was defined by Graneheim and Lundman (2003) as the obvious, visible components of the data. Manifest content requires less interpretation than latent content, defined as the underlying meaning.

In accordance with the process outlined by Hsieh and Shannon (2005), the student researcher read the data word by word to derive codes by selecting words from the text that capture key concepts. The student researcher then made notes on her impressions of the data, aiming to develop labels for the codes. She then sorted codes into categories based on how they related to one another. Codes were organized into clusters and multiple mind maps were used to identify the clusters and hierarchal structure and as a
supplementary tool for analysis. The student researcher, in consultation with collaborators, then developed definitions for each category and subcategory. Graneheim and Lundman (2003) defined a category, or theme, as a group of content that shares a commonality and identified that categories can include sub-categories, or sub-themes and are a description of the manifest content within the data. Researchers created themes that fit with this definition.

Graneheim and Lundman (2003) discussed the importance of trustworthiness in qualitative research, specifically content analysis. In order for research to be considered trustworthy, it must have credibility, dependability and transferability. Credibility refers to how well the data and process addresses the focus of the project. Graneheim and Lundman (2003) suggested that one obtains credibility by checking the accuracy of the data analysis with participants to ensure that the researcher was accurately interpreting their narratives. Researchers engaged in member checking to enhance credibility. Member checking, according to Creswell & Miller (2000), allows for participants to add credibility and contribute to the validity of a qualitative research study. Graneheim and Lundman (2003) also support dialogue among co-researchers and the researcher and the participant. Colleagues and participants were consulted in order to determine if the data appeared to be sorted in a way that could be agreed upon by contributors.

In addition, in order to maintain trustworthiness, researchers endeavored to achieve dependability and transferability. Dependability means ensuring consistency across data collection, and accounting for factors of instability in project design. In order to maintain dependability, Graneheim and Lundman (2003) suggested maintaining an open dialogue with all researchers and contributors and ensuring communication is fluid.
The researchers on this project ensured open communication throughout the duration of the project. Finally, transferability, or the extent to which findings can be transferred to other settings or groups, can be facilitated by providing a clear, distinct description of the context of the participants and the data, as well as by aiming for heterogeneity in the sample.

**Results**

Researchers had the contact information of 44 participants. Six were not interested, three set up interviews but later cancelled, one did not meet the minimum age requirement, and the remaining 22 were unavailable for contact, either because their phone was no longer in service, or had no voicemail service. Thus, 12 (27% response rate) participants were interviewed. The majority of participants identified as female, Canadian and between the ages of 15 and 19 years (M=16.6, SD=1.4). See Table 1 for the demographic characteristics of participants.

Table 1

*Characteristics of Participants (self-reported)*

<table>
<thead>
<tr>
<th>Category</th>
<th>Subcategory</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender, n (%)</td>
<td>Female</td>
<td>10 (83.3)</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>1 (8.3)</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>1 (8.3)</td>
</tr>
<tr>
<td>Education, n (%)</td>
<td>Grade 9, 10</td>
<td>5 (41.6)</td>
</tr>
<tr>
<td></td>
<td>Grade 11, 12</td>
<td>6 (50)</td>
</tr>
<tr>
<td></td>
<td>Post-secondary</td>
<td>1 (8.3)</td>
</tr>
<tr>
<td>Ethnicity, n (%)</td>
<td>Canadian</td>
<td>10 (83)</td>
</tr>
<tr>
<td></td>
<td>Aboriginal Canadian</td>
<td>1 (8.3)</td>
</tr>
<tr>
<td></td>
<td>Unknown</td>
<td>1 (8.3)</td>
</tr>
</tbody>
</table>
Participants were asked about four topic areas (Self-Harm, Stigma, Care Receipt, Stigma and Care Receipt), under which 13 themes were identified. Themes are presented in a mind map (Appendix D), which were established throughout the data analysis process to guide theme development and to serve as a visual representation of the results. Direct quotations are included and were selected in order display the themes, and represent the experiences described by the participants in attempt to facilitate transferability.

**Self-Harm**

Although researchers did not aim to specifically explore participants’ experiences of self-harm, the student researcher asked questions about self-harm to gather contextual information about the participant. Participants were eager to explain their self-harming behaviours, and as a result, researchers identified four main themes that relate to self-harm: functions of self-harm, secrecy versus openness, deciding to stop, and planning.

**Functions of self-harm.** All participants discussed the functions that self-harm served in their lives. The various functions discussed included: to cope (n=10), to self-punish (n=5), to fulfill a self-harm addiction (n=3) or compulsion (n=2), to feel anything (n=2), to gain attention (n=2), to maintain control (n=2), as a visual replacement for internal pain (n=2), to replace binging (n=2), to establish ownership of one’s body (n=1), to keep from attempting suicide (n=1), and to see blood (n=1). Researchers present some examples of participant’s stories of the function of self-harm:

**Coping:** One participant shared how she self-harmed to let out her emotions:

> um I don’t know, just whenever I have like an overwhelming of emotions, good or bad because I can’t really tell, I associate what I am feeling with the situation, so I can say I am sad or I am happy, but all my emotions feel the same, and when
they get really overwhelming, I [cut] that’s just my way of like letting it out (Participant 6).

Another felt negative feelings before self-harming, and then experienced a cessation of these feelings after:

Like before I would be like either anxious, sad, angry, normally one of those three. And then afterwards it would just be emotionless, like I would be, kinda that feeling of numb. So you’re just like, in your own bubble kind of (Participant 2).

**Addiction:** One youth described how she felt that self-harming is addictive:

Its addictive, like super-duper addictive and when you try to stop cutting, like a lot of people that have self-harmed have made videos about this on YouTube and stuff, you see blood like dripping down the walls and just like really weird stuff that shouldn’t happen, but its ‘cause your brain like needs it. So. It is definitely addictive behaviour (Participant 1).

**Compulsion:** Another still spoke of her need to self-harm as though it was compulsive:

Just kinda like a compulsion. Like something that you ultimately just go to after things happen and um that’s why I continued, its not like its awesome and its not like it gives you this awesome high or whatever, its just you do it because you have to to survive kinda thing (Participant 1).

**Ownership of Body:** One youth explained that self-harming gave her ownership over her body: “I guess also it’s kinda like an like an ownership of like ya, its my body and I’m going to do what I want with it” (Participant 6).

**To avoid suicide:** Another youth spoke about how self-harming stopped her from attempting suicide: “it helped me so I didn’t do anything stupid” (Participant 4).

**Secrecy vs. openness.** Most participants discussed their decision to cover or not cover their scars and cuts, and many participants explained how others’ perceptions factored into this decision. First, many youth reported that covering their scars was related to secrecy. One youth explained:
like before I tried to keep it a secret, and I would cut in different places. Like my um thighs and like on my stomach and stuff like that, so people wouldn’t see it, but in grades 7 and 8 when it was like on my wrist, and stuff like that my mom she would see it and she would question what that was. As well as my friends and some of my teachers (Participant 8).

Another youth stated that her decision to not cover her scars was related to acceptance of her decisions:

I find that people are going to find out eventually um, and … if you bandage you’re arm, people are going to be like oh what’s wrong. And sometimes it will make it more noticeable than the actual cut itself. So like, I just don’t see a point in bandaging it. And I feel like if you are trying to hide it, then you are regretting it and then you are going to feel bad about it and you are going to feel insecure about it” (Participant 6).

Many youth discussed how they assumed others would view their scars. One youth explained: “like in like society, like how people view that. And like that will never go away. So you could, and that could affect like jobs, your ability to get a job or something” (Participant 6). Another youth shared how she used to respond to self-harm scars, and how she expected that others might respond in the same way:

Um, I know personally, before being in CAIP, I had never seen any self-harm scars. I had no, that I know of, no friends that I saw would have scars. I had just never experienced it before. Didn’t really think it happened. Um, so like nobody, like nobody I know, I’ve never seen them. And I think it would probably scare someone if they saw them. And, I know at work, especially if, because I work at a private golf club, people would, if people saw it, it would just, it would probably ruin my reputation (Participant 4).

Finally, one youth explained how covering his scars was related to the stigma associated with self-harm; he covered them because he didn’t want to scare people:

I don’t care really if people see them, um, but, people tend to get a little freaked out by it. So I’d rather not. And like as my social base is expanding more now and I like not to put a halt on that, uh people finding out about the psycho kid. Also because of that stigma (Participant 7).
**Deciding to stop.** The participants all seemed to have many different experiences of quitting their self-harming behaviours. Some were directed to stop, others were confident in their quitting success, others had quit, but were unsure if they could maintain it, and others still had decided they were not going to work towards quitting. One youth expressed uncertainty and shared that she finally decided to stop because the hospital team advised that it was a good idea: “well, I’m not really sure that I wanted to do it, but everyone else like at the hospital… everybody was just telling me that I needed to stop cutting and so I was just like “ok, I guess I need this for myself” because everybody else was saying that it would be good for me” (Participant 1).

Another participant explained that she was very happy to have stopped, and that she made the right decision:

Like I actually like, I’m proud to be like cut free for a year now. It’s just something and like I got a tattoo on my wrist to just show me that I was able to do it and stuff. And like when some people say like they could never do it, I’d be like well I was able to do it, its just like, I don’t know. Like I feel like if I could do it, anybody could do it, so like its just kind of, it feels good (Participant 3).

Another was not so confident in her ability to stop, and hopes that she will be able to remain cut-free: “I regret it, wished I had never done it. But, but in some way, I’m kinda like “oh I would never do it again”, but I can’t say I would never do it again. But I hope I will never do it again” (Participant 4). Finally, another youth described how she had no plans of stopping and her psychiatrist agreed to accept this decision: “my doctor was like, like you, you self harm, you do that often you still do that, he’s like, “I don’t feel that there’s really a point in trying to get you to stop. Cuz that’s just what you are going to do.” So like, I was kinda relieved that he did that, instead of trying to do more self harm modules” (Participant 6).
Unique Case: Planning. One participant discussed her experiences with planning her cutting and the role of drawing in her self-harm. She discussed her process of self-harming, which included drawing her arm, detailing her already existing scars and the new cuts she planned to make. She also discussed her requirement of having these drawings complete before engaging in self-harm, as a source of control:

And I’ll like draw like my arm or something, and I’ll draw out stuff I already have and then I’ll draw what I could do, like what I could mix in with that. So it just doesn’t look like I’ve taken an animal claw to my hand…sometimes I’ll feel weak if I like look at it and it’s been something out of rage. Like I always plan stuff, because I know I am going to have it forever. So I’ll plan it and make sure that I am not going to regret it (Participant 6).

Stigma

In response to questions about stigma, researchers identified three subthemes that relate to the youth’s experience of stigma. The themes include: identification of common stigmatizing reactions, sources of stigma, and stereotyping. Researchers also identified the self as stigmatizer as a theme under stigma, but this theme is also connected to stigma in a clinical setting, and as a result will be discussed under that theme heading.

Six of the 12 youth were able to define stigma before being told what it means, examples of their definitions include: “Stigma is a kind of negative prejudice;” “like its just kinda like a dark cloud hanging around a subject that you can’t ya. Things people think about something that maybe isn’t necessarily true;” “it’s a misunderstanding, its like a generalization I guess, of like, what a bunch of people think this one thing is, and because of that, they are going to treat them all a certain way, regardless of what other issues they may have.” Three of the youth asked to have stigma defined to them, but were able to add their own understanding of stigma after prompted with a partial definition. They used words like “assumptions” and “stereotyping” to confirm with the interviewer.
that they understood the provided definition. Finally, three of the youth had stigma fully defined to them by the researcher. All of the youth were able to identify experiences of stigma from some area in their life. Their experiences are detailed below.

**Identifications of common stigmatizing reactions.** Youth were able to identify many experiences of stigma in their own lives, both that they had observed, and that they had experienced themselves. They shared the following as common stigmatizing reactions when people learn about their mental illness/self-harm:

a) People *invalidate* others with mental illness (n=10):

“Well, I don’t know, kinda made me feel like my problems weren’t like, valid, I guess because they were there for I don’t know, just made me feel like my problems weren’t valid…Um, really its just people being like, well you don’t look sick and me being like it’s a mental disorder, you don’t look like you have cancer, but you do. Like, you can’t say that, you know” (Participant 1).

b) People think those with mental illness should be able to *control* their illness (n=8): “[regarding her depression] you can’t help yourself, you can’t just get happy. Um, which is a thing I think a lot of people don’t understand, and also just um, the whole “Oh well just go on meds” you can’t just, that doesn’t always solve it either, and some people don’t want to go on meds” (Participant 9).

c) People are *scared* of people with mental illness (n=7):

“I do have friends that don’t really know what to do about it and I guess that’s part of the stigma is that they are just scared because they don’t know what to do. And um, I wish that part wasn’t there because if people weren’t scared of asking me what’s wrong, maybe I wouldn’t feel so crappy about myself because maybe I’d know that people care” (Participant 1).

d) People want to *avoid* those with mental illness (n=5):

“like a couple of my closest friends, like they knew I was like depressed and stuff like that and its almost like they kinda like distanced themselves away because like maybe they were just scared and they didn’t know how to handle it” (Participant 8).
e) People are **disgusted** by self-harm scars and cuts (n=3): “A lot of people would just say like ew, that’s ugly. And I, like this one kid, he like he would just say like oh that’s so gross” (Participant 6).

f) People **pity** those with mental illness (n=2):

I just wish um, I wish people wouldn’t feel so sorry for people who self harm because in schools and stuff, well especially in mine like everybody just looks down upon people who self harm as if like they are damaged I guess and they feel sorry for them. Like they aren’t necessarily rude to the people who self harm, its just like, oh poor baby kinda thing. Like I wish people didn’t feel so sorry” (Participant 1).

g) People think mental illness is **contagious** (n=1):

You think like the depression is going to go onto them if they stick around you. It would be like, if its like a disease getting sad maybe you’ll get sad, so you try to remove yourself from that person’s life and kind of turn yourself away (Participant 8).

**Stereotyping.** All but one of the youth in this study spoke about experiences that relate to stereotyping and labeling, whereby they were identified as a certain type of person and responded to differently as a result of that identification. Youth found that many people judged them or made assumptions about them or their behaviour based on what they know about the youth’s mental illness.

**Labeling.** Many youth identified labels that were given to them or their peers based on their mental health status. In addition to being labeled with their mental health diagnosis, youth shared how they were called “freak,” “crazy,” “special people” and abnormal; as one youth explained: “I think everybody just kinda wants to feel normal.”

The youth also discussed the impact that this labeling has, and how they want to be identified as normal and not atypical or abnormal. One youth explained:

Well it hurts for sure because, like just because I’m diagnosed or something with
a mental disorder, that doesn’t mean…I’m not just that mental disorder, I’m a person and I should be treated like the most respect and just because I have depression doesn’t mean I am just depression. I am a person, I have feelings as well” (Participant 8).

Another youth shared: “I’m just the same as everyone else. I just have struggles with certain things and I need help every once in a while. You struggle, you are just lucky enough that you don’t need help” (Participant 6).

One youth explained her understanding of stigma, and described how people with mental health are divided and labeled:

The overall picture is stigma can really separate you from the rest of the population. In terms of you’re a crazy person, and these are normal people. And like, it’s not something that, that type of stigma is a little more discrete. Its kind of, nobody will say that to you, outright, it’s just how you are treated, and there’s no faith in you” (Participant 5).

Assumptions. Youth also shared their experiences of having people make assumptions about their drug use and their behaviour based on their mental health and appearance. First people assume connections between mental illness and drug abuse:

“Uh, because they know, I guess they are putting me into this stereotype that I am more likely to become an alcoholic, to become a drug abuser, I guess in their opinion” (Participant 4). The youth also shared how people make assumptions about how youth with mental illness will behave:

I try to think of like people with mental health as being no different from anybody else and I can relate to this because like, when I was in the hospital, they diagnosed me as being clinically depressed, and people might see that as being like a stigma, like ok, this person is depressed, they are going to be sad all the time and then they are just going to be very pessimistic and stuff like that, but really I’m the type of person like, ok I may have depression, but at any time I can be happy and I can go out and have a great time” (Participant 8).

Finally, the youth described how people make assumptions about mental illness based on how people present themselves:
Um, and there’s also the stereotypes of boys who have mental health, they dye their hair, they have piercings, and they are bisexual, they dress like um skaters or goths or like stuff like that. So people are um, judging him on his appearance (Participant 2).

Sources of stigma. Youth were not only able to identify many experiences of stigma, and the stigmatizing beliefs that people held about those with mental illness, but they were also keen to discuss their opinion on the origin of stigma, or how it develops in people. They believed that these stigmatizing beliefs came from the media, parental influence, lack of education, and fear of the unknown.

Care Receipt.

Researchers identified three themes that relate to both the positive and negative experiences of care receipt in the hospital setting: positive qualities of care providers, role of trust, and negative qualities of care providers.

Positive qualities of care providers. Youth were able to identify positive experiences they had with nurses and doctors in the hospital setting, as well as identify the characteristics that make these people good caregivers. The following characteristics were identified as related to positive care: compassion (n=11), listening (n=9), compatibility (n=7), flexibility (n=5), being personable (n=5), having knowledge (n=4), humour (n=3), acceptance (n=3), providing suggestions for care (n=3) and transparency (n=2). While many of these characteristics were deemed important by many of the participants, some of the qualities were identified as particularly necessary in the delivery of positive care.

Compassion and care. Above all, youth seem to identify that a compassionate and caring disposition were important to the positive receipt of care (n=11). For example, many youth spoke about their experiences of care providers showing that they care by
providing helpful strategies for coping. One youth explained:

Um, actually like the ideal nurses are definitely at CAIP, so ya. I think really compassionate and caring about you and providing alternatives for when you want to self-harm. They were really good providing me with coping strategies…that’s really helpful actually, like a lot of people don’t know how nice that is, like if they give you like a stress ball instead of just telling you to read a book, its so much nicer when they actually care…” (Participant 1).

Many other youth spoke about how professionals showed that they cared about a youth by showing concern and engaging them in conversation. One youth explained:

Well in CAIP, it was a lot easier for them to show how they cared because they, if you seemed like you were not having a very good day, or just really just not happy, they would just take you into your room and they would take me into my room and talk to me and ask me if I was ok, like they would talk things over with me and ask me if they could do anything and that like it felt like they cared, so it was nice” (Participant 2).

Finally, many youth discussed the importance of care providers spending time with them and described that this communicated caring. One youth explained:

By taking time, you know he came in, he closed the door, you know, talked to me for a bit, like came up with a plan and then like we talked through it together. And then you know if something didn’t work, well then he came up with a different plan (Participant 4).

**Role of humour.** The youth also spoke about the role of humour in care receipt, which contributed to positive experiences of care receipt (n=3). Many youth spoke about their care providers being humourous, which created positive care receipt experiences. One youth explained:

He was just really cool, he did his job amazingly well and I respected him a lot for that. Um, and he just, like he, - he was very humourous, like that’s something that is fantastic in any type of clinical setting, like he’s funny and he can joke with you and have the same sense of humour as you (Participant 10).

Another youth shared her understanding of the importance of humour in care receipt, and the role of humour in building trust between the patient and the doctor:
I try to be a funny person um and finding a doctor who has the same sense of humour as me is almost like one of the main qualities in picking a doctor, its like…when you find someone who is compatible, and it just so happens to be the person that is taking care of you, like you feel more comfortable, you feel a lot less scared I guess, um, and you trust them more. I think that’s a huge thing is trust. I find it a lot easier to trust someone who can make me laugh than someone who just makes my life suck everyday, you know…its just straight to business and you can’t do that when you work with people. It can’t be strictly business because it isn’t. It’s people (Participant 9).

Role of trust. Trust played a significant role in care receipt for these youth. Many of them spoke about the role of trust in their relationship with their doctors and nurses (n=6). Trust worked to create circumstances of both positive and negative care. Some youth shared how they would work to earn the trust of the doctors and nurses, especially as it related to showing that they are well, or well enough to engage in specific activities within treatment. One youth shared her experiences with trying to get the doctors and nurses to trust her own assessment of her wellbeing:

For me it took a while to earn back my trust because I had done a lot of really stupid things, there and um, it was good that they didn’t trust me in a way because obviously it helped keep me safe. But um, it’s frustrating when you are in the situation where they need to trust you and they wont, like, I it was sad because I wanted to get out and I was feeling safe enough to get out, I was feeling so much better…I just wanted to be home for Christmas, and um they set me to [long-term treatment] anyways, and that, that was terrible because [long-term treatment] was actually really crappy. And I was feeling safe enough at that time to go home anyways, so the trust would have been nice if they would have trusted me a little bit more when I needed it (Participant 1).

This quote also speaks to how the doctors are expected to identify if a client feels safe. Many of the youth suggested that in order to make this decision, the doctors and nurses had to determine if they could trust the words of their patients. One youth discussed how the doctors and nurses made the right decision in putting her into isolation, and were right to mistrust her when she argued that she was better:

They had no right to believe me anyways, like I don’t think I was genuinely
feeling better, it was just like, I don’t know, it was a really weird mood swing that happens, like it wasn’t like all my problems were solved. So they had no reason to believe me (Participant 2).

Another youth shared how she was able to earn back the trust of her caregivers by displaying her wellness, and as a result was granted a privilege that had initially been removed. This showed her that her care team was paying attention and that they were invested in her wellbeing, thus improving her experience of care receipt. She explained:

They actually they are really good with self harm in the way that like in CAIP they would provide alternatives and they would like trust you compared to how much you were self harming I guess, because, like they staple your stuff for group, and I like, a lot of people end up taking the staples out of the paper and self harming with them. Like everybody I knew in there was doing that so, uh they like for me it was getting so bad that they were at the point where they needed to take out all the staples out of my paper and once I stopped for like a week or something, they gave me back, they staple all my paper again, so it was nice to know that they were paying attention and um, they were really good in the sense that they actually paid attention to uh, how you were self-harming and tried to relieve that and give you alternatives (Participant 1).

**Negative qualities of care providers.** Youth identified qualities that led to a negative experience with care receipt, which included experiences of: providers keeping a distance and presenting as cold (n=9), displaying poor clinical communication (n=9), not showing investment in helping (n=6), and adhering to strictly to the rules (n=6).

**Distance/coldness.** Many of the participants shared their experiences of feeling a distance between the hospital caregivers and the patients. One youth explained: “Well mostly the staff didn’t talk to the patients at all. Like, it was weird. A lot of the time, ya like honestly all they did was just order us around” (Participant 1). Another described how the seriousness of the staff scared her:

The social worker that came in as well. She kinda seemed a little bit too serious and stern and stuff. Its just, its very scary because they put me in this room with like a chair and a desk and that was it and it was just very scary and this woman just came in and she asked you know all these questions and it was very you
know, it was too serious in my opinion, and obviously it’s a serious issue, but you need to relax a little bit” (Participant 8).

That youth also discussed that doctors ought to improve their connection with patients in attempt to improve care receipt. She youth explained: “I’d have to say for the doctors definitely: become a little bit more involved with their patients, like more frequently” (Participant 8). Another youth explained how the health care providers did not meet her expectations: “Once I got there, I thought they were gonna be a lot, a lot like warmer than they were I guess” (Participant 1).

Poor clinical communication. Youth often discussed their frustration with being excluded from decisions about their own care. They discussed how their opinions were frequently ignored, and they stated that this reduced their quality of care. One youth was frustrated when decisions were made about her care without her input: “they said they thought it would help me. But I was like you didn’t you decided that on your own, you didn’t even let me have an input in that. Like there must have been something that made them do it without even talking to me about it” (Participant 6). Another youth explained how she was frustrated because she attempted to share her perspective on her care, but was thought to be lying and was thus ignored:

I just woke up and I felt so much better and I didn’t want to kill myself anymore and I didn’t want to self harm and so I communicated that, and I guess they thought I was lying but at the time, I honestly didn’t feel that way (Participant 1).

Another youth shared how she was frustrated because she expressed that she was not ready to go home and the doctor sent her home anyway:

I was really upset because like it seemed like [psychiatrist] didn’t really care if I was like alive or not. If I was telling [psychiatrist] that I’m obviously going to go and I don’t feel safe being at home, obviously, and [psychiatrist]’s like oh no go home, obviously it seems like oh go home and kill yourself, I don’t really care. That’s what it seemed like. So I don’t really get along with [psychiatrist]”
(Participant 3).

She then talked about how her psychiatrist did not listen to her when she responded to her questions:

Like [psychiatrist] has a way of like, [psychiatrist]’ll ask me a question and then [psychiatrist]’ll answer it. Like why are you asking me if you are just going to answer it yourself? Like [psychiatrist]’ll like sit there and [psychiatrist]’ll be like telling me how I feel and I’l be like no. That’s not how I feel (Participant 3).

Not only did the youth report feeling ignored by the health care professionals, but they also expressed feeling like they were not given certain important pieces of information about their care or treatment plan. One youth explained:

I only seen my doctor once, like the doctor in the hospital. And I find like, he didn’t really do much, he kinda just, asked me a bunch of questions, and that was it so I didn’t even know like what that was going for, like if I was being diagnosed with something, so I was very unsure when it came to the doctors” (Participant 8).

Another youth expressed frustration about not receiving a concrete diagnosis, which she needed to access services at her school. She explained:

[psychiatrist] wouldn’t give me a diagnosis, because [psychiatrist] didn’t want to say anything because [psychiatrist] didn’t want me to like live by my diagnoses, I guess. And [psychiatrist] wouldn’t tell me what I have and I needed to do that for school. I needed to be told what I had and I wanted to know what they have given me, why I am on certain meds. And [psychiatrist] was just like, oh well I guess depression, and anxiety, and oh ya that’s ok. And I’m like what kind of anxiety? What kind of depression? And [psychiatrist]’s like just depression and generalized anxiety and I’m like that’s not a diagnosis (Participant 6).

**Stigma and Care Receipt**

The youth reported to have experiences of stigma within their mental health care settings. Only one of the participants in this study reported that she never experienced any stigmatization within a clinical setting. She explained:

No one ever makes fun of you in the hospital. Everyone is the exact same as you and everyone treats you equally and they never try and tear you down, they just try and build you up, and I like, could come out wearing my pajamas and not
showered yet, and they would still say that they like my outfit or something. It’s just nice” (Participant 11).

However, most spoke about their experiences with stigma, and the resulting themes included both stigmatizing behaviour from health care professionals, as well as from other sources. Researchers identified three themes related to stigma and care receipt with health care providers: health care providers making assumptions, minimizing and belittling problems, and service gatekeeping. Researchers also identified two themes related to youth behaviour: patient to patient stigma, and self as stigmatizer. Finally, the youth identified a difference between the treatment and stigmatization they experienced in the emergency room compared to that which they received in the psychiatric unit.

One youth explained her understanding of clinical stigma, and suggested that stigma stems from a lack of understanding on the part of the clinicians. Her statement is a concise and powerful representation of the common experiences of perceived stigma from clinicians:

I see it in how it’s just they don’t understand it um, and they don’t, they don’t understand mental health issues…I guess they stigmatize by not getting it, and not educating themselves on it and learning to be understanding… And it makes people afraid of getting help in a hospital setting. Because they are going to run into nurses like that and they are afraid of not being heard, just being turned away. So they don’t ask and then they end up at a point where they are so deep into whatever it is they have that they can’t get out of it by themselves, but the problem with mental health issues is that they are mental health issues. No one notices them, they are not physical. You know um, so unless you have scars on your arm, or you have um, some sort of physical indication that you have obviously gone over the deep end, you know you are not, you can’t get help. Like I think it all just leads back to stigma when it comes to that… You get afraid to ask questions. Right? Because if you ask a question, they may treat it like its stupid, and when you have a mental illness, that’s the last thing that you want to happen, so… I think it definitely has to do with power and they think they know better because they are older and they went to school longer and they whatever, and this is just from me being, well like basically I’m a kid, right, this is from a kid’s perspective (Participant 9).
Clinicians are Stigmatizing

*Making assumptions.* Just as some in the general public do, some of the health care providers were considered by youth to engage in assumption formation around the youth’s appearance, and about their behaviour and drug abuse (n=8).

One youth described how a doctor disbelieved her story and assumed she was not mentally ill based on her *appearance.* The emergency room doctor thought she not mentally ill because she appeared “too well put together to be sick.” She explained:

> Um, the ER doctor didn’t really believe me, the same way. And then there’s the psychiatrist, he came in and I talked to him. And he was very understanding. Um, he told me that because of the way that I appear, because I guess I didn’t look [a certain way], I had my makeup on, I was dressed properly, he said that, this is kinda a clue for some doctors [like the ER doctor who came before] that people seem like unhygienic and stuff and I guess that set them off” (Participant 4).

Another youth described how the emergency room staff were surprised that she was mentally ill because she was dressed in bright clothing. She explained her reaction to this, expressing her frustration that the doctor placed too much emphasis on the way she presented: “I’m sorry I’m not like what you expected: dressed in black, like, nails painted, seriously?! You’re a doctor, you should realize” (Participant 12).

Youth also identified that health care staff also made assumptions about drug *abuse.* For example, in the middle of a psychotic episode, one ER doctor told the youth’s father: “this isn’t how mental illness works, this isn’t how this works. This has to be either she has a brain damage problem or she’s taken some type of psychoactive drug. I think she’s on acid” (Participant 5). The youth went home untreated and the doctor refused to listen to her protests. The youth explained that she was not on drugs, and later described how her own psychiatrist confirmed that her state was likely due to her diagnosis of bipolar and psychosis.
Finally, many youth identified that the clinicians made assumptions about the way they expected youth to behave based on their mental illness diagnosis. For example, one youth described how she believed that the nurses were regarding her differently as a result of a mental illness. She was unable to specifically explain why she felt this way, only that she did:

You don’t know how some of the nurses view you as being a person with mental health. Like they may think, you, like obviously I don’t want to say they think you are weird and all that stuff, but they maybe kind of a little bit scared because maybe some of them have never experienced it, so they might treat you a little bit more, like, I don’t know how to describe it, but they might treat you differently based on like your mental health disorder or issues” (Participant 8).

Minimizing/belittling problems. Many of the youth told stories about their experiences with doctors and nurses minimizing what they determined to be serious mental illness concerns (n=8). One youth shared her experience watching a friend on the unit received by staff during a crisis. She described:

This one girl, not me, but she was freaking out really badly out in the hallway and she was crying and she was actually bleeding from her arms and the staff literally told her to shut up and go back in her room and it was, ya it was at nighttime, it was at 11 o’clock at night maybe…and she was just screaming and crying and staff were just like shut up and go to bed, and that’s like really rude, especially when someone is having an issue, like you are supposed to help them” (Participant 1).

Another youth shared her experience of being told that her suicidal feelings are things that “normal teenagers deal with and just too much hormones going through my body.” The youth felt that the doctor was minimizing her thoughts and feelings, making assumptions about her experience as a result of her age and mental health status. Notably, the result of this doctor’s behaviour was that this youth felt unsupported and disbelieved:

Um, personally, I just. It kind of breaks you down. It breaks me down at least. I don’t believe myself. I feel shot down, um, it’s a really hard feeling, especially that, when they are telling you this is supposed to be normal, its not really great,
the greatest way to feel (Participant 104).

Many of the youth also reported that they experienced situations in which they felt belittled by the clinicians because they were questioned about the legitimacy of their feelings and experiences related to mental illness. One youth explained:

I feel like belittled. Um, I feel like my like, what I think doesn’t really matter and that like they are just going to laugh at me no matter what I say and they’re not going to believe anything that I say, so like what is even the point of trying to talk to them. Um they just, it does not make me feel like they are there to help me. It doesn’t feel like there’s a point of trying to see them, and it just makes me feel like they are ignorant’ (Participant 6).

Another youth told the story of a nurse telling her friend “if [she] really wanted to kill [herself], [she] would have already” (Participant 9), when attempting to get accepted into the CAIP unit through the emergency room. Another participant explained that the nurses seem to minimize the youth’s problems, and he suggested that they do not take the youth and their illness as seriously as they would on an adult ward:

they are patronizing, they know that they are there to keep you safe, and there they take that seriously, but I think they also take it as a bit of a joke. Um, ‘cause they’re nurses in a kids psych ward, so they’re watching a bunch of crazy kids…Well I don’t think they really took it as seriously as they would in the adult psych ward (Participant 107).

Service gatekeeping. When asked about their experiences of stigma in care receipt, many youth spoke about service gatekeeping (n=6). As noted above, many of the youth discussed how they were often scrutinized for the legitimacy of their feelings, sometimes based on their age or mental health status and often resulting in minimizing of their feelings or belittlement. There were many occasions where this scrutiny was connected to access to services. Youth described how they were often put in situations in which they had to prove their illness in order to be admitted into the hospital. One youth explained how she felt that she had to threaten the doctors in order to be accepted into the
One youth discussed her frustration with the power that the doctors have to decide if someone is well or ill. She explained:

But you know, as a kid and as a teenager, you just like, see someone you see a doctor as someone who has power over you and you see someone, you see a doctor as someone who is telling you what is wrong with you without asking (Participant 9).

Another youth explained her experiences attending the emergency room in attempt to receive mental health treatment. She reported that she initially had difficulty convincing the hospital that she needed hospitalized treatment:

I had trouble getting in at first, with trellis and with CAIP, just because I wasn’t, I didn’t check off the box, that was the only reason they didn’t let me in was because I wasn’t suicidal. Like I didn’t want to commit suicide, so they were like you know we can’t accept you. So that took, that, I was just really mad about that (Participant 102).

Youth are Stigmatizing.

*Stigma between patients.* Many of the youth discussed the relational dynamic between those they identified as the “depressed” or “suicidal” patients and the “violent” or “angry” patients (n=6). Interestingly, many of the assumptions they made about one another are also the same assumptions that others made about them, including that they were to be feared, avoided, and the subject of gossip. One youth shared her understanding of this unique relationship, identifying how the two groups were scared of one another:
um sometimes it’s a little cold, like the people with depression will be scared of the people who have anger issues and the people who have anger issues will be scared of people with depression. Um, but like with me, I’m kinda like that mediator I guess, like I will go within both groups, ‘cause I also have anger issues. But I go in primarily for my depression um so like I don’t really have like a say in either. Um, so like I don’t know (Participant 6).

Another youth explained that while there was patient to patient stigma, it didn’t impact they care they received:

There was some patient to patient stigma and that I saw at least. I wouldn’t say it was as, like it didn’t keep you from getting the help you needed, so it wasn’t as bad as it could be, but that’s how it starts, right, so I mean, it was definitely there (Participant 9).

One participant explained how people with anger issues were often excluded from group activities on the unit:

Everybody who was there just for self-harm and stuff and we all basically knew each others’ stories even though we were there for just a short time just like we were there for similar reasons and we knew it I guess? Except for like the people who were violent and obviously violent and were dealing with psychotic episodes, that was a little off in social settings, like the other people would recognize that and um, especially in group, like the people who were there for psychotic episodes didn’t come to group because they felt like they were being excluded (Participant 1).

Another youth explained her experience of other patients making assumptions and judging others based on their mental health:

Um, so I think there’s stigma between patients in just thinking that we are all alike in our mental whatever. And you know, so its not even necessarily a bad stigma, its just like, its an assumption and you know they just assume that everyone is the same. Um and I guess, as far as like a negative stigma, I think the main thing I saw is like, because teenagers judge, they judge all day long that’s all they do” (Participant 9).

**Self as stigmatizer:** Although all participants were able to identify experiences of stigma associated with their own mental illness, or that of a close friend, many were also able to identify times when they took on the role of the stigmatizer rather than the
stigmatized (n=6). One youth stated: “I’ll admit, I am part of the stigma” (Participant 7).

Some examples of this are listed below.

One youth described experiencing fear when confronted with someone with mental health concerns. She explained her reaction:

Well like I was in this waiting room and I was beside this older lady and she obviously had mental health issues and I don’t know, she was just starting to talk to me and I guess it kind of scared me a little bit and like I know I shouldn’t be like saying stuff like that like, talking to people like strangers is bad, but like when you are in that scenario, it’s just kinda scary. Like ok, I’m in a mental institution and oh my god... So now when I look back on that, I shouldn’t have been scared because she could have been exactly like me. Just something different (Participant 8).

Another youth described her experience of judging a person she knew from school, assuming that she did not have anything in her life about which to be depressed:

And like, I did that, everyone, I think everyone does. At some point, like you know, because like when someone comes in and you do kind of know them, you’re like well I know a little bit about their lives, like and they have no reason to be depressed and then you’re like wait, but depression is a chemical thing and then you’re like I’m just like a total hypocrite. What? So, you you know, I think its just in general, there’s just a stigma and its from everything (Participant 9).

**Differences between the emergency room and psychiatric unit.** A final novel theme that surfaced from the analysis was the differences between the emergency room (ER) and the inpatient psychiatric unit. Many of the participants reported differences in the level of stigma and negative care receipt occurring in these two units (n=8). Most were able to identify that they experienced a much more accepting and positive level of care in the inpatient psychiatric unit than they did in the ER.

One youth explained the differences she noticed between the ER and CAIP, highlighting that the ER was scary, and personnel seemed to withhold information and made her first experience of care receipt fairly negative:
Um yes, a big difference. When I was first in the emergency room, I was just admitted into the like mental ward I guess... And it was very scary and I wouldn’t, I didn’t know what was going on and there are all these nurses and security guards, and I was so scared, I didn’t know what was going on. And then I got into the CAIP unit and they were more like informative, they were saying ok this is what is going to happen, and stuff, so it kinda relaxed me a bit …So it was better in CAIP for sure (Participant 8).

One youth identified her experiences of the differences between the ER and CAIP, identifying that the ER was much less understanding and caring, and she suggested that the difference was due to their lack of specialization in mental health and how busy they are in the ER:

But I feel like in the emergency room, they are, I think it just goes with their job, and their job, because they are more fast-paced, they are dealing with everything all at once, whereas in the psych ward, it’s like, you have one job right, and that’s like deal with the kids that come in for their mental health issues, whereas like, in the emergency room, you are dealing with broken legs, pregnant women, um, you know, crazy kids and then you also have to deal with whatever else, whatever other problems that brings. Um, but like its definitely different. Like it’s more, uh I guess clinical in the emergency room, than in the psych ward, and it’s a lot less understanding. As well…just like they’re not, I don’t think they are really focusing on your issues, they just, like they care to a certain extent, but they don’t. They don’t really care enough to help you. Um, and they just, they’re very cold I guess, towards the patient…Um, I think that just goes with the overall stigma thing. Ya um, they don’t take it as seriously because they don’t see it as an issue (Participant 9).

Another youth explained her understanding of the differences between the ER and CAIP, citing their lack of time as a reason for the reduced quality of care in the ER. She too notes the difficulty in getting the doctors to listen to her opinion and in accessing the services she thought she needed:

They didn’t spend as much time, which I know is difficult in the ER, but I felt that’s what I needed. I needed a lot of time, and patience, especially to open up. Um, they just, they didn’t seem to care as much, they kind of just wanted you out of there, they didn’t believe me, which hurt (Participant 4).
Results of Member Checking

All 12 youth consented to member-checking and provided their email address as a means of contact. Researchers sent out a brief summary of the results to each participant via email. Of the 12 participants, only one responded with comments about the summary. She stated: “I find that really awesome and a good reflection on what actually goes on within our minds and in the hospital. Thank you for sending that to me!”

Discussion

Many of the identified themes support previous research on self-harm, and experience of positive care receipt and stigma by providing the congruent perspective of the youth. In addition, youth reported similar experiences to those of adults, especially as they relate to negative care receipt, and stigma in a clinical setting. Finally, novel themes were identified: youth are not only stigmatized, but also stigmatizing, there are dynamics of stigma between patients and there are differences between the emergency room and psychiatric ward in both care receipt and experiences of stigma. This research adds to the current understanding of youths’ experiences of self-harm, care receipt and stigma by providing details about care receipt and clinical stigma that have been previously underrepresented in the literature and by providing a youth perspective on self-harm and stigma.

Functions of Self-Harm

All youth reported functions of self-harm that are consistent with those that are already documented in the literature on self-harm (Klonsky & Glenn, 2009) including endorsing the most common function of self-harm, emotion regulation (Klonksy, 2007). Furthermore, participants also described how they often experienced negative feelings
prior to and a reduction in these feelings after engaging in self-harm, which is consistent with the literature on the relationship between self-harm and emotion regulation (Klonksy, 2009; Nock & Prinstein, 2004). Participants also endorsed the function of self-punishment, whereby they were engaging in self-harm to deal with feelings of self-criticism and self-loathing (Kolnsky, 2007; Linehan 1993; Nixon, Cloutier & Aggarwal, 2002). Participants of the present study also engaged in self-harm for interpersonal reasons that have also been documented in previous literature, including to communicate their pain to others and to get attention (Nock, 2010). Finally the participants’ stories support the perspective that self-harming behaviour is addictive and the behaviour displays addictive and compulsive features (Nixon, Cloutier & Aggarwal, 2002).

Regulating emotions using self-harm is an idea that could be considered consistent with recent literature on self-harm and alexithymia. Alexithymia is presently understood as a personality trait that is generally related to deficits in emotion regulation (Taylor, 2000). Informally defined as no words for feelings, alexithymia is identified by three dominant features: difficulty identifying feelings, difficulty describing feelings, and externally-oriented thinking (Leising, Grande, & Faber, 2009). Polk and Liss (2007) reported an association between two characteristics of alexithymia (inability to identify feelings and difficulty describing feelings) and self-injurious behaviour, such that those who self-injured were more likely to have higher scores in those two areas. Similar associations were found by Zlotnick et al., (1996) as well as Paivio and McCulloch (2004). The youth in this study reported using self-injury to help control feelings, implying that they have difficulty doing so by other means, which is consistent with both emotion dysregulation and with alexithymia. One youth specifically spoke about how all
of her emotions feel the same, and she was only able to identify them as happy or sad or angry by the cues in her environment. This finding is consistent with descriptors of alexithymia, including difficulty identifying and describing feelings. While the present study did not delve into experiences of emotion dysregulation or inability to identify and describe feelings, the findings could suggest that continued exploration into the relationship between alexithymia and self-harm might be warranted.

Unique within this study, only one youth spoke about the role of planning in her self-harm experiences and her story sheds light on an interesting complexity in defining self-harm. Some feminist researchers speak about a difficulty distinguishing self-harm from other forms of body modification, including tattooing, scarification and plastic surgery (Potter, 2003). The youth who spoke about planning described her self-harm in a way that presented the resulting scars as body art, speaking about how she plans and draws in attempt to ensure that the scars look nice and complement one another. Her story provides support for the perspective that there is a thin line between socially-unsanctioned self-harm and socially-sanctioned body modification. Later in her interview, she mentioned this to the researcher, pointing out the researcher’s tattoos and claiming that the only difference between this researcher’s body modification and her own is that the tattoos are more visible because they are black. Her story and interpretation of her self-harm appears consistent with the work of critical theorists who suggest that self-harm has been medicalized and pathologized by popular culture and psychiatry (Potter, 2003). It is difficult to conclude that self-harm is no different than other forms of body modification in many cases, such as those where a youth is harming in a lethal way or is actively trying not to harm. However, for this particular youth, it
seems that her self-harm does not necessarily need to be pathologized. This is indeed the perspective that she reported her doctor might have taken towards her body modification practices, as she described that he was taking a harm reductionist approach, encouraging her to self-harm safely because he recognized that she was not willing to stop harming altogether.

**Care Receipt**

Researchers of the present study found that youth were able to recall both positive and negative experiences and qualities that make a good or bad mental health care provider, from youth’s perspectives. Furthermore, many were able to comment on their outcomes as a result of the care they received, indicating how a particular staff’s behaviour aided in treatment success or setbacks accordingly. Because youth are able to comment on these experiences, they can be viewed as a valuable resource in care evaluation and in developing plans for care improvement.

Almost all of the youth spoke about trust, and identified how it impacted the care that they received by creating a positive or negative care environment. Youth identified that they needed to form a trusting relationship with their care provider in order to engage in treatment. In addition, youth identified that a lack of trust for their health care providers could severely impact their progress in treatment. This idea is consistent with the notion of the therapeutic alliance. The therapeutic alliance is defined as the working relationship between a professional and his or her client (Manso & Rauktis, 2011). Trust, or a positive emotional bond, is viewed as the most important component in the therapeutic relationship, and is seen as the foundation for all other treatment tasks (Manso & Rauktis, 2011). Trust, among other qualities including respect, time-shared, and
openness, were determined to be the most important traits of a mental healthcare professional, from the perspective of adolescents receiving therapy (Martin, Romas, Medford, Leffert & Hatcher, 2006). Finally the development of the therapeutic alliance is seen as crucial to the success of therapy outcome (Ackerman & Hilsenroth, 2003). Thus, the results of the present study are consistent with research on the importance of trust, and other qualities, in the therapeutic alliance and toward creating effective treatment.

In addition to being consistent with the literature on the therapeutic alliance in mental health treatment, the descriptions of the importance of trust are also consistent with the literature on the role of trust in the treatment of self-harm specifically. Walsh (2006) wrote about the importance of developing rapport and building trust with clients who are experiencing issues with self-harm. Furthermore, Walsh (2012) noted that clinicians must suspend their instinctual negative reactions to self-harm and should respond to their clients with compassion and positive attentiveness in attempt to build a positive trusting relationship that is free from negative clinician attitudes. Consistent with this perspective, the youth in this study do report sensing when a clinician responds negatively towards their behaviours and also report that they can have difficulty trusting their care providers if they receive negative care.

Not only must the patients trust their care providers, but care providers must also determine if they can trust their patients. Many youth spoke about wanting their health care provider to trust them and listen to their opinions on their care and their wellness. Conversely, others spoke about how many youth tried to lie to their care providers in attempt to protect themselves or manipulate the care they were receiving. For example, some would say that they were well when they were not in order to get out of treatment
early. As a result, health care providers face the difficult task of determining when to trust their patient, and thus follow their directives on treatment and wellness, or when to distrust their patient, and go against their patient’s wishes. Given that the youth stated how important it is for them to feel trusted by their health care providers, care providers must be very careful about choosing to distrust their patients, as doing so could result in a loss of treatment progress. However, clinicians must also concern themselves with liability, as they could be held responsible if they trust too easily and someone injures himself or herself.

**Negative experiences of care.** Indeed, youth reported that negative experiences of care receipt were associated with health care professionals who were perceived as cold or distant and who reported to have poor clinical communication. Difficulty with communication with care providers has been a documented concern for a variety of patients as they access health care. For example, this concern has been researched with Latinos (Morales, Cunningham, Brown, Liu, H. & Hays, 1999), breast cancer patients (Kiltzman & Greenberg, 2002), gay and lesbian patients (Lerman, et al., 1993), and parents of children in the hospital (Bekeljia Wanzer, Booth-Butterfield & Gruber, 2004). In all cases, the adults reported less than adequate communication from health care providers, including issues with physicians feeling comfortable with certain topics, staff listening to their patients and answering their questions, and difficulty with care providers providing information about medications and treatment. In addition, Walsh (2012) discussed common issues faced by people who self-harm when communicating with a health professional and included being inattentive, refusing to discuss certain topics and being argumentative with clients as behaviour that is counterproductive and should be
actively avoided. The youth in the present study reported concerns about communication with care providers that were similar to those reported by adults in previous research and to those mentioned by Walsh in his discussion of appropriate communication for therapists with clients.

Despite some available research about adults accessing health care broadly, communication issues with care providers and adolescents have not been well documented in research. Nevertheless, many mental health care facilities, including those in hospital settings, have codes of ethics that govern the respect and dignity of patients, which includes treating them with care and compassion and providing a standard of open communication to ensure that the patients are fully informed about their treatment practices. Care should be taken to ensure that these practices are implemented to their fullest extent, which may call for more training on positive care receipt and dissemination of information about helpful care receipt practices amongst clinical health care providers.

**Stigma**

Researchers of the present study were interested in determining if youth understood and could talk about their experiences of stigma. Some previous research about stigma in other areas of adolescent life, including school and the community, indicated that youth could indeed identify stigma in these areas (Chandra & Minkovitz, 2007; Corrigan & Watson, 2002; Hinshaw, 2005; Mickelson, 2001). The results of the present study are consistent with those studies, as most of the participants were able to define stigma, and all were able to identify experiences of stigma in their lives. Furthermore, the participants’ definitions and descriptions of stigma were consistent with the definitions discussed in the literature review (Corrigan et al., 2005; Stuart et al. 2012).
Finally, common misconceptions and assumptions were identified in the literature review including the notion that people respond to those with mental illness with fear, avoidance, pitying, and so on (Link et al, 1999; Pescosolido et al., 1999; Jorm, 2000). These notions were represented in the adolescents’ stories of stigma in their own lives, supporting previous literature.

Cognitive appraisal theory may have utility in the context of understanding perceptions of stigma. This theory suggests that people cognitively assess their experiences through their own perspective (which is influenced by their values, commitments, and perception and thinking styles) in an attempt to understand and interpret their environment (Lazarus & Folkman, 1984). Thus, people will perceive stigma in their environment differently based on their own values, commitments, perception, and thinking styles. Researchers have examined the way that people perceive stigma through cognitive appraisal in an attempt to understand why some view stigma as more or less stressful (Rusch et al., 2009). Rusch et al. (2009) determined that people were more likely to perceive stigma as more stressful when they were sensitive to rejection, when they perceived that they had experienced a lot of societal stigma, and when they viewed others with mental illness in low regard. These findings will be important to consider in discussing adolescents’ perspectives of stigma in the clinical setting because these adolescents reported experiences of stigma in their daily lives and they reported stigmatizing others, thus they might be more likely to experience stress from stigma when they encounter it with health professionals. Experiencing stress could have the effect of making them more vulnerable to the effects of stigma, and more likely to perceive additional stigma as stressful.
Clinical Stigma

Previous research has documented that many adults report having experienced stigma from mental health care professionals (Goldney & Bottrill, 1980; Harris, 2002; Harrison, 1995; Lindgren et al., 2004). In these studies, stigma was documented as a component of negative care receipt and was often found to impede treatment progress. Comparatively, few studies have focused on the adolescent experience with stigma, mental health and care receipt. In the present study, it was found that not only have adolescents experienced stigma during care receipt, but they have many experiences of stigma from a variety of people within the clinical environment, including from health care providers and other patients.

Within the reported experiences of stigma in a clinical setting, a large number of youth experienced stigma from their care providers. Health care providers were reported to engage in labeling, assumption making, and minimizing youths’ perceived problems. These behaviours were regarded as stigmatizing by the participants of this study, and in previous research (Jorm, 2000; Link et al., 1999; Phelan, Bresnahan, Stueve & Pescosolido, 1999) including research with adults in clinical settings (e.g., Caldwell & Jorm, 2001). Thus, perceived stigma not only occurs in the general population, for adults in clinical settings, but also for youth in clinical settings by health care providers.

Youth also reported many experiences of service gatekeeping, which was framed by many of the youth as contributing to stigma. Unfortunately, service gatekeeping is a necessary and important part of health care providers’ jobs, as they are working with limited spots in programs and limited funds, and they are trusted with the responsibility to ensure that those who need the most help have access to it as soon as possible. The
current climate of available mental health care funding and available services places clinicians in the unfortunate position where they must engage in service gatekeeping in order to support as many people as appropriately possible. However, this also means that they must engage in the behaviours that can be perceived as stigmatizing. Moving forward, it would be advantageous for researchers to test new ways of service gatekeeping that are less dependent on these potentially stigmatizing practices in attempt to support their patients. It will also be important to ensure that youth are provided with the support to select and access appropriate mental health care services.

**Labeling.** The single most common theme revealed in this present study was that of labeling (n=10). Youth in this study reported many experiences of being labeled, either as different, as abnormal, or with a specific diagnosis. As expected, and consistent with the person-first movement, which concerns the need to use inclusive language that focuses on the person first, rather than his or her diagnosis or label (Jensen et al., 2013), many of the youth did not want to experience this labeling, and identified it as part of their experience of stigma. Youth were often able to identify when they felt labeled, and were also able to identify some of the concerns and outcomes that they faced as a result of this labeling. Corrigan (2013) theorized that labeling by way of a clinician diagnosis might exacerbate experiences of stigma by creating a dichotomy between the ill and the well. This theory is consistent with some of the youth’s perspectives on the role of labeling in their experience of stigma. For example, two youth spoke about being put into metaphorical boxes by their parents and by clinicians, which they deemed as stigmatizing and hurtful. Others described how they were judged, stigmatized and avoided in school as a result of their known diagnosis, resulting in loss of friendships and difficulty in school.
Some of the youth were even physically segregated from others both in school and in the hospital as a result of the labels in their files (as one youth in particular described). This segregation could result in a loss of social supports via rejection from peers (La Greca & Harrison, 2005) thus leading youth seek support in other areas, such as mental health care. In summary, many youth spoke of wanting to be viewed as a person not a label because they were differentiated and treated poorly as a result of people knowing about their diagnoses.

Paradoxically, youth also occasionally identified their need to be labeled. In some cases, youth wanted a diagnosis because they needed it to access certain services or to feel validated in their experience. These stories demonstrate the complexities of labeling, and the difficulty with the movement to abolish labels (which is often a goal of anti-stigma programming). While these youth are mainly consistent with their desire to be label-free, there are some circumstances under which they request a label. Researchers explained that people might seek and benefit from a diagnosis because it allows them to access social support and treatment (Gillman, Heyman & Swain, 2000). Nevertheless, these youth are requesting these labels in attempt to live within their present environment, which is one that values labels in order to govern access to services, and values diagnoses as a result of the medicalization of mental illness. Given that, in some cases, youth desire to be labeled in order to feel validated or to access certain services, it will be important for researchers to explore methods of accessing services and validating experiences without stigmatizing and stereotyping.

**Stigma between patients.** Not only did youth report stigma from health care providers, but they also reported experiencing stigma between patients. Many youth
identified a divide between patients who were attending the hospital with depressive symptoms compared to those who were attending with psychotic or violent symptoms. Researchers were unable to locate any previous research in which this phenomenon was documented in either the adolescent or adult populations. In the future, investigators could explore the relationship between patients, looking specifically at the tendency for groups of like patients to stigmatize other groups of like patients. In addition, it would also be interesting to explore the impact of the between-patient stigma on treatment progress and support system formation within a treatment facility.

**Self as stigmatizer.** In addition to concerns with stigma between patients, the youth identified their own experiences as the stigmatizer against others. Many youth shared stories in which they stigmatized someone else with mental illness. Researchers were unable to locate research on the experience of a stigmatized person in the role of stigmatizer towards other people. However, there is a great body of literature on the experience of self-stigma, in which people with mental illness internalize the stigma to which they have been subjected and begin to turn these perceptions on themselves, resulting in reduced self-esteem and self-efficacy (Corrigan & Watson, 2002). Perhaps both self-stigma and self-as-stigmatizer are products of youth growing up in a society in which stigma against mental illness is common and as a result, they have internalized these opinions and then applied them to both themselves and to others who also struggle with mental illness. Masuda, Price, Anderson, Schmertz and Calamaras (2009) investigated the relationship between stigmatizing attitudes and levels of psychological distress and concluded that those who held stigmatizing beliefs were also more likely to report psychological distress. Their study provides support for the idea that those who are
experience psychological distress may be more likely to have stigmatizing attitudes. Future research ought to explore this theme in more detail in attempt to understand why those who have been stigmatized also engage in stigmatization of others.

**Emergency room and psychiatric unit.** A final unique finding was the differences in stigma and care receipt between the emergency room (ER) and the psychiatric unit. Youth reported that the hospital staff in the ER were more stigmatizing, more likely to be cold and distant, and generally provided a lower level of care than the staff in the psychiatric unit. Many of the youth attributed the discrepancy between their experiences in the ER and the in the psychiatric ward to practitioners’ lack of time in the ER. It is commonly understood that care providers in the ER have a lack of time and many patients to serve. Care providers potentially see stigma as a necessary requirement of doing their job as quickly and efficiently as possible in an attempt to help the greatest number of people in a given amount of time. Future research should explore if this discrepancy is unique to this hospital and the participants in this study.

Interestingly, although researchers were unable to identify research on the discrepancies between stigma and care receipt received in the ER versus a psychiatric unit, there are examples of research that has identified that the ER can be stigmatizing (Harris, 2000, for example). In addition, there have been attempts to reduce stigma faced in the emergency room in Canada by the *Open the Doors* global anti-stigma program (Stuart et al., 2012). Researchers involved with this program conducted patient interviews on overall experience of ERs, addressing topics including: privacy and security, wait times, use of restraints, patient rights policy, and staff training. They concluded that none of the four hospitals involved in the project met the expectations in these topic areas and
that there were gaps in the quality assessment process (Sartorius & Schulze, 2005). As a result, they successfully lobbied to add specific anti-stigma criteria in the accreditation survey that would be used to evaluate all hospitals and emergency rooms across Canada. This demonstrates the type of instructional and policy changes that might be helpful in reducing stigma faced in hospital settings. Future research should provide support for the increased inclusion of anti-stigma programming in hospitals and emergency rooms.

**Considerations of Social and Emotional Development for Youth Experiencing Mental Illness**

Many of the findings of this study point to the difficulties that youth may have with social development. There are connections to social development in the way the youth spoke about positively received care, accessing services and labeling. When youth discussed the positive qualities that health care providers possess when delivering positively received care, they consistently valued personal characteristics over expertise and knowledge of mental health. The most important quality identified was that of compassion, followed by listening, compatibility, flexibility and being personable. Thus, youth seemed to identify that the most important qualities of care are also those that are intuitively valued in a good friend. For example, previous research has documented that compatibility in demographic characteristics and behaviours is important in adolescent friendship development (Berndt, 1982; Urberg, Degirmencioglu & Tolson, 1998) and adolescents who are considered the most likeable by peers are cooperative, friendly and sociable (Rubin, Bukowski, & Parker, 1998). In addition, Sullivan, Marshall and Schonert-Reichl (2002) identified that adolescents seek help from friends based on how nurturing and supportive their friend will be and that this help seeking can be used to
create closeness in friendships. The youth in the present study reported seeking supportive, personable and compatible practitioners and identified distance in the relationship as a hindrance to care receipt, suggesting that the youth are seeking the qualities of a good friend in healthcare providers.

Furthermore, Offer and colleagues (1991) identified that adolescents prefer to seek help from friends rather than from mental health care providers. However, the youth in this study appeared to be seeking the benefits of close friendship from mental health professionals instead of friends. One explanation for this discrepancy could be that the youth in this study, given their unique mental health challenges, might have difficulty finding supports from others for their more complex concerns and, as a result, turned to the mental health profession for support. Indeed it has been found that youth who are self-harming lack communicative support from their parents (Tulloch, Blizzard & Pinkus, 1997). In addition, adaptive coping abilities are associated with the formation of close relationships in adolescents, suggesting that those with difficulty coping may have fewer, less salient close relationships to depend on for support (Shulman, 1993). Finally, youth who have identified symptoms of depression or anxiety are more likely to be rejected by their peers (La Greca & Harrison, 2005). Within the present study, a few youth spoke about how labels were used to literally and figuratively segregate them from their peers in both the hospital and in other settings and this segregation negatively affected their close relationships. These findings provide support for the suggestion that youth turn to mental health professionals, despite desiring care from close personal relationships from family members and friends, because they may have difficulty finding support in their close relationships.
Alternately, attachment theory may provide a framework for understanding this shift, as adolescents seek to transfer their strongest attachments from adults to their peers during adolescence (Allen & Land, 1999). This finding provides support for the idea that adolescents would prefer to help seek from friends as they are learning to build attachment in friendships, and use friends as a base for safety. While the youth may have been seeking help outside their first preference, the characteristics they value in a helper seemed to remain consistent. The adolescent focus on personal characteristics rather than clinical skill in positive care receipt provides an interesting commentary on the similarities between the qualities youth value in care providers and those they value in friendships, and insight into what might be important to consider for treatment planning for youth.

Considering not only social but also emotional development could provide us with a framework to understand how these adolescents might form their perceptions of positively and negatively experienced care. Adolescents are in a developmental period that has a reputation for being particularly difficult and stressful. Adolescents are simultaneously experiencing physical maturation, independence-seeking, decreased inhibition, increased social motivation, and the development of reasoning and emotion regulation skills (Blakemore & Choudhury, 2006; Casey, Getz, & Galvan, 2008). Many researchers summarize these difficulties and the adolescent experience as “storm and stress,” a term originally coined by Hall (1904). The storm and stress thesis currently conceptualizes adolescence as a difficult period of time where various types of problems (including conflict with adult authority, mood disruptions, risky behavior) are more likely to occur (Arnett, 1999; Casey et al., 2010). While this theory does not apply to all
adolescents ubiquitously, and has received much criticism, it does provide a framework for understanding how the adolescents in this study might perceive the care they receive. For example, if adolescents are more prone to conflict with adult authority, they may perceive and experience conflict with adult care providers and thus might perceive more negative care receipt. This is one framework through which we can understand the adolescent experience and formation of perception. Knowing that adolescents are experiencing a period of increased difficulty allows us to anticipate that they may experience conflict in care receipt and may have stressful experiences to report.

Limitations

One of the most significant limitations of this study is the characteristics of this sample. The sample was homogenous and did not have many variations in gender, racial or ethnic identification. In addition, researchers sampled from only one hospital, which may have limited the heterogeneity that might come from sampling multiple hospitals. This is a limitation because Graneheim and Lundman (2003) advise that attempting to achieve heterogeneity in sample results in increased trustworthiness of research and can allow for transferability. However, this study was designed to explore the experiences of the youth selected for this project rather than generalizing the findings to a wider population, thus, obtaining a representative sample was not a major goal of this study. In the future, researchers might aim to sample a diverse population in order to explore if others have similar experiences to those in this research study.

Another limitation of this study is that researchers only gathered the perceptions of youth and were unable to compare to that of the health care providers. Although one of the main aims of this project was to access youths’ perceptions, it would be an important
contribution for health care providers to provide their perceptions of stigma and care receipt in health care settings, as they are likely to have a different perception on their contributions to stigma and negative care receipt specifically. Furthermore, the youth potentially lack an understanding of the system in which they are receiving treatment; they might perceive their experiences differently if they understood the present climate of mental health service delivery, specifically around service gatekeeping, liability, and labeling. However, researchers of the present project thought it most important to hear from the youth, as most previous research in these areas are focused on practitioner or system’s perspective.

Researchers also identified the difficulty of selecting a definition of self-harm to use for the present study. Given that self-harm is defined and titled in a variety of ways (D’Onofrio, 2007), it can be difficult to find consistency across studies, which will be a limitation of this study as well. Researchers selected the broad definition of self-harm proposed by Hawton et al. (2006), aiming to encompass a greater variety of self-harming behaviours to allow for varied perspectives on an exploratory project. However, this definition is not the most commonly employed in North America, since the DSM-V is presenting NSSI as a disorder and is thus promoting the use of that term ubiquitously (Plener & Fegert, 2012). As a result, this study will lack generalizability to other studies that use other descriptors and definitions of the behaviour. However, given that this study used engagement in self-harm as a context, rather than a main focus, and given that the aim of this study is not necessarily generalizability, but exploration of a topic, researchers accept this limitation and made the purposeful decision to include a less commonly used, but broader, definition.
Finally, there are limitations with conducting interviews. First, participants may have been under the strain of a recall bias, whereby they were having difficulty recalling their experiences without bias. Second, participants were interviewed one-on-one about difficult topics and as a result, they may have felt some pressure to provide socially desirable responses. These limitations were understood prior to the onset of the study but researchers valued the flexibility of interviews, and the potential to yield rich, detailed and novel insights into self-harm, care receipt and stigma.

**Implications for Research and Practice**

Researchers could explore in more detail the experience of the stigmatized becoming the stigmatizer, and the experience of stigma between patients, narrowing the scope of the projects to focus on these important themes. Researchers could also explore the complexities of trust, service gatekeeping and labeling within care provision in an attempt to develop positive solutions that improve care receipt and limit youths’ experiences of stigma. It is important that we strive to make care as positively experienced as possible in attempt to increase help-seeking and reduce fear in youth who avoid asking for help because of stigma. If care was experienced more positively by youth, perhaps more youth would seek help, resulting in a reduction of self-harmful behaviour.

This research also has clinical implications, and should these results be replicated with future research, the knowledge may lead to identifying the need for improved training and awareness around issues of care receipt and stigma in a clinical setting. For example, improved regulation and training for clinicians about treating patients with care, respect, and dignity will be important. In addition, an increase in anti-stigma
programming within clinical settings could be warranted, as these efforts have previously been focused to the general public, or within school settings, and have been deemed successful in these venues (Stuart, Arboleda-Florez & Sartorius, 2012). This anti-stigma programming ought to include a component in which clinicians are informed that they are potentially being perceived as stigmatizing, as it is likely that they may be unaware of this perception. Also, it will be important to continue to armor youth against stigma through youth-focused anti-stigma programming in schools and in mental health treatment facilities, such that youth will be able to better withstand stigma and maintain resilience against the damaging effects of stigma. Emergency rooms should be targeted in attempt to reduce the negative care receipt and stigma that is uniquely associated with that care provider. Finally, it will be important to ensure that youth have both access to appropriate services, and that youth are provided with education on how to choose the right service to suit their needs.

Conclusions

In this study on the perceptions of youth who self-harm about their experiences with stigma and care receipt, youth reported stories of receiving both positive and negative care in the hospital, which included stigmatization from clinicians and other patients. They also shared their stories about the functions of self-harm, reported experiences of stigma, including common stigmatizing reactions from others, and spoke about their own experiences as stigmatizer. Finally, they reported differences in the care received and stigma experienced in the emergency room compared to the psychiatric ward. It is clear that youth have a wealth of information to provide on their perceptions of self-harm, care receipt, and stigma and moving forward, it will be important to continue
to hear their stories and consider their perspectives in planning future care. Researchers and clinicians must work, both through future research and through changes in clinical practice, to reduce negative care experiences and experiences of stigma in healthcare settings in attempt to provide the most support and the best chance of success for youth engaging in self-harm.
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Appendix A: Informed Consent

**CONSENT TO PARTICIPATE IN RESEARCH**

**Perceptions of stigma and care receipt among youth who self-harm and have received mental health treatment in a hospital setting**

You are asked to participate in a research study conducted by Nicole Mitten and Dr. Michèle Preyde from the Family Relations and Human Development Department at the University of Guelph. The results of this study will contribute to Nicole Mitten’s thesis project for her Masters of Science degree.

If you have any questions or concerns about the research, please feel free to contact Nicole Mitten (519 580 9968) or Dr. Michèle Preyde (519-824-4120 Ext 58599).

**PURPOSE OF THE STUDY**

The purpose of this study is to speak with Canadian youth who self-harm and who have been hospitalized for mental health concerns. Specifically, we are interested in hearing how youth feel about the treatment they received from hospital staff. We also want to hear about youth experiences with stigma and self-harm. This research may provide information that will be useful in planning care for youth like you.

**PROCEDURES**

If you volunteer to participate in this study, we would ask you to do the following things:

I will ask you to meet in a place that is comfortable for you. This can be a place in the community, like a library or a park, a place in your family home, like the living room or at the kitchen table, or a place at the University like a private meeting room, or in my office. When we meet, I will ask you questions about your experiences with care received from the clinicians you worked with, and about your feelings about the treatment you received. I have prepared a list of questions that I will ask you and we can talk about your answers to these questions, as well as anything else that you think is important or related to our conversation. Please note that this conversation will be audio recorded, so we will not use names during the interview. This conversation will likely take between one and two hours. After our conversation, you will have the opportunity to hear about the results of the study. I will send you a summary of the results if you are interested in learning more about the research to which you contributed.
POTENTIAL RISKS AND DISCOMFORTS

Given that you are going to be talking about your own experiences as they relate to self-harming behaviours and mental health treatment, you may feel uncomfortable at some points during the interview. The interview questions may bring up feelings of sadness, anger, frustration, discomfort, shame, fear or any other of a number of uncomfortable feelings due to the topics we will discuss. If, at any time you would like to stop talking, take a break, or end the conversation, you are welcome to do so with no issue. You will not upset me or affect the research in any way. It will be my goal to make you as comfortable and as secure as possible throughout the interview. Also, we will provide you with a list of people you can call or talk to if you have feelings of discomfort once you leave the interview. There is one instance in which researchers may not be able to maintain confidentiality: Researchers have a duty to report instances of child abuse to the authorities (Child Welfare), and this is the only instance where researchers would not be able to maintain confidentiality.

POTENTIAL BENEFITS TO PARTICIPANTS AND/OR TO SOCIETY

As a participant in this research, you will have the benefit of contributing your thoughts and feelings about stigma around self-harm. You might also benefit from discussing your experiences about your interactions with mental health professionals. You might experience feelings of pride because you contributed to important research that might help other youth who are similar to you.

PAYMENT FOR PARTICIPATION

You will not receive any payment for your participation in this study. We are very appreciative of you and we thank you for giving your time to us.

CONFIDENTIALITY

Every effort will be made to ensure confidentiality of any identifying information that is obtained in connection with this study.

You will only ever provide your first name to the researcher. All of your data will be assigned an ID code, which can only be linked back to your first name by the investigator if needed for the purpose of withdrawing the data. For the purposes of reporting the data, none of your identifying information will be used or reported.

All data will be stored on an encrypted computer and in locked cabinets behind locked doors. Interviews will be audio recorded, so the digital recordings and the transcriptions will be saved on an encrypted computer and will only be accessible to the investigators. All informed consent and paper survey data will be stored in a locked cabinet in the locked office of the investigator.
As stated above, there is one instance in which researchers may not be able to maintain confidentiality: Researchers have a duty to report instances of child abuse to the authorities (Child Welfare), and this is the only instance where researchers would not be able to maintain confidentiality.

PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may exercise the option of removing your data from the study. You may also refuse to answer any questions you don’t want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise that warrant doing so.

RIGHTS OF RESEARCH PARTICIPANTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. This study has been reviewed and received ethics clearance through the University of Guelph Research Ethics Board. If you have questions regarding your rights as a research participant, contact:

Sandra Auld
Director, Research Ethics
University of Guelph
437 University Centre
Guelph, ON  N1G 2W1

Telephone: (519) 824-4120, ext. 56606
E-mail: sauld@uoguelph.ca
Fax: (519) 821-5236

AGREEMENT TO PARTICIPATE IN THE INTERVIEW:

I have read the information provided for the study “Perceptions of stigma and care receipt among youth who self-harm and have received mental health treatment in a hospital setting” as described herein. My questions have been answered to my satisfaction, and I agree to participate in this study.

I have been given a copy of this form and I am providing my verbal agreement to consent to participate. By moving forward with the interview, I am displaying that I agree to participate in this study.
Appendix B: Debriefing Form

You have just participated in a research study conducted by Nicole Mitten and Dr. Michèle Preyde, from the Family Relations and Human Development Department at the University of Guelph. The results of this study will contribute to Nicole Mitten’s thesis project for her Masters of Science degree.

If you have any questions or concerns about the research, please feel free to contact Nicole Mitten (519 580 9968) or Dr. Michèle Preyde (519-824-4120 Ext 58599).

PURPOSE OF THE STUDY

The purpose of this study is to speak with Canadian youth who self-harm and who have been hospitalized for mental health concerns. Specifically, we are interested in hearing how youth feel about the treatment they received from hospital staff. We also want to hear about youth experiences with stigma and self-harm. This research may provide information that will be useful in planning care for youth like you.

PARTICIPATION AND WITHDRAWAL

This is a reminder that you may exercise the option of removing your data from the study. You may do so today, or anytime before the completion of the data collection and analysis by contacting the primary researchers (contact information listed above). Also, the investigator may withdraw you from this research if circumstances arise that warrant doing so.

RIGHTS OF RESEARCH PARTICIPANTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. This study has been reviewed and received ethics clearance through the University of Guelph Research Ethics Board. If you have questions regarding your rights as a research participant, contact:

Director, Research Ethics                              Telephone: (519) 824-4120, ext. 56606
IF YOU ARE EXPERIENCING FEELINGS OF DISCOMFORT

If you are experiencing feelings of discomfort as a result of your participation in this study, or as a result of the topics you discussed with the interviewer, there are many people who would be happy to talk to you about your concerns. You may contact Kids Help Phone, which is a free, national, bilingual, confidential and anonymous, 24-hour telephone and online counselling service at 1-800-668-6868.

KW Counselling has walk-in counseling services every Thursday from 12-6pm. More information about this program can be found at: http://www.kwcounselling.com/walk-in or please contact Joanna Bedggood at 519-884-0000 x249.

KW Counselling Services
480 Charles St. East,
Kitchener, ON
N2G 4K5
P: 519-884-0000
F: 519-884-7000

If you are in a crisis, you may access services through the emergency room at any hospital. We provide a list of hospitals in the Waterloo Region, including Cambridge Memorial (Cambridge), St. Mary’s (Kitchener) and Grand River (Waterloo).

Cambridge Memorial Hospital,
700 Coronation Blvd.,
Cambridge, Ontario,
N1R 3G2
Main phone line: 519-621-2330
Automated teller: 519-621-2333
fax: 519-740-4938
e-mail: information@cmh.org
TTY: 519-621-9180

St. Mary’s General Hospital
911 Queen’s Boulevard
Kitchener, Ontario
Canada N2M 1B2
Telephone (Direct): 519-744-3311
Telephone (Auto): 519-749-6578
Administrative Office Facsimile: (519) 749-6426

Grand River Hospital
P.O. Box 9056
835 King St. West
Kitchener, ON N2G 1G3
Main switchboard: 519-742-3611
Automated attendant: 519-749-4300
Email: info@grhosp.on.ca
Appendix C: Interview Guide

**Background**  *Could we start by you telling me a bit about yourself?*

- How old are you?
- Do you consider yourself male or female or something else?
- How would you describe your ethnicity?
- What is the highest grade you completed in school, do you have a job or a volunteer position?
- Perhaps you could tell me a bit about yourself and your family. Who typically lives in your home?
- Do you have brothers or sisters? How many brothers and sisters do you have and are you the oldest/youngest, etc.?
- Are both your parents working and which jobs do they do?
- Do you see much of your grandparents? (If not raised above)
- What about friends?
- Prompts: What are they like? How would you describe your relationship with them?
- Have you accessed many different mental health services before? What types? Where? How often? When was the last time?

**Self-Harm:**

- Tell me about your self-harm. What does it look like to you? When did you start and why
- Prompts: how often, how severe, where, when, why, what methods

**Care Receipt:**

- Tell me about a time when you were receiving care in a hospital setting for mental health concerns. Were they addressing self-harm behaviours? (Reasons for admission and reason for care)
- How do you describe the care you received from staff and clinicians while you were staying in the hospital?
- Tell me how you were treated by staff?
- If participants reported that the staff did not treat them in the way they expected, ask: How do you think the care should have been?
- How would you want to have been treated by the staff?

**Stigma:**

- Tell me about what stigma means to you
- Have you experienced stigma in your life? (If participants respond in the affirmative, then I will ask: What did/does stigma look like in your life?
- Think back to that time you just told me about when you received care in hospital setting. Have you experienced stigma while receiving care for mental illness, or for self-harm specifically? (If yes, then ask what did that look like?)
Debrief

‘Those were all my questions.’ Thank you for participating in this study. Please see the debriefing form. (At which point I will orally review all details of the form, including purpose of the study, directions for future support, etc. with the participant, and give a copy of the form to the participant for future use if needed)

- Do you have any questions about what we’ve been talking about?
- Do you have any interest in being contacted again once I have completed my data analysis and I have some results of this study? We would like to share our early results with participants to see if they have anything to add and to make sure that we understood what you were saying. We want to be sure that we are representing our participants in the way that they expect. If you have an interest in this, can you provide me with some contact information and your preferred means of receiving this information (explain that I can email or send a hard copy of the results)?
Appendix D: Mind Map of Themes

Themes

Stigma
- Identification of common stigmatizing reactions
- Stereotyping
- Sources of Stigma
  - Clinicians are stigmatizing
  - Youth are stigmatizing

Clinical Stigma

Care Receipt
- Positive qualities of care providers
- Role of Trust
- Negative qualities of care providers
- Secrecy vs. openness

Self-harm
- Planning
- Deciding to stop
- Functions of self-harm

Differences between emergency room and psychiatric unit