

2015

# A Phenomenological Investigation of Suicide Stigma

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A PHENOMENOLOGICAL INVESTIGATION OF SUICIDE STIGMA

by

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B.A Psychology, Wilfrid Laurier University, 2013

THESIS

Submitted to the Department of Psychology

in partial fulfilment of the requirements for

Master of Arts in Community Psychology

Wilfrid Laurier University

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### Abstract

Suicide is a stigmatized phenomenon within our society, and the stigma felt by individuals who struggle with suicide (suicide stigma) must be reduced if society aims at lowering suicide rates. Research on mental health stigma indicates that stigma can reduce help-seeking, lead to low self-efficacy or negative self-talk, and can be detrimental to the recovery process. Suicide stigma research has focused on the perpetrators of the stigma, but research on those who are stigmatized has not been conducted. Research objectives for the current study are to explore public stigma, self stigma, and recommendations for reducing stigma giving voice to seven individuals who have experienced suicide stigma. Interpretive phenomenological analysis was used, indicating that suicide stigma is prominent in many forms in society, and negatively impacts those who experience it. Participants had strategies to manage and/or resist suicide stigma, and they called for greater education about suicide in society and a paradigm shift in the mental health system away from the medical model and towards a consumer-driven approach.

### Acknowledgements

Thank you first and foremost to Geoff Nelson, who has supported me as a thesis supervisor and advisor for the duration of two thesis projects (undergraduate and graduate) over three years. Your understanding of my beliefs and experiences and your direction in harnessing my passion has left a life-long impression. Secondly, special thank you to Allan Strong for shaping and supporting many of my idea and theories around mental health. Your expertise in your capacity as a community expert on mental health and suicide has strongly influenced me over the years. The collaboration between the three of us has been something I will always treasure - although with all the basketball talk that always entered our meetings I am amazed that we accomplished anything sometimes.

Another thank you to the other professors I have encountered in the Community Psychology program, namely Robb Travers, Terry Mitchell, and Manuel Riemer who all pushed me in different ways to challenge myself while being wonderfully compassionate and understanding when it was necessary. Thank you as well to Eliana Suarez for sitting on my committee and providing a unique perspective to this research

Finally, a thank you to my personal support systems, as well as the entire Skills for Safer Living team. Undergoing a thesis on a topic so personal to me and struggling with many of the self-revelations I have had in the process has been a very emotionally draining process for me, and I would not have been able to continue until completion without the support system I have had. One last special thank you to my Mom, who I only became open with about my suicidality this year and who has been extremely understanding and supportive.

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## A Phenomenological Investigation of Suicide Stigma

The World Health Organization states that there is approximately one death by suicide worldwide every 40 seconds, as well as 20 suicide attempts for every death by suicide (World Health Organization, 2012). Within Canada, there were 3,890 reported suicides in the year 2009 alone (Navaneelan, 2012). Lost within these statistics are the individual stories - stories of lives that have been tragically cut short by suicide. My uncle's is one such story, and no one saw it coming. Like my uncle, there are individuals who die by suicide without ever revealing their struggles or seeking help. I myself have also experienced this silent struggle with my own suicidality. In this research, I am defining suicide stigma as the actual and/or perceived stigmatization an individual experiences due to their suicidal thoughts, gestures, behaviours, or attempts. This stigma has been indicated as a reason that individuals do not seek help or openly discuss their struggle with suicide (Thornicroft, 2008). Unlike many individuals who have dealt with their suicidality in silence, my story continues, and is filled with a passionate determination: reducing suicide stigma and preventing suicide despite the risk of stigmatization this personal revelation may put me at. The current research is within this lens, and through an analysis of suicide, suicide prevention, and suicide stigma, a rationale will be developed for this research investigating suicide stigma and possible pathways for stigma reduction.

### Literature Review

This research is phenomenological in nature, and within phenomenological qualitative research there is a debate over whether a literature review should be done prior to the data collection and analysis phase or whether this may influence the research process. I concluded that for my research a literature review would be necessary to gain a wider perspective on the subject area outside the context of my personal experience, as well as to provide support for the

inherent need for this research. The literature review that was completed for this research is meant to unveil the conceptual frameworks that have shaped my research and to create an urgency for a change in perspective related to the phenomenon of suicide. The literature review was a purposeful review shaped by my experiential knowledge and will provide a rationale for my research goals. When searching for literature on suicide stigma, I comprehensively searched the psychinfo and ebcohost databases for all articles containing the keywords suicide, suicidality, suicidology, stigma, discrimination, prejudice, mental health, mental illness, wellbeing, and stigmatization. Randolph (2009) describes how phenomenology can be used as a method not only to conduct research but also to complete a literature review. In performing a literature review from a phenomenological standpoint, steps include giving meaning to the data and creating a thick, rich description of the phenomenon as it is presented in the literature. This is what I hope to accomplish with the following literature review. In this review, I describe the context of suicide, critically analyze dominant suicide intervention techniques, review literature on stigma relevant to suicide, and provide a rationale for a shift in perspective in suicidology that takes a more holistic view of the issue of suicide.

### **An Overview of Suicide and Suicide Interventions**

**Terminology and scope.** The suicide rates previously presented represent a 60% global increase over the past 45 years (World Health Organization, 2012). Suicidality is an inclusive term that accounts for a pressing variety of issues such as completed suicides (death by suicide), suicide attempts (self-injury aimed at death that does not fulfil its intention), suicidal gestures (self-injury or self-harm without an intent to die), and suicidal ideations (thoughts about and intentions of killing oneself) (Davidson, Blankstein, Flett, & Neale, 2008). Speaking from personal experience, suicidal gestures and ideations can be crippling. Unfortunately, through my

comprehensive literature review I found little qualitative research examining this phenomenon, but a quantitative study of U.S undergraduate and graduate students estimated that 55% of students have experienced suicidal ideations at some point in their lives (Drum, Brownson, Denmark, & Smith, 2009). In the current research, the term "individual with experience of suicidality" is used for someone who suffers from any of the experiences noted above, not necessarily someone who has attempted suicide. Another relevant term that should be clarified, since it is frequently misunderstood, is "survivor of suicide". The American Association of Suicidology (2012) defines a survivor of suicide as a "family member or friend of someone who died by suicide", and estimates that approximately 1 in 65 Americans in 2012 could be classified as a survivor of suicide. It should be noted that these statistics come from developed countries, and research shows that meanings of suicide as well as risk factors for suicide may differ cross-culturally and between developed versus developing countries (Vijayakumar, John, Pirkis, & Whiteford, 2005). Specifically, Vijayakumar and colleagues (2005) have found that while some risk factors, such as a previous suicide attempt and low socioeconomic status, may be universal, many risk factors differ between countries. For this reason, I will be focusing specifically on the Canadian context, while recognizing that within Canada there will still be differences between provinces and even neighborhoods due to the differing social, cultural, and political contexts across the country.

**Canadian context.** As reported by Navaneelan (2012), Statistics Canada has shown that individuals aged 40-59 have the highest suicide rates among all age groups, which may be related to statistics showing that divorced or widowed individuals have higher rates of suicide than those who are married. Suicide rates are higher among Aboriginal Canadians and new immigrants to Canada (Government of Canada, 2006). There is also a known gender difference

regarding suicide and suicide attempts with males completing suicide at a rate three times higher than that of women, while females are more likely to unsuccessfully attempt suicide. This difference may be due in part to the fact that men tend to use more violent methods in their attempts (Hirvikoski & Jokinen, 2012). Beyond the gender difference, suicide rates for trans people are higher than rates for non-transgender individuals of either gender (Bauer, Pyne, Francino, & Hammond, 2013).

**Critical analysis of suicide interventions.** As suicide has become an increasingly visible societal concern, the need for interventions has been recognized and suicide prevention efforts have been developed. The Institute of Medicine (IOM) provides a model for prevention in general that profiles three types of prevention (Rae Grant, 1994). These three types are: (a) universal prevention which targets an entire population, (b) selective prevention which caters to specific at risk sub-groups, and (c) indicated prevention which targets individuals already exhibiting symptoms by reducing further harm. As observed by Knox, Conwell, and Caine (2004), suicide interventions tend to focus on individual-level change, and therefore predominantly take the form of indicated prevention. Not only does this approach neglect the complex contextual ecology of these individuals, but it may also attribute the causes of suicide solely to characteristics at the individual level. O'Neill (2005) speaks of the ethics of problem definition, stating that the solution taken to a problem - for example harsh punishments for drug dealers and users as a solution to the drug problem - leads to implications about the cause of the problem. This individualization of the War on Drugs illustrates how a social issue becomes an individual problem due to the intervention techniques used within the "solution". The dominance of interventions designed for individuals with suicidality may be a reflection of the societal view that these individuals are at fault and are, themselves, the cause of their own problems. Suicide

must be treated as a larger societal issue and must be addressed in a more holistic way that takes the external context in to account as well.

The ecological model as presented by Bronfenbrenner (1977) emphasizes that the individual as well as the larger social context must be considered, and that there may be a dynamic interaction between the person and their environment. His ecological model contains four nested components: (a) the microsystem, (b) the mesosystem, (c) the exosystem, and (d) the macrosystem, with the individual being at the core of this nested model. An individual's microsystem comprises the relations and roles they hold within their immediate setting, such as their home, school, and workplace. The mesosystem is conceptualized as the interrelations between the settings in the microsystem. Moving outwards in this nested model, the exosystem contains other social structures in which a person does not directly participate, but that indirectly influence an individual. Within the exosystem, structures such as school boards and the workplace of a child's parent(s) are considered. Lastly, the macrosystem contains the more abstract concepts, beliefs, ideologies, and cultural aspects of a given society that influence all of the contained systems and structures (Bronfenbrenner, 1977).

Placing the IOM model of prevention within the ecological model, indicated prevention methods can be seen as targeting the individual, while selective measures may target the middle three systems (microsystem, mesosystem, and exosystem) that may define high-risk populations or lead to the understanding of risk factors for suicidality. Universal methods may be conceptualized as acting on macrosystems and aiming to create change within abstract ideologies that shape a society's dominant beliefs, behaviours, or values. By conceptualizing the prevention model as coinciding with the ecological model, I am trying to point out that just as the multiple layers of the ecological model are interconnected, so must prevention efforts at the different

levels of focus be interconnected. This leads to the notion that individual change may not be sustained unless change also occurs at multiple levels. Drawing further on this, it could be argued that interventions for suicide must target all interrelated ecological system levels if it is to create sustained change.

The critical perspective I hold of the dominance of medicalized, individual-level interventions for suicide is necessary to challenge beliefs before accepting new ones. Within phenomenology, bracketing current beliefs or preconceptions is required before attempting to research the experience of a phenomenon so that the researcher can better understand the phenomenon from the perspective of those who have experienced it. Therefore this critical perspective complements the phenomenological approach of this paper by challenging assumptions that may be held. One field that has successfully developed a critical view of dominant perspectives is Mad Studies, an emerging antipsychiatry field. The Mad Studies movement is driven by mental health consumers and activists re-claiming the word "mad", commonly used as a derogatory term for an individual with mental health struggles, and fighting sanism (discrimination against those considered not sane). This field values the lived experience perspective of the phenomenon of mental illness and strives to change the context within which sanism occurs. (LeFrancois, Menzies, & Reaume, 2013). The shift this field is creating involves changes at all levels of the ecological model and challenges beliefs at the macro-level, and I argue this shift needs to happen within suicide research and interventions as well.

**A holistic view of suicide.** Durkheim can be considered a father of suicidology research, and he took a broad multi-level view to suicide, acknowledging a classification of suicide that he titled "egoistic suicide". He theorized that this sub-type of suicide is brought on by excessive individuation and a lack of social integration (Durkheim, 1897/1952). This theory is still

prevalent in sociological studies of suicide (e.g., Wray, Colen, & Pescosolido, 2011). This theoretical conceptualization of suicide implicates that society is a perpetrator, and places the issue of suicide within larger contextual and ecological levels. The Interpersonal Theory of Suicide states that for a suicide attempt to occur, an individual must have both the capacity and the desire to die. In this model, the desire comes from feeling of isolation, lack of belongingness, and burdensomeness (Van Orden, Witte, Gorgon, Bender, & Joiner Jr., 2008). These theories all have a commonality of indicating poor social integration as a cause of suicide, and this cause occurs at the societal level. These factors such as lack of belongingness, burdensomeness, and isolation work at multiple levels since they involve the perception of these feelings at the individual level, the acts involved in creating these feelings occurring within one's immediate context, as well as societal beliefs at a macro-level which may determine how individuals interact with those who experience suicidality. This interplay related to a lack of social integration may be part of what I will later describe as the "Cycle of Suicide Stigma".

Suicide interventions have a tendency to focus on changing factors at the individual level, but often neglect to view suicide holistically as a complex issue requiring solutions at multiple ecological levels to complement each other. I have stated that this perspective must be shifted to fill the gaps within suicide prevention efforts. I have chosen to target stigma due to my own beliefs which stem from my personal experience, and because stigma reduction has been suggested as being an important focus for suicide prevention within the literature (e.g., Batterham, Callear, & Christensen, 2013; Reynders, Kerkhof, Molenberghs, & Audenhove, 2014).

## Stigma

**Theoretical conceptualization of stigma.** To begin exploring this "Cycle of Suicide Stigma", suicide stigma must be further defined, and a precursor to that will be to outline the framework used to conceptualize stigma within this research. A comprehensive review of general stigma theories would be too lengthy for the purpose of this proposal, so I will begin with a few select theories of stigma that I find most relevant, then move into the stigma of mental illness and the largely unexplored topic of suicide stigma. One researcher who has explored stigma from the perspective of a stigmatized person was Erving Goffman in his iconic book, *Stigma: Notes on the Management of Spoiled Identity* (1963), titled so due to his belief that stigma is a mark of disgrace and creates a spoiled identity. Goffman outlines three types or sources of stigma (a) character traits, (b) bodily attributions, and (c) group identities. Stigma of character traits would be the realm mental illness and suicide stigma fall within, as it encompasses perceived faults or weaknesses of individuals.

Two models of stigma have attempted to identify the processes by which stigma occurs: Labeling Theory (Scheff, 1966), and a corresponding Modified Labeling Theory (Link, Cullen, Struening, & Shrout, 1989). Both approaches suggest that an individual who holds a certain role within society is labeled because they occupy that specific role. There is then a response to that label which leads to negative consequences and a vulnerability within the individual to "fulfil" the stigma of that role with which they have been labelled. Scheff's (1966) original theory focused on how others responded to the individual who has been labeled, while the modified theory emphasizes the response of the individual who has been labelled, such as withdrawing into secrecy about their label. The original theory also proposes that the process of being labelled may have the power to cause someone to become that label, whether it was originally valid or



not. In the modified theory labelling does not have this much direct power but instead suggests negative outcomes for the labelled individual that can increase their risk of being confined by the label. A final difference between the two approaches is that Scheff's model sees community attitudes towards a label as being unanimous, while the modified theory leaves room for variation within the attitudes individuals may have towards a role (Link, Cullen, Struening, & Shrout, 1989). This theory explains the negative and self-fulfilling role stigma may have and provides a model of its operation within society. Although this model is useful in mapping the process of stigma, it lacks an explicit definition of "stigma".

Link and Phelan (2001) address the differing definitions of stigma within different fields by creating an integrative sociological definition that attempts to combine the multiple aspects of stigma recognized and emphasized within the literature. Within their definition of stigma are five main components: (a) labeling human difference, (b) stereotyping in accordance with dominant cultural beliefs, (c) separation of labeled persons, (d) status loss and unequal outcomes for labeled persons, and (e) social, economic, or political power which allows the labeling to occur and the previous components of stigma to unfold. Further, this framework allows for discrimination, exclusion, prejudice, and disapproval to occur (Link & Phelan, 2001). Their definition is what I have used to operationalize stigma within the context of this study.

Parker and Aggleton (2003) go beyond the theories of stigma that I have discussed thus far by indicating stigma as a method for deepening the divide between social groups, or enhancing pre-existing inequalities. In their work on stigma specifically with the field of HIV and AIDS they analyse how stigma is highly related to power and power imbalances such as those between differing social classes, genders, or racial groups. This theory provides a

framework for interpreting how stigma may effect societies and individuals from an ecological perspective.

An additional theoretical framework of stigma that has shaped this research is the recognition of public stigma and self stigma as two different but interconnected concepts. Corrigan and Kleinlein (2005) differentiate between public and self stigma. Public stigma is the reaction the general population has to a labeled group due to stereotypes that may manifest in outward prejudice and discrimination. Self stigma is the internalization of these reactions and beliefs that causes inward prejudice and discrimination in the form of low self-efficacy or low self-esteem. Corrigan has focused efforts on understanding and reducing the internalization of self stigma as well as reducing public stigma (Corrigan & Rao, 2012; Corrigan, Kosyluk & Rusch, 2013), but the effects of public stigma on the individual seems to be less often explored. This research will investigate both categorizations of stigma, but with a specific interest on describing the experience of public stigma from the perspective of those who have been stigmatized and exploring how it may be shifted.

**Stigma management and/or resistance.** Although a response to stigma by the stigmatized individual was not part of the original labelling theory, it was included within the later modified labelling theory. These responses to stigma, particularly an individual's ability to manage or resist stigma, has been a growing research interest although not a new one. Goffman's original work on stigma included a chapter on responses to stigma. Goffman reported finding that individual's may try to compensate for their stigma or hide from it. He suggested that hiding may lead to further isolation and self-consciousness, as proposed in the previously reviewed theories of stigma. Interestingly, Goffman saw the value of self-help groups and suggested that stigmatized individuals create their own communities or support systems with others who share

their stigma. (Goffman, 1963). Goffman speaks of stigma management, while more recent theorists have looked at the resistance of stigma and agency for changing stigma. For example, Campbell and Deacon (2006) suggest that stigma is not always internalized, and if it is, it may not always be a disadvantage. They state that stigma may become a call for mobilisation and create agency for change to occur. For example, those who are stigmatized may become motivated to advocate for change in societal beliefs.

**Suicide stigma.** I previously described suicide stigma in my own words as the stigmatization of individuals who have lived experience of suicidality. The term "suicide stigma" is not commonly used within the literature, as it has not been widely explored. That being said, Australian researchers have developed a Stigma of Suicide Scale, which is the first validated scale developed to measure suicide stigma within communities (Batterham, Calear, & Christensen, 2013). This scale contains stereotypical descriptors that may be used to characterize an individual who completes suicide, and is administered at a population level to measure the amount of stigma present in a certain societal context. An initial study investigating the psychometric properties of this scale showed that more than one quarter of research participants agreed that individuals who died by suicide could be considered "weak", "selfish", or "reckless" (Batterham, Calear, & Christensen, 2013). While this scale may be able to successfully quantify the suicide stigma present in a cultural context, no objective scale could be able to adequately describe or explain the subjective phenomenon of stigma as a lived experience. Lester and Walker (2006) undertook a quantitative study with a sample of 160 U.S undergraduate students on the prevalence of stigma towards those who have attempted suicide with the following results: (a) suicide attempters are the target of more prejudice and discrimination than various ethnic and racial categories who are overtly ostracized; and (b) there has been no decrease in stigma since

the original study over two decades earlier (Kalish, 1966) that Lester and Walker (2006) replicated. More specifically, results showed that 25% of students who participated would not buy a house next to an individual who they knew had attempted suicide, and 20% would not allow an individual who had attempted suicide to become a U.S citizen if they did not already have U.S. citizenship.

**Impacts of stigma.** The impacts of mental health stigma and stigma in general have been well documented within the literature, but suicide stigma has not. Within the mental health literature, it has been indicated that stigma in itself may actually be a clinical risk factor leading to discrimination, isolation, and heightened difficulties (Shrivastava, Bureau, Rewari, & Johnston, 2013). It has also been indicated that stigma reduces the likelihood of an individual seeking help, or in other words acts as a barrier to accessing mental health services (Reynders, Kerkhof, Molenberghs, & Audenhove, 2014; Thornicroft, 2008). Further, Corrigan and Kleinlein (2005) suggest that stigma has detrimental effects on society by promoting injustice, undermining communities, perpetuating fear of becoming part of a stigmatized population, and depriving society of the contributions stigmatized individuals could make if they were not segregated.

To conclude this section on the consequences of suicide stigma I would now like to return to a concept I posed earlier in this paper - that of the "Cycle of Suicide Stigma". Within the literature reviewed on stigma theories, it is evident that a central aspect of stigma is the negative feelings and actions towards individuals who are stigmatized. This may manifest itself in the exclusion and therefore isolation and lack of belongingness felt by individuals who are the targets of stigma (Link & Phelan, 2001). Referring back to the Interpersonal Theory of Suicide, Van Orden et al. (2008) state that desire for suicide comes from these feelings of poor social

integration, isolation, and burdensomeness. Stigma theories such as modified labeling theory (Link et al., 1989) suggest that having this desire for suicide would begin the process of stigmatization. The stigmatization, specifically the negative outcomes from it including isolation and a lack of belonging, then feeds back to the desire and creates a vicious cycle which is illustrated in Appendix A.

### **The Importance of Reducing Stigma**

To return to the larger picture, a reduction in stigma would be an intervention targeting the macro-level societal beliefs, as well as addressing factors at the inner levels such as feelings of isolation and a lack of social integration. A stigma reduction approach could provide one important piece of a comprehensive multilevel suicide preventive intervention that complements existing efforts at the individual level and other ecological levels. Importantly, reducing suicide stigma would be the most efficient way to break the "Cycle of Suicide Stigma" and eliminate the negative impacts of stigma on individuals and communities that may perpetrate or reinforce suicidality. These suggestions about the importance of stigma reduction are supported by the literature (e.g., Knox, Conwell, & Caine, 2004). To summarize key findings from this literature review, as well as the gaps in the literature, it is evident that suicide stigma exists, has negative impacts, and that stigma reduction is not typically included as an integral part of suicide interventions. Reducing stigma may act as an intervention technique at the macro-level that would complement prevention efforts at other ecological levels to shift the focus of suicide intervention to one that is more comprehensive and holistic. A large gap in the literature is the lack of research on suicide stigma, specifically the absence of qualitative literature that attempts to understand the lived experience of suicide stigma from the perspective of those who have been stigmatized.

### **Research Goals, Objectives, and Questions**

A theoretical framework for reducing stigma cannot be achieved until the phenomenon can first be understood. The goal of this thesis is to investigate the phenomenon of suicide stigma and build a depth of understanding from a lived experience perspective that may inform future stigma reduction and suicide prevention efforts. The three main research objectives are:

- a) To describe the experience of suicide stigma as a social phenomenon (public stigma) from a lived experience perspective,
- b) To understand the subjective, personal experience of suicide stigma (self stigma) from a lived experience perspective, and
- c) To examine what those with lived experience believe needs to change within communities to reduce stigma.

These three research objectives correspond with four research questions. The first research question, which corresponds with the first research objective, is: a) how is suicide stigma publicly manifested, displayed, and experienced socially? The second research question, corresponding with the second research objective, is: b) how is suicide stigma subjectively experienced, and how do those who are stigmatized feel impacted by it? Research questions three and four correspond with the third research objective, and are as follows: c) what do individuals who experience suicide stigma feel they need from the larger community and its members to reduce stigma, and d) what do individuals who experience suicide stigma feel they need from service providers and mental health organizations? A summary of these research objectives and questions, as well as a rationale for each, can be viewed in Appendix B.

## Methodology

### Reflexivity and Research Paradigm

Findlay (2002) states that reflexivity can be understood in a variety of ways, depending on which paradigm is endorsed by the researcher. My epistemological and ontological views are most congruent with the constructivist paradigm. Denzin and Lincoln (2005) describe constructivism as having a relative view of reality, as valuing transactional knowledge, as using a dialectical methodology, and as having a focus on producing new perspectives of societal phenomena and an orientation to action. Working from this paradigm, I see reflexivity within constructivism as an ability to recognize the meanings I attribute to my experiences of reality, and to acknowledge how my experiences and privileges influence my view. Reflexivity also entails accepting and respecting the meanings and experiences of others as valid and as contributing to an understanding of the phenomena under investigation.

Finlay (2002) states that researchers should examine personal motivations, assumptions, and interests in the research topic to uncover biases shaping their research. My motivations and interests in the topics of suicide, suicide stigma, and suicide prevention all come from lived experience with these issues. First and foremost, because of my own struggles with suicidality and my experience of having to handle these struggles alone, I have developed an interest in and motivation for reducing stigma and preventing suicide. Secondly, my experiences of losing loved ones to suicide have further motivated my passion for preventing suicide. As I have mentioned, one of the loved ones I lost was an uncle who died unexpectedly by suicide without disclosing his intentions or exhibiting any warning signs. While these experiences have provided me with a profound motivation, they may also lead me to hold biases towards others with similar

experiences. I have developed assumptions about the experience of suicide stigma based solely on my own lived experience, and I acknowledge that my preconceived notions have shaped my literature review as well as my methodology and interview guide. A third experience I will add that shaped my criticisms of individual, indicated suicide prevention programs is my experience as a researcher with the Skills for Safer Living (SFSL) program. In my two years working with SFSL, an evidence-based program run by the Self-Help Alliance of the Canadian Mental Health Association Waterloo-Wellington-Dufferin, I have encountered many individuals who have spoken about the hardships of going back to the same reality and same context even though they have been changed through the program. Comments about a lack of change within people around them and their social circumstances that hinders their recovery are commonly heard in focus groups that I have facilitated during program evaluation. It was these experiences that really drove me to question uni-level intervention techniques for suicide that target only the individuals experiencing suicidality, even though these programs may have profound outcomes for those who participate.

Contextualism is another research paradigm I have drawn from heavily within the development of a theoretical framework within which to situate this research. Kingrey-Westergaard and Kelly (1990) state that within a contextual epistemology, individuals are recognized as being embedded within a sociopolitical context. This approach embodies my critique of dominant individually-based suicide prevention techniques and my advocacy for a conceptualization of suicide as operating within a social context where stigma is prevalent.



## Methodological Framework

Social constructivism draws on qualitative methodological frameworks. Darlaston-Jones (2007) asserts that qualitative methods are aligned with a relativist epistemology, and can provide the means for uncovering deeper understandings that may lead to action. Within the field of suicidology, it has been advocated that more qualitative research is needed to fully "understand" the phenomena that has widely been "explained" quantitatively, yet rarely investigated using qualitative research methods (Hjelmeland & Knizek, 2010). There are various methodologies within qualitative research as outlined by Creswell (1998), and my research aligns with phenomenology.

**Phenomenology.** Phenomenology as a conceptual approach was originally developed by Husserl, a German philosopher, and is rooted in criticisms of positive psychology and of philosophical views denying the existence of external reality (Baker, Wuest, & Stem, 1992). The phenomenological movement is a shift towards a descriptive study of experiences and involves an investigation of consciousness. The intention of phenomenology is to describe how a phenomenon is experienced and interpreted. (Davidsen, 2013). Within phenomenological research, reduction is used to uncover the essence of a phenomenon as it is experienced by the participants of research, and to discover common meanings across variations of the phenomenon (Baker, Wuest, & Stem, 1992). Other research approaches may be more focused on explaining or developing theory about a certain experience, but I find phenomenology to be best suited to my research questions, given their attempt to explore the phenomenon and develop an understanding of common meanings and experiences across variations of this phenomenon without necessarily explaining them. Since suicide stigma is a poorly researched and poorly understood experience, a

phenomenological study may provide an initial exploratory investigation into the lived experience of this phenomenon.

### **Sampling**

Within phenomenology the only source of data seen as legitimate is the descriptions and reports of those with lived experience of a phenomenon (Baker, Wuest, & Stem, 1992). For this reason, my population of interest was individuals who have had experience with suicidality and therefore may have experienced suicide stigma. I used purposive sampling within this research and interviewed a total of seven research participants so that the richness of experiences of each individual participant was not lost in a large compilation of stories. The sampling was purposive since I selected participants because of their self-identified experience with suicidality.

A problem I had with sampling this population is that, due to the nature of suicide stigma, they are hard to reach. This is reminiscent of a story a clinical psychology professor once told me about the seemingly paradoxical problem of trying to get a group of individuals with social anxiety together in a social setting for a focus group about their anxieties - the nature of the research may be contradictory to the nature of the target population. For this reason I used a form of facility-based sampling, which has been described as recruiting participants from a facility or facilities often visited by members in the target population (Magnani, Sabin, Saidel, & Heckathorn, 2005). To be more specific, I recruited individuals who have completed the Skills for Safer Living (SFSL) program that I will soon describe. Once individuals have completed the group they can attend a weekly peer group open to all consumers of the SFSL program. My recruitment process involved creating a promotional letter about my research that was given out to individuals who attend the weekly post-intervention peer group, and this letter was also mailed out to individuals who receive the bi-annual Peers for Safer Living newsletter created by SFSL

staff. The research was described as a project to investigate the negative attitudes about suicide within society and how they can be reduced. The advertisements also informed participants that the researcher was seeking anyone with lived experience of suicidality who would like to partake in an interview to talk about how stigma has affected them and how it could be reduced.

**Context: Skills for Safer Living.** SFSL is a 20-week group intervention for individuals who have had multiple suicide attempts. The program strives to help individuals develop strategies and skills to intervene and prevent their suicidal behaviours. The four main modules in SFSL focus on reducing suicidal tendencies by instilling new strategies within the client. These modules are: (a) personal safety, (b) emotional literacy, (c) problem-solving, and (d) managing interpersonal relationships (Bergmans, 2009). The skills participants have learned in this program may influence their interpretation of meaning and their experience of suicide stigma. Particularly, this program teaches skills that help participants resist or challenge stigma. Therefore, the experiences of self-stigma that participants share may have been shaped by the program content. SFSL is run through the Self Help Alliance, a consumer-driven organization that uses peer workers to design and implement a variety of self-help groups and programs. This organization holds a recovery-oriented framework embracing the knowledge and contributions of consumers. (Self Help Alliance, n.d). Sampling from the population within this context may influence the descriptions of the phenomenon of suicide stigma that participants hold since this context itself is in line with a critical view of sanism and the medical model for treating mental health.

**Demographic information.** All participants in this research had completed and/or facilitated a SFSL session. The requirements for participating in SFSL include: being over the age of 18, having a history of multiple suicide attempts, or a history of recurrent suicide ideation.

Demographic information was not explicitly collected from research participants, although an estimation of demographics can be given. Participants varied in age from approximately early 20's to mid 50's. Of the seven participants, six identified as female, one as male, and all appeared to be Caucasian. The dominance of the female voice within this study is not surprising. As I reviewed in the literature, although more males complete suicide, more females attempt. This means a larger proportion of those who have experience with suicidality that remain alive would be female. The dominance of the Caucasian voice in this study may be explained by the dual stigmas that an individual of a minority race would hold as someone with experience of suicidality. Since the literature reviewed earlier revealed that stigma tends to silence people, it can be assumed that the greater stigma one feels the less likely they may be to talk about it. Demographic information was not collected since I wanted the participants to have the freedom to choose to mention certain aspects about themselves that they regarded as relevant.

**Rationale.** Since there are advantages and limitations to this sampling method, I will provide a rationale for it. First, since this is a hard to reach population, the easiest way for me to reach it is through SFSL since I have been doing collaborative research with this program for multiple years. Within SFSL, participants are taught skills to help them understand their experiences, and are encouraged to openly talk about their interpretations of these experiences. Due to the experience participants have with analyzing and deriving meaning from their experiences they may be able to provide richer qualitative data, which is of great value within phenomenology. They may also simply be more comfortable with talking openly about the subject area. This is connected to a third rationale for using this sampling method, which is also an ethical one. Since the issues being discussed within this research are emotional and personal, this presents a risk to participants of being triggered or entering crisis mode during or after the

research. SFSL has a module that teaches participants how to avoid entering crisis and how to be safe once in a mode of crisis. Undertaking this research with participants who have been taught these skills acts as a protective factor against this risk - although I still kept stringent ethical considerations in mind as this precaution does not completely negate the risk.

With regards to sample size, Pietkiewicz and Smith (2014) state that there is no rule regarding how many participants should be included in phenomenology, but in general sample size will be dependent on: (a) how deeply each interview is analyzed, (b) the level of richness in each participant's story, (c) how each interview is compared and/or contrasted, and (d) the practical considerations or limitations. I considered my sample complete once I had reached seven because the difficulty in reaching this population was greater than I had expected. I had exhausted all options for recruiting more participants and therefore the sample size was most dependent on this practical barrier. I also believed that seven was appropriate since each participant in the research told a very rich story, that there was great depth to their exploration of their experience of suicide stigma, and that I had sufficient diversity in perspectives to meaningfully compare and contrast each story. Turpin et al. (1997) recommend that for an interpretive phenomenological study, six to eight participants are needed to sufficiently analyze a phenomena without becoming overwhelmed in the data collection or analysis process. On the other hand, Smith and Osborn (2008) state that three participants would be more than sufficient for an in-depth, rich description of a phenomenon for a student conducting interpretive phenomenological analysis for the first time.

Some research methodologies might see this type of sampling and the sample size as a limitation to a study. Facility-based sampling is purposive, targeted sampling technique, which means there is no way to achieve a probability sample and therefore the sample cannot be

considered representative (Magnani, Sabin, Saidel, & Heckathorn, 2005). Within phenomenology, the goal of research is not to uncover generalizable findings, so the type of sampling does not hinder the research goal of describing the phenomena for the individuals who participate in the research. This research is exploratory, and instead of being generalizable I would like it to be generative so that it may be investigated further and under different paradigms or methodological frameworks in future research. Pietkiewicz and Smith (2014) argue that homogeneous samples should be strived for in interpretive phenomenological analysis, so the sampling method here is in line with the research methodology since it provides homogeneity to sample from participants who have completed the same program in the same community.

### **Data Collection and Analysis of Findings**

Within phenomenology, it is commonly expected that researchers "bracket" their previous knowledge so that they can approach the data without preconceptions (Baker, Wuest, & Stem, 1992). As I was learning about phenomenology, I saw this as problematic since - although I can acknowledge and be reflexive about my prior knowledge, it has shaped by research design and methodology in a way that I cannot possibly approach the research without preconceptions. LeVasseur (2003) describes a subtype of phenomenology called hermeneutic phenomenology that proposes a dialectic approach to bracketing within this classification of research. Instead of denying our assumptions and previous knowledge, the goal should be to temporarily suspend them in an effort to increase our natural curiosity and become open to new and possibly contradicting understandings of the phenomena (LeVasseur, 2003). I took this approach to phenomenology within my methodological framework by recognizing my preconceptions while indulging my curiosity and being willing to listen to and accept experiences that differed from my own.

**Data collection.** The specific data collection method that was within this research is semi-structured individual interviews. This method is a natural extension of the paradigm and methodological framework used in this research. The interview guide can be seen in Appendix C. The interview consisted of nine questions, with prepared prompts within each question. During the interview procedure, this guide was used as a facilitation tool if the participant required prompts. Often, the guide was only loosely followed since I wanted to let participants guide the interview in a way that would allow them to express whatever they felt was most essential to their experience of stigma. The interview guide questions were designed to collect rich descriptions of experiences, answer the research questions, and achieve the research objectives. Appendix D contains a table showing how the interview guide questions correspond with these research questions and objectives. A note to make about the interview guide is that a question was added on the end about how the SFSL program may have affected an individual's interpretation and evaluation of meaning of their experience and how it may have modified their experience of stigma. As well as addressing context, this question may also uncover how this suicide prevention program interacts with societal stigma.

**Procedure.** The interviews took place at whichever location best suited participants, with the option of the SFSL site in either Cambridge or Kitchener, or Wilfrid Laurier University. Interviews were conducted one-on-one, and ranged in length from approximately 40 minutes to approximately one hour and 45 minutes. The interviews were audio-recorded and later transcribed. Prior to the initiation of each audio recording, participants were asked to read and sign an informed consent sheet, were given additional information about the research, and were given the opportunity to ask questions or make statements before the recording began. Participants were also given the opportunity for a break part way through the interviews, they

were told the recording could be paused at any time if they wanted to make a comment off the record, and they had the chance to make further comments or ask additional questions once the audio-recording had been stopped. Participants were asked for consent to use direct quotes from the interview in any reports or presentations and could choose not to consent but to still participate in interview. As an incentive, two adult Grand River Transit bus tickets were offered to each participant. The rationale behind this incentive was to ensure that individuals under financial strains who did not have a bus pass or a vehicle would not feel excluded from participation. Each interview was recorded using a Sony voice recorder, and audio files were played at .5 regular speed in Sound Organizer (a computer software program) during transcription in Microsoft Word. During transcription, interviews were anonymized and any personal information or possible identifiers were removed from the script.

**Analysis of findings.** An interpretive phenomenological analysis (IPA) was performed with the data from this research. Within IPA, it is important to both give voice to the participants and to contextualize or interpret their stories. The purpose of this process is to describe how a person experiences a phenomenon, and further, how they interpret and explain it (Larkin, Watts, & Clifton, 2006). The process of IPA is that of double hermeneutics, since the researcher's role is to interpret the meanings that participants have given to their experiences, while curiously and critically questioning the participants own analysis of their experience (Piekiewicz & Smith, 2014). To do this, I roughly followed the same steps of data explication as taken by Groenewald (2004), which represents a simplified version of the explication process as formulated by Hycner (1999). All analysis of the data was done in Microsoft Word without the use of additional software, since the use of additional software would not have allowed for the depth of analysis



required in phenomenology without risk of losing the individual voice in the coding process.

These steps taken were as follows:

1) The first step in this process is bracketing and phenomenological reduction, which involves attempting to put aside preconceptions about the phenomenon and understanding it from the language and experience of the participants in context. Specifically, my procedure for bracketing my experiences involved an analysis of my experiences to identify where my thoughts and biases may come from, and how my individual experiences may have shaped me. This stage was completed during the process of designing the research and writing the thesis proposal, and resulted in the reflexivity I have explicitly stated in the earlier sections of this thesis as well as in the afterword of this document.

2) The second step I took is delineating units of meaning. This step involved extracting units of meaning from the interviews and composing a list of the relevant meanings after careful inspection. According to Pietkiewicz and Smith (2014), this stage involves multiple in-depth readings of the transcript as well as re-listening to the audio files. As I was extracting units of meaning in each transcript I ensured to consider the context that each meaning was given in by looking at surrounding statements and the most recently asked question, and referred to audio files for vocal cues for additional contextual cues.

3) A third step in the explication process is to extrapolate from the units of meanings to form more general themes of grouped meanings. These themes should summarize the units of meanings. This phase involves an extrapolation from the units of meaning to less concrete, overarching themes. To ensure my conceptualizations of these themes was still a product of the participants own experience and that their initial meaning making was not lost in the analysis, transcripts were re-read multiple times during this stage as well.

4) Next, I summarized each individual interview using the themes that I used to interpret the participant's experiences. In this stage I created tables to organize the themes that I extracted from the participant's stories by which research objective they explored. I also included quotes that represented each theme into these tables as an organizational technique to assist me in the write up of findings. Additionally, the table included a category for information participants gave about the SFSL program that I asked one question about in the interview.

5) The final step in this process was to re-assess all interviews and identify the dominant themes that may be present within most or all of the interviews, as well as identifying the themes that may be less common or more specific to one individual experience. This process can be seen as a compare-and-contrast process that acts to increase the depth of the analysis. Groenewald (2004) emphasizes that this step should reflect the data and stay true to the interviews while transforming the language and experiences into something meaningful to the academic and research discourse. In this step I created a document where I could consolidate themes and re-assess the validity of each theme with the individual interviews, as well as check which themes were more prominent and which were unique. This step results in what Groenewald (2004) refers to as a "composite summary" reflecting the themes and the context in which they emerged. The results section of this thesis acts as the composite summary for this research.

**Trustworthiness.** A means of checking the trustworthiness of the data was implicit within the data explication process by listening to the interviews at differing times during the analysis phase and re-reading transcriptions also ensured trustworthiness and faithfulness to the original language of participants. Groenewald (2004) also states that the process of bracketing one's preconceptions of the phenomena will help ensure trustworthiness. Although I have expressed my skepticism of completely bracketing my experience, the high degree of reflexivity

I have held since the research proposal stage and have included within this paper enhances the trustworthiness of the research. Shenton (2004) outlines various means of ensuring trustworthiness in qualitative research, including frequent debriefing sessions between a researcher and a supervisor, reflexive commentary, examination of previous research findings, and thick descriptions of the data. All of these processes have been described within my research methodology and have contributed to the trustworthiness of this research. By including discrepant information in the key findings that follows, I also ensured a faithfulness to the experiences of participants and their personal meanings.

### **Key Findings**

In this section I will review some of the major themes that arose from the data, as well as comparing and contrasting the perspectives of research participants. Fulfilling the aim of phenomenology, I will attempt to give voice to the participants and describe their lived experience with suicide stigma. This section is organized by research question, and will use the language and the phenomenological analysis of the data to answer each of the questions this study was meant to explore. One additional theme added to this key findings section that did not fit with any one research question is the contrasting role of religion, which will be discussed after the four research questions. Research participants are referred to using the gender-unspecified pronoun “they” in the singular form to protect the anonymity of participants and to avoid making assumptions about the gender of each participant.

### **Research Question 1: How Is Suicide Stigma Publicly Manifested, Displayed, and Experienced Socially?**

All research participants felt strongly that there is a negative stigma towards individuals who struggle with suicide in our society, and that this stigma manifests in many ways. Perhaps a surprise to some readers, this stigma came mostly from strangers or acquaintances and from the mental health / healthcare system. Few participants spoke about stigma from close friends and family, while all of them spoke of the system as the source of stigma, and most spoke about stigma coming from strangers. Themes that were prominent across interviews include: (a) judgement statements and stereotypes, (b) misconceptions about and dismissal of suicide / mental health issues, and (c) stigma within the healthcare and mental health system.

**Judgement statements and stereotypes.** This is the overall theme that I believe captures the beliefs and negative attributes that participants had heard others use to describe an individual who struggles with suicide. Although a few participants noted that positive judgement is sometimes experienced, such as individuals recognizing the resilience or strength of someone who has attempted suicide but is still living, the consensus was that most judgements made about individuals who struggle with suicide are negative. The sentiment that was quoted most often by participants was that others see those who attempt suicide as selfish. One participant stated, "We're seen as being selfish. Very selfish. Not thinking of others when in fact sometimes it's because we think of others that we do it right? Because we think we're a burden". Participants also frequently reported experiences of being called "crazy," "nuts," and/or "stupid." Being considered weak was an additional judgement that multiple participants had experienced, with one remembering being called "the weaker link of society" due to their struggles with suicide. Another unit of meaning extracted from the experiences of participants was being told that they

didn't fit with the stereotype of a "typical suicidal person". One participant spoke about an incident in which the police were surprised at her state of cleanliness and her appearance since she was known to be suicidal, and joked "next time I'll have unwashed hair for five days, like what do you want me to do? Go throw my clothes in a mud pile and then wear them? It's like, would that be better?" Less frequently reported experiences were participants being perceived as not trying hard enough or crying for attention because they had attempted suicide. These negative judgement statements were prominent in all participants' accounts of their experiences with public stigma, and one individual offered speculation as to the reason why such judgements may be so prominent:

"They tend to make judgements because they're not talking to us. They're just talking about us or yelling at us for acting.... so crazy or stupid is a lot easier to say and tell us than ask us if they can do anything."

**Misconceptions about and dismissal of suicide / mental health.** When asked how others think about those who attempt suicide, a commonly shared experience from research participants was, in one participant's words, "I don't think they understand. I don't think they can possibly get it". Research participants all expressed a perceived inability on the part of individuals who had not experienced suicidality to really understand what it is like. This resulted in misconceptions and a dismissal of suicide or of mental health issues as a serious struggle. This is illustrated in one participant's description of her perspective, "it's a lot of the old thinking of, well, snap out of it. There's nothing really wrong it's just emotional and it doesn't matter." Participants also referenced a public misconception about recovery, exposing a perceived expectation to get better and just recover which only added to their experience of stigma. One participant compared experiencing suicide to experiencing addiction, stating that suicidality

should be considered a life-long issue and each day without an attempt should be celebrated, not expected, since the expectation causes pressure and anxiety that can contribute to thoughts of suicide. Multiple participants reported that society just doesn't know how to help and doesn't understand the phenomenon of suicide which leads to the stigma, and leads to manifestations of the stigma such as being told to just take their own life already, or being told that mental illness isn't a real issue. One participant had attributed meaning to their experiences of this theme by speculating that people who have not experienced suicide just found it easier to hold these misconceptions and dismiss the issue than to try to understand it. Another stated that they believe these misconceptions are because "they don't tend to engage" with someone perceived as crazy, and that they only "talk about us, not to us".

**Stigma within the healthcare system.** The most widely spoken about theme was stigma within the healthcare system, manifested in outward displays of mistreatment of the “psych patient”. As one participant explained, "In hospital settings, flat out, they flat out tell you ... you have no rights as a mental health patient. You have no rights". Another participant described their experience with visiting the hospital after a suicide attempt as follows,

"You actually might wait one or two days if you're admitted to go in to this little section because someone in .... and you have to sit up in a chair doing absolutely nothing. But you're a psych patient, it's okay, it doesn't matter. 'Cause they don't want crazies in the hall anymore!"

Participants also said that healthcare professionals generally held the notion that they knew best about the treatment of suicidality, meanwhile participants disagreed and felt that those with

personal experience know best about how to treat and prevent a suicide attempt. One participant describes their experience as,

"Except when people like the doctors and the nurses and some police and not all again, but a lot of them are like 'well, I'm a professional, you're not, you're the one that had the suicide attempt so what do you know?'"

Most participants found that they were commonly outwardly stigmatized for reaching out and seeking help, and almost all said that being in a hospital setting made the stigma as well as their suicidal thoughts worse even if they came to hospital to seek help. Reasons participants attributed to these feelings included professionals expressing the judgement statements previously described and that professionals tend to dismiss individuals experiencing suicidality or make them feel like they're a burden. Furthermore many participants experienced a professional telling them not to talk about their suicidality or to lie about it by saying they were not suicidal if they wanted treatment for the underlying abuse and/or trauma some participants reported having. One participant articulately explained their experience of how professionals stigmatize individuals without acknowledging their part in perpetuating the stigma. This participant stated that,

"They just see it as you're the revolving door and I'm like - you're not seeing your part in the revolving door... again it's like, seeing with blinders, so, you feel defeated, and again, and again. And it's like, because they just, they put it all on the individual."

A final unit of meaning reported by one participant in relation to this theme was tendency for health professionals to focus on mental health issues and attribute physical health to mental

health even when the two were unrelated. This participant expressed their frustration with this by saying,

"If you come with any kind of physical illness they look 'oh well you have mental health issues maybe it's this.' It's like well on, maybe there's something physically wrong with me that has nothing to do with one another. So when I see certain professionals I don't want to bring up the mental health piece because it has nothing to do with that, and they kind of hyper focus on that."

To conclude this section on public stigma, it should be stated that while all participants experienced the stigma of suicide as a prominent negative stigma, there was acknowledgement from most participants that it was not all negative. Some participants recalled positive experiences with the healthcare system where they had been treated with respect and dignity, or where they had been shown compassion and kindness from a stranger. One participant referenced these positive experiences as being the difference between life and death for them.

### **Research Question 2: How is Suicide Stigma Subjectively Experienced?**

While the previous research question explored how individuals who have struggled with suicide have been outwardly judged and mistreated due to stigma, this section looks at how these individuals attribute personal, subjective meaning to these outward experiences, and how they are affected by the stigma. In general, participants spoke less about the internal stigma than they did about the public stigma they experienced. Themes extracted from participant interviews include: (a) the experience of stigma as reinforcing their negative feelings about themselves, (b) the effect stigma has of repressing sharing and help-seeking, (c) the struggle participants experienced with managing stigma, and (d) the role of advocacy work in fighting internal stigma.



**Stigma as reinforcing negative beliefs about the self.** When asked about how others' judgements may affect how participants view themselves, some spoke about how the judgements of others often reflected the ways they already felt about themselves. One participant stated that "Nobody had to put me down, I was already putting myself down," and further commented that the stigma "reinforces it, the negative we already see in ourselves, and it helps perpetuate it." Another participant felt that they judged themselves harshly based on others' judgements, causing them to "never feel good enough". Within this theme is also the idea that the stigma heightens the stress and anxiety an individual may have when they have experienced suicide. One participant experienced this as a paranoia that everyone knew that they were suicidal and were judging them, as well as an inflation of how bad the stigma really was in this person's mind. These participants had slightly different experiences, but all held the perspective that the stigma contributed to their mental health struggles and perpetuated their own negative self-talk.

**Stigma prevents sharing and help-seeking.** Participants expressed a wariness to share their experiences with others due to a fear of being stigmatized, and an unlikeliness to seek help due to the stigma they felt when they had sought help in the past. Most related back to the public stigma they felt from the mental health system, and said this deterred them from seeking help. Multiple participants shared feelings of enhanced anxiety from worrying about what others may think if they are open, such as,

"I start to worry about, well, if I'm open about it, what do people think....I don't even think it gets to the point where I'm actually worried about what they're thinking.... it's just what am I thinking they're thinking."

Beyond help-seeking, the stigma also silenced individuals who were trying to find their voice or be a mental health advocate. These participants shared that because advocating involves being open about one's experiences, taking on this role means facing increased stigma. One participant spoke of this as a punishment for taking on the role of an advocate: "you're living it live and you're trying to go through and advocate, and uhm, bring out the gaps and the cracks in the system, but you're taking the punishment back, holy cow".

**Managing and resisting the stigma.** This theme encompasses how participants felt about attempting to manage the stigma they experienced, as well as methods they used to do so. Although all participants said that they did not believe the judgements of others about themselves, most expressed that these judgements still had the power to affect them. Some shared shame or embarrassment such as:

"I know 100% the quality of person that I am. So it's infuriating to know that I feel ashamed. Like, I don't want to share what happened to me and, and who treated me whatever way they treated me because it's embarrassing. It's ridiculous. It's even more ridiculous and even more embarrassing that I'm letting them control my life by accepting the labels that they're placing on me as being pertinently real. Because they're not. They're rubbish."

Others acknowledged that they should not let the labels affect them, but struggled to not be bothered or upset by the stigma. One individual is quoted as saying,

"It hurts that I can hear them making comments about me behind my back, and then I'm not supposed to freak out, or I'm not supposed to let what they say bother me. And it bothers me a lot..... I know I shouldn't be upset (about) how society treats me, I shouldn't be upset about how society labels me. But they do, every single day..... I have to remind

myself that, that my life does matter. That I am a person. And, that I don't deserve to be judged just because I have mental health issues, just because I've experienced suicide for myself."

For this individual, the act of a self-reminder that they matter is one way to combat stigma. Others reflected on their own thoughts and beliefs, interpreting their own inner dialogue, and assessing where their beliefs came from. Some found comfort from the stigma in knowing they were not alone in their struggles to connect with other individuals who had similar experiences in group therapy or anonymous internet forums. One participant said that learning about world leaders or famous individuals who had struggled helped them to reject suicide stigma. Another paid tribute to crisis lines for helping to ground them when they were overwhelmed with negative judgements from others. Some participants chose avoidance of the stigma through isolation; one said "that's why I don't like to be out in society that much. It's like, every time I'm out there it's like I'm judged by just being me and it's not fair, because it hurts". The commonality between the various methods used by participants to cope with the stigma is that they all have a need to manage or the public stigma they face, and they all were trying to minimize the effect that stigma has on them.

**Advocacy.** As expressed in the last theme, all participants found ways to manage the stigma and to fight it, but all also expressed that it took a long time to get to the point that they were able to do this. Up to this point, I have only briefly mentioned references participants made to advocacy work in the system. Participants stated that being an advocate increased the public stigma that they face, but inversely taking on this role seems to also have a pivotal role in their ability to fight the internal stigma. When discussing their advocacy work and involvement in local suicide prevention movements, a participant stated "I just find that if I'm able to do more

out in the community, keep involved with my community, then I feel better inside". Another said,

"I've gotten to a point where, like I said I've been able to use my own experiences, mental health issues and suicide, and turned it around to make it empowering, and to give me a passion and a purpose. I think before....I perceived mental health and suicide as just miserable and it was a horrible part of my life and I was a horrible person because of it. Then when you have that shift or, 'oh I can use this to help other people' then it starts getting more into the positive labels."

In total, five participants mentioned their role as either an advocate for mental health or their work in the mental health system. Three of these participants expressed that being able to take on these roles was extremely positive for them, referencing their advocacy work as a motivation for them to live or a part of their recovery.

### **Research Question 3: What Do Individuals who Experience Suicide Stigma Feel They Need From the Larger Community and its Members to Reduce Stigma?**

Within the interview process, participants gave examples of positive experiences they had where they didn't feel stigmatized or when they felt valued and dignified because of the treatment they had received, whether it was from a professional or a stranger. Participants also had many suggestions on how to reduce stigma, including: (a) public education and awareness, (b) the power of small acts of kindness, (c) successful interpersonal relationships, and (d) mental health accommodations.

**Public education and awareness.** The need for education and awareness of mental health issues within the general public was the most prominent theme in the data that pertained to

this research question. All seven participants discussed this theme, and the sentiment most widely expressed was a need to share the lived experience perspective with the public to achieve a greater understanding of what it is really like to experience suicide and to dispel some of the misconceptions and judgements related to it. Some suggested ways in which we could achieve this sharing of lived experience, such as removing the focus on celebrities with mental health issues, and covering real stories of real people in our community with lived experienced. Others suggested that we need to make the experiences of stigma and mistreatment that participants shared more public to ensure the severity of the stigma and its impacts is understood in society. Some participants focused on the faults of current campaigns, specifically four participants mentioned dissatisfaction with the Bell “Let's Talk” campaign, with reasons such as one day of awareness not being enough, or the campaign being too focused on getting people to talk without providing them with proper avenues to be able to do so. As for public education, two participants saw a necessity to begin educating about mental health at a young age to prevent stigma from forming within youth. They also believed it would be beneficial for youth to already be educated about mental health issues before experiencing them so that they could be better prepared if they encountered them later in life. Specifically these participants thought that mental health education should be in the school system,

"I think people can walk around on eggshells sometimes out of fear but it's because they just don't know. People aren't educated in this stuff. To me that's, let's get it in the schools. Let's make it a talk of, 'hey, how's your day' normal conversations about how to support people, whether it be around suicide or to support people in general."

A last suggestion for public education given by two participants is the need to educate individuals on how to properly support someone who is struggling, as well as providing

educational resources that are easily available for families of an individual experiencing suicide. Participants suggested that such education would reduce the stigma that is perpetuated when an individual who doesn't know how to help passes a struggling individual off to the system.

**Small acts of kindness can make a big difference.** At least half of participants indicated that little acts of compassion or kindness to an individual suffering could be the difference between life and death. These participants emphasized that a small act can make a difference, that it takes little effort to have an impact on someone's life, and that all it takes is making an authentic connection. One participant spoke at length about this perspective, stating,

"The best thing that you could do right now is acknowledge that it sucks to have thoughts of suicide. And what's one little thing I can do that's going to make a difference for you? .....

We gotta start meeting real needs, in real little steps, because those are the real big steps that are going to make a difference.....People jump in to cars to pull people burning out. Where's that response to seeing a person struggling with suicide? If they're not on the precipice so to speak. How do we bring that to the forefront so that people are making individual differences as they go along on their individual paths throughout the course of the day? .....

There is something that everybody can do to help everybody along their way. And it's simple. It's one word. Kindness. It's free. It's in every single one of us to give. There's no room for all these ridiculous comments that come out of people's mouths."

Others spoke about the importance of validating statements about one's suffering from others, while another spoke of the need to truly listen with an open mind that is judgement-free when someone expresses their pain. One individual went even further and stated that individuals have

to show their compassion by standing up against the stigma with those who struggle, implying that "if you don't speak out, then you're perpetuating the stigma."

**Interpersonal relationships.** To answer the question of what they need from communities to reduce stigma, two participants focused on the successful interpersonal relationships they have that have been a support for them, while others alluded to this theme in their suggestions about compassion and kindness. Specifically, the two individuals who described their experiences with positive interpersonal relationships spoke about the necessity of effective mutual communication to ensure an understanding without stigma, and a mutual support resulting in a reciprocal relationship that does not make the individual experiencing suicide feel that they are a burden. Through effective communication and reciprocity in support in their relationships, these participants reported feeling understood and less stigmatized. One participant explained the relationship they had with their family as,

"Everybody is supporting everyone. It's not just 'oh we're supporting you because you have this issue'. It's, well, 'we're supporting you because you have that, but we're going to support you in this and in this way'. Not just, 'oh we have to watch you so that you don't try to hurt yourself or kill yourself or anything.'"

**Accommodation for mental health in daily life.** This theme was less prominent within the interviews, but encompassed two different perspectives held by participants. The first is the comparison of mental health to physical health, and the imperative in society to accommodate physical disabilities without a consideration for the invisible mental health issues that can also cause significant barriers to daily functioning. The types of accommodation asked for include consideration of previous traumas and a willingness to accommodate someone who may

experience panic or anxiety in a situation that wouldn't produce those feelings in everyone, and who may be stigmatized for outwardly experiencing that panic or anxiety. A concrete example of this is one participant who shared a story about being unable to exit a stopped bus since the driver had locked the door when he had gotten off. This individual had previous trauma related to being on a bus that contributed to their suicidality, and experienced panic in this situation. They recalled that they were stigmatized because of their panic instead of accommodated to relieve the panic. They mused that their mental condition was not accommodated in the same way a physical one would be, remarking "if I was a person (who) fell off my wheelchair what would they have done? Help me back on my wheelchair, got me on the bus. They have to."

Two participants spoke about the need for accommodation in the workplace. One mentioned the lack of understanding workplaces and colleagues can have when a day off is required for a reason that is not related to physical health. One other shared their experience as follows,

"In some jobs I've felt not supported and in other jobs I've just been overwhelmed with the amount of, like, how much they're going to try to accommodate and, and even to the point where, you know all I'm asking for is, you know, an inch and they're, they're like kind of forcing, you know, a mile on me kinda thing."

Their experience led them to reflect that policies and procedures for mental health accommodation should be standard in workplaces, so that there was consistency and a balance between receiving the necessary accommodation without receiving excess.



#### **Research Question 4: What do Individuals who Experience Suicide Feel They Need from Service Providers and Mental Health Organizations?**

After many participants shared their experiences of stigma and mistreatment within the healthcare system, they were willing to express their perspectives on how the system needs to change. Themes that will be discussed here include: (a) transforming the mental health system, (b) greater access to available resources, (c) the role of the peer worker, and (d) the impact of the Skills for Safer Living program.

**Transforming the mental health system.** When asked about how organizations and service providers could provide better mental health care, all participants alluded to a transformation of the system that they felt was necessary. One participant voiced their call for this shift in the following statement:

"The hospitals are not equipped to deal with mental health issues, they are equipped to deal with physical health issues that you can see and you can treat.....Like, I've heard of people who have gone to hospital because they've been feeling suicidal and they've been told to leave because there's nothing they can do for them.....so I think there needs to be, I don't know what it would look like but I think there needs to be a shift in how we deal with mental health in the hospitals and things here. From the moment the person walks in to the moment they leave, the whole thing needs to be re-configured."

One recommendation that was expressed by participants for service providers is the need to teach concrete skills and tools around coping to help an individual struggling with suicide to manage their struggle and feel less stigmatized in the process. Participants stated that the lack of follow-up care and the focus on medication and treatment perpetuated stigma and was not

helpful for their recovery journey. Another perspective participants shared is that the approach to mental health needs to be less medicalized, and should focus on the needs of the individual not the label or diagnosis. The imperative for these changes in the system was expressed by one participant in the following statement:

"I think there needs to be an understanding piece because for that person to go to hospital and to reach out for help is probably one of the most courageous and amazing things that they could do. And then to be told like, to go home and not be taken seriously is very invalidating it's, you know, so they're not going to reach out for help when they need to. So there needs to be more resources available for people who are struggling and at that point that they need help and to, to not be treated with disrespect."

Feelings about police and hospitals were negative from all participants. The police system was targeted as another way to change the system by better educating police about how to properly help an individual in crisis rather than perpetuating stigma. The role of crisis lines as a support drew contrasting opinions. One individual stated that crisis lines need to change to provide links to useful resources, while another individual said that crisis lines could fulfil the purpose of crisis relief by grounding in the moment.

**Access to resources.** A perspective outwardly endorsed by three research participants was the need for greater access to resources. One individual in particular shared a unique experience of inability to access resources such as crisis lines due to the lack of payphones within Waterloo Region. This individual conceptualized this as a significant problem with the model of referring individuals to resources without providing them with access to these

resources. Specifically, this participant saw an issue with the influx of promotion around crisis lines, stating,

"If the resources are there but you can't access the resources then nobody's going to get help. I can't even give people this card and say call because there's no place to call from. And when I do outreach in the community I try to get people the services they need or point them to the right direction. But if they can't make the phone call because there is no payphone then no one is going to get the help."

Other participants mentioned a lack of awareness about resources as a barrier to access, and suggested that any awareness campaign for suicide prevention should always include information about resources in the community.

**The role of a peer worker.** As mentioned earlier, participants referenced advocacy and peer work as something that helped them in their recovery process, but some expressed a struggle when taking on this role due to the stigma that accompanies being open about experiences with suicide. One expressed this hardship as a difficulty in defining their role when they worked in a system that they still used, and one expressed the scrutiny that they undergo as a peer worker where their qualifications or abilities to work in the mental health field as someone with lived experience are questioned. It is interesting to note that although these difficulties were noticed by participants, they still considered their advocacy work or work in the mental health system to be something that has helped them to stay alive and to value their own strengths. All participants that spoke about peer work held the opinion that peer support is a vital resource that should be included in mental health systems. No participants had specific suggestions on how

this could be done, but all agreed that peer workers need proper support in an organization to assure they are providing the best care that they can.

**Skills for Safer Living program.** This program was briefly introduced earlier, but to re-iterate, Skills for Safer Living (SFSL) is a program for individuals who have had multiple suicide attempts. The program always operates with at least one peer facilitator (a program facilitator who has experience with suicidality). The program teaches concrete skills in different areas meant to increase the participants' ability to live safely and to cope with their suicidality. All research informants felt that SFSL had a positive in their recovery process and in their management of stigma. Some participants had some contrasting views that while the program helped them manage internal stigma, it increased their awareness of the existence of the public stigma through the stories of others. Most prominent was the experience that being able to talk openly with others who shared similar experiences had a profound impact in reducing the stigma the participants felt about themselves. Others expressed that they valued the skills and tools they learned in the program most, and used them to overcome their belief in the public stigmas. One tool taught in the SFSL program is NMI that stands for Not My Issue and represents a re-framing individuals should take to decrease the weight they bear from the issues of others. One participant in this research used this term in the interview, stating that after the program, stigma now "goes in the NMI pile" for them. One participant also expressed that simply the fact that the program exists and is publicly promoted has a positive effect on reducing societal stigma. Overall, participants felt that more programs similar to this one should be available, and that programs such as this would benefit all individuals not just those struggling with suicide.

**Additional Theme: Contrasting Role of Religion**

While religion was only mentioned by two participants, it was the only theme in which there was a very strong contrast in experiences between different participants. Since phenomenology aims to describe not only the similar but also the unique perspectives held by participants about a common phenomenon, this contrast deserves mention. One participant held a strong distaste for religion, stating that religion held a strong disapproval of their struggle with suicide and highly stigmatized them as being not normal. This person had experienced a rejection from the church and an exclusion from attending services or participating in the church that their family ran. In direct contrast to this, another participant referenced no direct experiences with religion or the church but often referenced God in the interview, making statements about how no one but God could judge them. This individual believed that God had a purpose for them and wanted them alive. Therefore this person was motivated to overcome the stigma of others and their own suicidality. This strong clash between one participant experiencing religion as a perpetrator of stigma and one participant experiencing faith as a support in overcoming stigma illustrates two unique experiences.

**Discussion**

In this section, I review each research objective and interpret the main themes that were prominent in the interview by relating it back to relevant literature. I will then speak to my knowledge transfer strategies, the research limitations, and suggestions for future research. Finally, I will conclude this thesis by tying the results and the discussion back to suicide prevention.

### **Research Objective 1: To Describe the Experience of Suicide Stigma as a Social Phenomenon (Public Stigma) from a Lived Experience Perspective**

After describing the results from this section and giving voice to the perspective of those who have experienced suicide stigma, it is very clear that suicide stigma does indeed exist. Within the five components of stigma that Link and Phelan (2001) describe, participants spoke most about stereotyping in accordance with dominant social beliefs. This was evident in the narratives of multiple participants who described being told they did not present as a suicidal person. The dominant beliefs about a person struggling with suicide, according to the perspectives of participants, seems to be that they are weak, selfish, dirty, poor, and not smart. Status loss and unequal outcomes is another main component of stigma described by Link and Phelan (2001) and was reflected in participants' accounts of differing treatment by professionals due to their status as a "psych patient".

In one of the initial studies investigating suicide stigma the three most common attributes ascribed to someone struggling with are "weak", "selfish", and "reckless" (Batterham, Calear, & Christensen, 2013). Being referred to as "weak" and "selfish" were two of the most commonly referenced terms recounted by participants. The matching results here show that suicide stigma occurs in more than one culture since the original study was done in Australia and the current study was within Canada. I pointed out earlier that the scale these researchers developed to measure stigma from the perspective of those who stigmatize could never describe the experience of being stigmatized. Although the main descriptors were the same in each study, the current study was able to provide a rich description of how that stigma resulted in prejudice, mistreatment, and discrimination. I believe the description of this stigma from the lived experience perspective adds a valuable contribution to literature on stigma by filling the gap left

by only investigating stigma from the perspective of perpetrators. The experiences of this phenomenon from those who have lived it humanizes the experience and may make it more real than hearing only from perpetrators of stigma.

I have theorized earlier that the definition of suicide as an individual problem may be related to the stigma surrounding suicide, and these results seem to reinforce this belief. Participants spoke about being stigmatized, by the public and by the health care system, because of their label. The narratives of participants showed that people tend to assume there is something wrong with people who struggle with suicide (seen in the “snap out of it” perspective and misconceptions about mental health). Participants spoke about being blamed by health care professionals for their suicidality, and as one participant stated, the system does not see their part. This creates and perpetuates the stigma that was richly described by participants in this phenomenological study.

### **Research Objective 2: To Understand the Subjective, Personal Experience of Suicide Sigma (Self Stigma) from a Lived Experience Perspective**

The discussion of this research question is broken up into two sections: one on the impacts of stigma, and one on the management of stigma. Although participants spoke less about self stigma than they did about public stigma, the information on self stigma may be more novel and require greater interpretation before it may be applied.

**Impacts of stigma.** I would like to return to modified labelling theory (Link, Cullen, Struening, & Shrout, 1989) to frame the process of stigma and how it is subjectively experienced. This theory claims that once an individual becomes labeled due to a role they hold within society, they respond to the label in some way, and they experience negative

consequences that confine them to their label. Some of the responses to suicide stigma that participants gave include secrecy, withdrawal from society, and an unlikeliness to seek help. This reduction in help-seeking behaviour has been found by other researchers regarding mental health stigma (Thornicroft, 2008). I would further extrapolate from the narratives of participants in this research that the reduction in help-seeking could also be due to the fact that they experienced the most stigma in the health care system or in systems where they sought help.

Corrigan and Kleinlein (2005) suggest that some of the negative consequences of experiencing stigma could be self-stigma, or lowered self-efficacy or self-esteem. Since these feelings are core aspects implicated in leading to suicidal desires (Van Orden, Witte, Gordon, Bender, & Joiner Jr., 2008), it makes sense that participants did not speak of having these negative effects as a result of the stigma. Participants did speak about having negative self-talk, and did express that the stigma made it much worse for them, but they expressed that the negative self-talk was present before the stigma and was reinforced instead of introduced by the stigma. These impacts of stigma that participants expressed during the interviews support my idea of the cycle of suicide stigma. To return to this idea I have suggested, with support of prominent research (e.g., Link et al., 1989; Link & Phelan, 2001; Van Orden et al., 2008), that there is a cycle in which stigma reinforces feelings of isolation or negative self-talk, which increases suicidal desires, and these suicidal desires drive the stigma towards this person. Participants' interpretation of suicide supported this; stigma reinforced negative feelings about themselves, negative feelings increased their suicidality, and they were stigmatized because of this suicidality. Participants all spoke about ways they had found to stop the stigma from influencing their thoughts about themselves, or to halt this cycle by managing the internal stigma.



**Stigma management and resistance.** Participants spent a significantly longer part of the interviews speaking about their fight against the stigma than they did about the internalization of the stigma. After hearing the meanings participants attribute to their experiences, it has become clear to me that in a society where stigma is so prominent, this ability to manage and/or resist stigma is essential. I believe that the ability to manage stigma by dismissing the beliefs of others as being true may be necessary for the survival of an individual struggling with suicide. Within this stigma management, all participants spoke about reaching a point where they were able to dismiss the stigma and recognize their own strengths. This was seen as a pivotal revolution for each participant, which some attributed to finding their voice (their ability to express themselves and take control of their own life and recovery) or to finding a way to use their experiences to help others.

While no participant explicitly used the phrase “turning point”, this shift in perspective participants spoke about experiencing from believing the stigma to fighting it and acknowledging their resiliency seems like it may have acted as a turning point for individuals in their battle between dying and living. That being said, I asked participants who spoke about this transformation to explain what caused it, and they could not pinpoint any exact point or moment that caused the transformation. Instead, participants expressed that this recovery from self-stigma or metaphorical turning point was a long journey of self-discovery. A qualitative study completed on the suicide prevention group from which SFSL emerged showed similar experiences of this turning point being understood as gradual and continuous (Bergmans, Langley, Links, & Lavery, 2009). This phenomenon of recovery has been sparsely investigated with regards to suicide. Participants in the current research spoke about misconceptions around recovery, stating that it was a life-long process for them and not a finite concept as they had

heard others refer to it as. This notion of recovery is now a common one in community mental health literature, with some researchers theorizing recovery as a process that involves an exploration of the self to uncover hope and personal revelations (Kogstad, Ekeland, & Hummelvoll, 2011).

To conclude this section on self stigma, I would like to reiterate that the impacts of the stigma and the effort required to manage stigma both make the experience of suicidality more difficult and add to the struggles of someone already struggling with suicide. Patricia Deegan, PhD, an individual who herself has lived experience of mental health issues, explained this quite well when she claimed that "one must recover not only from mental illness, but also from internalized stigma, low expectations and dehumanizing clinical practices" (Deegan, 1997, p. 11).

### **Research Objective 3: To Examine What Those With Lived Experience Believe Needs to Change to Reduce Stigma**

This research objective encompasses research question 3 and research question 4, what individuals believe they need from their personal communities and when they need from the larger system respectively. I feel that the themes from each of these sections can be combined and deduced to two sections for discussion: (a) greater education (for the public and for service providers), and (b) a paradigm shift in the mental health system.

**Education and awareness.** Participants spoke about needing certain accommodations, about the impact of small acts of kindness, and about navigating personal relationships as well as speaking about education when asked how communities can better support them. Education seems to be a grander theme that may be the solution for the other three needs expressed here.

By translating this knowledge of needs and of what supports help, the stigma around suicide and misconceptions about needs may be reduced. Awareness was one priority within the strategic direction of *Promotion and Prevention within the Mental Health Strategy for Canada: Changing Directions, Changing Lives* (Mental Health Commission of Canada, 2012). Many of the strategic directions and priorities within this strategy are in line with what research informants recommended in this research, such as improving access to services, increasing capacities to reduce stigma, and peer support. Unfortunately since this report was released three years prior to this research study, I feel that the repetition of these needs after the country promised to address them three years ago shows a lack of progress. Admittedly, these tasks could not feasibly be completed fully within this time frame so I am still hopeful that the strategy seems to be heading in the right direction.

Other education and awareness campaigns come from communities that have been affected by suicide directly, such as one community in Philadelphia that lost a string of local firefighters to suicide and took action. The community came together and designed a community art project meant to reduce suicide stigma by spreading awareness, which included educational workshops. The mural that came out of this project was collaboratively designed by community members, and became known as *Finding the Light Within* (Mohatt, Singer, Evans, Matlin, Golden, Harris, Burns, Siciliano, Kiernan, Pelleritti, & Tebes, 2013). This awareness movement came out of tragedy and was controlled by the community and those affected, which led to much more immediate results for that community than the Canadian government's mental health strategy. Perhaps community-driven projects such as this will be more effective overall in raising awareness to shift public perception and reduce stigma. Participants in the current study seemed to allude to this same conclusion when they shared feelings expressing the value of lived

experience. This was illustrated through their narratives of the usefulness of peer workers and self-help groups, and their belief that they were the expert on their own treatment needs. The clear disapproval of all participants of Bell “Let's Talk” day also shows that larger initiatives to create awareness may not be doing it in the right way, reinforcing my belief that those with lived experience should drive the awareness and education of the rest of the community. One other opinion shared by perspectives that reinforces this notion was their belief that exposure to those who have attempted suicide is the best way to reduce the stigma. This perspective of participants is one that literature has also proven; recently, a study on an anti-stigma initiative that was part of the Canadian strategy for mental health showed that personal testimonies from individuals experiencing mental health issues had the most impact on decreasing the stigma of mental health (Kopp, Knaak, & Patten, 2013).

**Paradigm shift in mental healthcare.** The idea of a paradigm shift involves changing many well-established systems, and may be more difficult to achieve than raising awareness and increasing literacy. That being said, there are some researchers who have previously made claims that this paradigm shift is possible, and Nelson, Kloos, and Ornelas (2014) speak at length about this transformative change. While reviewing strategies and recommendations for this transformative change is well beyond the scope of this paper, it is noteworthy to explain this perspective and how it may be a solution for the recommendations given by participants in this research. Participants called for a less medicalized system where they will not be defined by labels, where they can have a say in their recovery instead of being told that the professional knows best, where they can learn concrete skills, and where they can use and become peer workers. Their perspectives seemed to be aligned with the emerging and critical field of Mad Studies, since participants held the antipsychiatry belief and the value of consumer-driven

knowledge that are central within Mad Studies. Nelson, Kloos, and Ornelas (2014) state that community mental health must shift towards a stronger inclusion of lived experience perspectives. Further, they call for transformative change to the system that looks to reduce the power hierarchy between professional and consumer. This perspective seems to mirror that of the participants that I have interviewed. This perspective is also shared by other researchers, and is referred to by Deegan as personal medicine. Deegan defines personal medicine as the methods devised by consumers to advance their recovery, and states that clinicians must start to value this insider knowledge from those with lived experience (Deegan, 2005). All research participants called for some sort of shift in the system, and many called for their own personal expertise to be valued by professionals in their treatment. Although I do share the perspective of one participant who stated that I do not know what this change would ultimately look like, I do feel that it is necessary, and that the movement must be led by those with lived experience.

### **Knowledge Transfer**

I have framed this research as an exploratory, generative research study with the aim of shifting the dominant discourse about suicide, suicide stigma, and suicide prevention within the domain of research as well as within mental health services and the general public. Since my research is taking on this orientation to action and is interested in raising dialogue within varying ecological levels, knowledge transfer strategies are an essential extension of this research. It has been indicated by multiple researchers that the gap between research and application is large and results in outdated care that is not up-to-date with the ever-growing knowledge base (Graham, Logan, Harrison, Straus, Tetroe, Caswell, & Robinson, 2006; Landry, Amara, Pablos-Mendes, Shademani, & Gold, 2006). To close this gap, there has been an increased research interest in specific knowledge transfer or knowledge mobilization strategies for researchers to follow

through with an application of their research. Landry et al. (2006) describe knowledge transfer as successions of transformations from reality to data then to information and finally to knowledge that can be mobilized. The transformation from reality to data was completed during the research that captured the phenomenon of suicide stigma from a lived experience perspective.

Transforming this into information involves creating messages and the sharing of the data through reports. From information, the translation to knowledge involves actions derived from an interpretation of the given information (Landry et al., 2006). I would like my research to both influence change within public perspectives of suicide and have an application in mental health and the healthcare system. As such, I have conceptualized two types of knowledge dissemination that will be important conclusions to this research: (a) education and literacy (transforming the data to information), and (b) practical recommendations (transforming the information into knowledge).

**Education and literacy.** One purpose of this research is to shift public perspectives about suicide to reduce the stigma. Since this research was conducted on a sparsely investigated topic in a novel way for the field, I am hoping the research can be disseminated in a way that increases the education or literacy around the topic. Raising awareness of the lived experience of the phenomenon and including the voices of people who have experienced suicide, alongside the well known research and prevalence rates of this issue, may increase the literacy and bring a more human, empathic view of suicide into the dominant culture. Such knowledge transfer could decrease suicide stigma. To achieve this knowledge transfer goal, I plan to create brochures and/or flyers that are descriptively rich and may achieve a greater societal understanding of the phenomena. I will also use my networks within the Canadian Mental Health Association and the Suicide Prevention Councils within Waterloo, Kitchener, and Cambridge to host public forums

or open discussions about the findings within my research and the application of these findings within the community. Following the recommendations of participants in my research, I will bring the lived experience perspective in to public knowledge to increase the understanding of suicide, I will raise an awareness of the stigma and its impact, I will advocate for the imperative role of small acts of compassion in making a large difference, and I will explore avenues for publicizing suicidality and the real individuals who experience it. Further, my research could assist in increasing the academic knowledge of suicide by informing future research efforts and re-assessing previous works of research that have not been informed by the lived experience perspective.

**Recommendations.** A second knowledge transfer strategy I would like to carry out is to bring the recommendations of changes in the mental health systems to the stakeholders who may be able to implement the changes participants advocated for. I would be interested in creating two sets of recommendations: first, a set of guidelines for service providers, front-line workers, and mental health organizations on how to break the stigma of suicide, and second, a guide to creating more inclusive and accepting communities that diminishes suicide stigma. Based on the research findings, I believe the most important role of this research may be to provide recommendations to service providers on how to diminish mistreatment of patients with mental health issues by increasing the education of these mental health workers on the lived experience of suicide and making them aware of the actions they may take that stigmatize individuals. I would like to share the stories of mistreatment of the participants in this research with mental health workers and suggest compassion and empathy as a replacement for judgement of the phenomenon of suicide that many health professionals do not understand. Additionally, I would like to prepare follow-up treatment plans for mental health professionals to implement with

individuals who come to hospital in crisis that will better prepare the individuals to manage their crisis and re-direct them to more appropriate sources of support when they do reach crisis. Along with promoting resources, this research process has also brought up the importance of increasing availability of and access to resources. My part in this may be to create resources such as informational and educational resources for individuals who struggle and those who support them, and to advocate for equal access to resources such as calling for an increase in the number of payphones for individuals to reach crisis services.

I would also like to advocate for a paradigm shift in the mental health system within my recommendations. It seems that the current use of emergency rooms and hospitals as a crisis centre for mental health only creates a revolving door, and a more effective model would be to implement stronger prevention initiatives to decrease the usage of these services by individuals experiencing suicidality. I will recommend to health care professionals and to policy-makers that prevention programs and health promotion initiatives as well as follow-up treatment after crisis become more strongly implemented to decrease emergency room and crisis centre use. The recommendations I provide to health care providers on how to support individuals with suicidality and remove the stigma they perpetuate will also help to reduce the revolving door of the emergency services. I acknowledge the lofty task I have embarked upon and realize that I, myself, will not be able to create this change. The paradigm shift I am calling for will require collaboration with system-change theorists and involvement from all stakeholders in the mental health system. My aim in the recommendations and guidelines I would like to create is to fuel the movement already occurring towards this shift, to hopefully speed it up.



## Research Limitations and Reflections

**Reflections on being an insider.** One thing to keep in mind about my interpretations of the data is the fact that I am an "insider" to the phenomena of suicidality and suicide stigma. I could also be considered an outsider to my specific sample since I have not gone through the program from which I sampled participants. That being said I do know the program and the content very well through studying the manual and conducting research on this program. Breen (2007) discusses the issues of being an insider, such as embracing an illusion of sameness and making erroneous assumptions. In my data collection and analysis process I paid strong ethical consideration to the harm that could be produced from these insider biases, such as participants feeling their voices were not properly heard or communicated or that their interpretations were not given proper consideration in the analysis of finding. In my knowledge translation I would like to be the megaphone through which these voices can be heard, and by using LeVasseur's (2003) modified framework for bracketing within phenomenology in the research process I hope I have achieved this.

It would be an ethical violation to let my insider role place myself in a situation of greater power or importance than research participants by letting my voice speak louder than theirs in the research findings. Due to this, I placed a large emphasis on trustworthiness of the data by constantly referring back to the audio-recordings and transcriptions throughout the research process and ensuring that I retained the voice of the participants in my research. One reflection I have completed after the data analysis has been a consideration of how I may have influenced the data. From reading the interviews, I have noticed that I only expressed my own opinions once a research participant had first expressed that they held the same view. One problem I faced was resisting my instinct to converse with the participants that would have focused the interviews too

much on my own opinions. Although I do not believe I influenced the opinions of any of my research participants, I do feel as though my engagement in conversation with participants around certain themes may have focused the research more on these themes than others.

**Influence of the Skills for Safer Living Context.** I introduced Skills for Safer Living (SFSL) earlier as being a peer-led initiative, housed within the Self Help Alliance in Kitchener, ON. The values and beliefs of this organization influence the structure and content of the SFSL program. The belief of this organization in the recovery model and of self-help as a necessary tool on this path of recovery may have influenced the way in which participants interpreted their experiences. Participants felt strongly that efforts to reduce stigma and improve mental health should be peer led. This belief is a core one in the Self Help Alliance, and this context have shaped or strengthened the belief in this model by participants who successfully completed the SFSL program. The SFSL program content encourages introspection and the analysis of the root cause of thoughts, which may explain why participants in this study were capable of such deep interpretations of their experiences. A sample taken from a suicide prevention program with different core beliefs may not have yielded the same results, specifically with regards to the recommendations participants had. It would be interesting to conduct similar research with a different sample and compare the dominant beliefs between the groups with differing contexts.

**Limitations.** A limitation of the current research is inherent to the nature of phenomenological research itself, and of qualitative research in general. Phenomenology provides a rich description of a phenomenon from a small, usually homogenous sample. While I viewed the investigative nature of this research as a strength since it was generating new knowledge to fill a gap within current literature, this focus on rich descriptions of a small number of perspectives means that the data cannot be representative of the perspectives of all individuals

who have struggled with suicide in the Region. As the strong contrast over the impact of religion in my data shows, two individuals experiencing the phenomenon of suicide stigma may interpret their experiences differently. My research covered a diverse range of experiences, but this diversity was limited by my sample since six of the seven participants were female, and all of the participants were Caucasian. Since this was a homogeneous sample with respect to race and ethnicity and no participants mentioned gender identities or sexual preferences, I cannot interpret whether experiencing stigma based on any of these phenomenon intersects with the stigma experienced from identifying as someone who struggles with suicide.

### **Future Research**

**Intersectionality.** Intersectionality refers to "analytic approaches that consider the meaning and consequences of multiple categories of social group membership" (Cole, 2009). In other words, intersectionality looks at the interactions between or additive effects of being a member in multiple social groups. Since this research did lack in a diverse perspective and did not explore the experience of individuals who held status within multiple stigmatized groups, investigating suicide stigma from an approach of intersectionality may be an interesting extension of this research. For example, individuals who identify with the LGBTQ population and individuals who hold status as an Aboriginal Canadian have higher suicide rates within society (Government of Canada, 2006), and are also marginalized populations. In a paper focusing on HIV and AIDS-related stigma, Parker and Aggleton (2003) hypothesized that stigma simultaneously grows out of and reproduces inequalities within society. Since my belief is that stigma contributes to suicide and reducing stigma would decrease suicide rates, I think it should be investigated whether the identification with multiple stigmatized groups is seen as being related to the increase in suicidality by individuals who hold status in these populations. It should

be explored how the phenomenon of suicide stigma may differ when one faces other stigmas as well.

**Larger sample size.** This research fulfilled its purpose as an initial exploratory study into the phenomenon of suicide stigma from a lived experience perspective. A next step in this exploration would be a larger study that could be seen as representative of the experiences of the entire population of individuals who struggle with suicidality. A caution I forewarn for a study of this fashion would be to ensure that the focus on being representative does not overshadow the experiences of the individuals. A multi-methods study (data triangulation) using both qualitative and quantitative data may be able to fulfil this role. To ensure a larger study does not lose sight of the lived experiences, I would recommend a consumer-driven research (research driven by the input and participation of individuals with lived experience) catered to incite action. The use of this participatory action research (PAR) or a more involved form of Community Based Participatory Research (CBPR) would allow for a larger study of this phenomenon that still values the lived experience perspectives. CBPR engages the community or the insiders of the phenomenon being investigated and allowed them to actively participate in research. It involves collaborations and co-learning between the researchers and those with lived experience (Lazarus, Bulbulia, & Taliep, 2015). The active participation of marginalized individuals in CBPR has been shown to reduce their feelings of being silenced and increase their self-esteem (Flicker, 2008). Participants in the current research called for this perspective to be more highly valued in the mental health field, and this call should extend to research in this field as well since the involvement of individuals who have experienced suicidality in suicide research may decrease their internalization of suicide stigma.

## Conclusion

The existence of suicide stigma is confirmed by the findings of this research that corroborate reports from quantitative studies on suicide stigma. The experience of this phenomenon has been described by those who have lived it as enhancing their suicidality and hindering their ability to talk about it or seek help. Clear recommendations have been generated by the voices of lived experience, and efforts will be made to translate these recommendations to action. Importantly, any stigma reduction strategies must involve the voices of those with lived experience. If these voices are listened to, we as a society may be able to begin to shift suicide prevention efforts away from the initiatives that target and indicate individuals as the sole cause and solution and perpetuate stigma. Acting as a means to amplify the voices of those who participated in this research, I call for stigma reduction efforts to become an integral part of all suicide prevention strategies, or at the very least a critical awareness of how suicide stigma may inadvertently be perpetuated and disadvantaging individuals struggling with suicide. Let us all come together, under the direction of the real professionals (those with lived experience), and start listening to their needs. Once we can stomp out the stigma and begin to do this, we will be able to collaboratively create more informed and more effective models of suicide prevention.

### **Afterword: Personal Reflections**

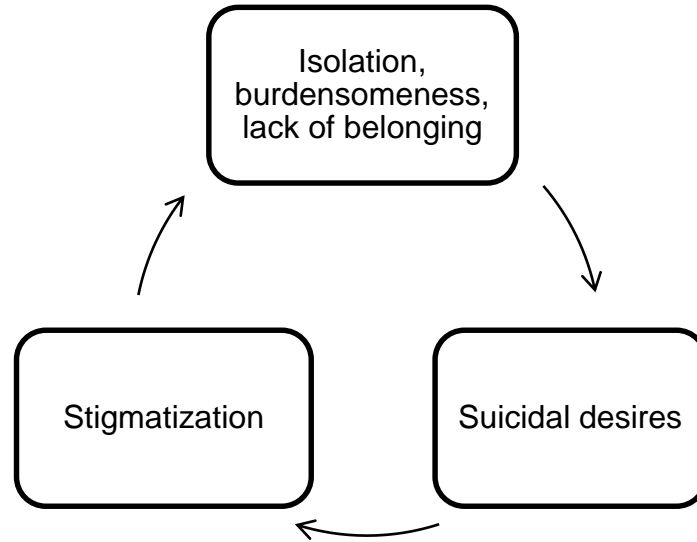
Due to the personal connection I have with this thesis topic and my research, I felt that this paper could not be complete without a reflection of how the research process has impacted me. First, I have to state that the research affected me in both positive and negative ways, often leaving me with what felt like emotional whiplash from quickly oscillating between feeling high and feeling low. This past year was very emotionally draining for me and caused a lot of strain on my personal mental health, while at times, heightening my suicide ideations. I identified very strongly with research participants who expressed their struggles with and barriers to advocating for mental health and suicide prevention. I was often disheartened by stories of mistreatments endured by participants and largely discouraged on my journey to change the system.

The identification I felt with participants also helped me to share not only their pain but also their own motivation towards change. Many of the participants I interviewed were very passionate about advocating for mental health and suicide prevention, and many already had their own avenues of doing so through political activism, peer work, or community involvement. Although hearing their struggles greatly affected me, bonding over a shared passion and collective goal had an even larger effect. After all of the ups and downs of completing this research, the largest impact the research had on me was an increased passion and heightened motivation. Just as participants stated that advocacy work to help others gave them a purpose, this research has solidified mine. Meeting those who participated in this research has renewed my passion for fighting the stigma and strengthening suicide prevention efforts. It has also left me with feelings of responsibility to the community in which I have entered in this research process.

My original goal after completing this work was to head to Alberta where I have always wanted to live and carry out my suicide prevention work there. This research has bestowed upon me a perceived duty to stay within the Kitchener-Waterloo community and follow through with my research while supporting the endeavours of those who I have met throughout this process. I now hope to follow every opportunity to translate and apply the insights from this research within the KW community, and ideally would like to become involved in a larger-scale, community-based study to continue on where my Master's work has left off.

## Appendices

### Appendix A: The Cycle of Suicide Stigma





**Appendix B: Research Objectives, Questions, and Rationale**

<b>Research objectives</b>	<b>Research Questions</b>	<b>Rationale</b>
1. Describe the experience of suicide stigma as a social phenomena (public stigma) from a lived experience perspective	1. How is suicide stigma publicly manifested, displayed, and experienced socially?	A qualitative understanding of these phenomena from a lived experience perspective is missing from literature. Research focuses on quantitative methods that collect data from those who do the stigmatizing.
2. Understand the subjective, personal experience of suicide stigma (self-stigma) from a lived experience perspective	2. How is suicide stigma subjectively experienced, and what impact does it have?	
3. Examine what those with lived experience believe needs to change within communities to reduce stigma (action oriented, social change)	3. What do individuals who experience suicide stigma feel they need from the larger community and its members to reduce stigma?	These questions lend themselves directly to action – they may uncover some key information that can be translated to stakeholders to create social change with a transformative potential
	4. What do individuals who experience suicide stigma feel they need from service providers and mental health organizations?	

## Appendix C: Semi-Structured Interview Guide

Thank you for agreeing to participate in this project. The purpose of this project is to develop a deeper understanding of how we may be stigmatized, labelled, or judged because of our suicidal thoughts or behaviours, as well as how to reduce this stigma. I will be asking you about your experiences with stigma as someone who has struggled with suicide. The interview will be recorded in order to be transcribed later. After being transcribed, all personal information that could identify you will be removed. Feel free to ask me any questions at any point during the interview. We can also pause the recording if you would like to clarify anything off the record. We will let you know at the end of the interview when we have stopped recording. The interview should last no longer than 90 minutes. If you need a break at any point, just tell me and we will pause the recording.

I know that interviews can sometimes be stressful but this isn't meant to feel like that, There are no right or wrong answers; I want to hear about your own experiences and perspectives. I have some questions written down to get us going but we can talk about other things that come up as we go. If you need some time to think before you answer any questions feel free to take your time. Questions can be skipped if you feel answering them may be too emotional or triggering. You can also ask me if you would like a question repeated.

Before we start, do you have any questions?

*Wait for response, respond to questions asked*

I will now turn on the recorder.

[Turn on recorder]

### Public Stigma

**1. These first questions are about public stigma, or the way others think about those who have struggled with suicide. In your experience, how do people who haven't struggled with suicide perceive those of us who have?**

- a. What personality traits?
- b. Negative descriptive words?
- c. Positive descriptive words?

**2. Are there particular situations you have faced in which others have judged you because of your struggles? If yes, please describe the situations and how you felt judged.**

- d. what circumstances
- e. which people
- f. certain public settings?

**3. What are some of the things that people have said or done to you regarding your struggles that you have perceived as mistreatment?**

- g. exclusion?
- h. isolation?
- i. compensation or being overly sensitive?
- j. discrimination examples?

### Self Stigma

**4. The next questions are related to how you think about yourself. Sometimes other people's beliefs about us can change how we see ourselves. How have other people's thoughts about you influenced how you see yourself?**

- k. what do you believe
- l. what do you not believe
- m. negative thoughts?
- n. positive thoughts?

**5. How have other people's thoughts or actions affected what you believe you are able to do in your daily life?**

- o. competence?
- p. help-seeking?
- q. social ability?

**6. What personal qualities do you attribute to yourself when you think about your struggles?**

- r. strengths?
- s. weaknesses?

Now as I have mentioned, my interest in doing this project is to create change in the way society talks about and may stigmatize individuals who have struggled with suicidal thoughts or behaviours. The last few questions will be looking at your ideas on how that can be done and will hopefully end the interview on a positive note. Before we get into these, would you like me to turn the recorder off so that you can take a break?

*Wait for response, do as participant wants. Welcome them back if they do take a break then continue with questions*

**7. Thinking about your community or social networks in the community, how could people think or act differently towards you to minimize your experiences of judgement or mistreatment?**

- t. How can they assist you
- u. How could they be made to better understand your struggles

**8. What could be changed in larger structures, such as mental health organizations or other settings to reduce feelings of judgement and mistreatment?**

- v. Mental health organizations?
- w. Service providers?

- x. Current suicide prevention campaigns?
- y. Educational institutions?

**9. In what way do you think participating in the Skills for Safer Living program has shaped your experience of stigma?**

- z. less stigma?
- aa. more stigma?
- bb. self stigma?
- cc. public stigma?

This is the end of the questions I have prepared. Before I turn off the recorder, do you think there was anything important left out of our interview today?

*Wait for response, dialogue if they do bring something up*

I would like to thank you for sharing your experiences with me, especially on a topic that may have been emotional. This is the end of the interview so I will now turn off the recorder.

[turn off recorder]

**Appendix D: Connection between Research Goals, Objectives, and Interview Questions**

Research objectives	Research Questions	Interview guide questions
1. Describe the experience of suicide stigma as a social phenomena (public stigma) from a lived experience perspective	1. How is stigma publicly manifested, displayed, and experienced socially?	<p>1. These first questions are about public stigma, or the way others think about those who have struggled with suicide. In your experience, how do people who haven't struggled perceive those of us who have?</p> <p>2. Are there particular situations you have faced in which others have judged you because of your struggles? If yes, please describe the situations and how you felt judged.</p> <p>3. What are some of the things that people have said or done to you regarding your struggles that you have perceived as mistreatment?</p>
2. Understand the subjective, personal experience of suicide stigma (self-stigma) from a lived experience perspective	2. How is suicide stigma subjectively experienced, and what impact does it have?	<p>4. The next questions are related to how you think about yourself. Sometimes other people's beliefs about us can change how we see ourselves. How have other people's thoughts about you influenced how you see yourself?</p> <p>5. How have other people's thoughts or actions affected what you believe you are able to do in your daily life?</p> <p>6. What personal qualities do you attribute to yourself when you think about your struggles?</p>
3. Examine what those with lived experience believe needs to change within communities to reduce stigma (action oriented, social change)	3. What do individuals who experience suicide stigma feel they need from the larger community and its members to reduce stigma?	7. Thinking about your community or social networks in the community, how could people think or act differently towards you to minimize your experiences of judgement or mistreatment?
	4. What do individuals who experience suicide stigma feel they need from service providers and mental health organizations?	<p>8. What could be changed in larger structures, such as mental health organizations or other settings to reduce feelings of judgment and mistreatment?</p> <p>9. In what way do you think participating in the Skills for Safer Living program has shaped your experience of stigma?</p>

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