AVOIDERS, ACCEPTERS, AND ADVOCATES: A GROUNDED THEORY OF WOMEN'S DISCLOSURE OF SELF- INJURY

By

Meagan A. Hubbard

A THESIS

Submitted to
Michigan State University
in partial fulfillment of the requirements
for the degree of

MASTER OF SCIENCE

Human Development and Family Studies

2012

ABSTRACT

AVOIDERS, ACCEPTERS, AND ADVOCATES: A GROUNDED THEORY OF WOMEN'S DISCLOSURE OF SELF- INJURY

By

Meagan A. Hubbard

Self-injury (SI) has been defined as "the direct, deliberate destruction or alteration of one's body tissue without conscious suicidal intent" (Favazza, 1998, p. 260). Over the past few decades, scholarly research has provided a better understanding of SI-what it is, who does it, and how and why it is done. Notably absent in the research, however, is an examination of the process and consequences (both positive and negative) of disclosing SI. This exclusion is significant, as choosing whether (and when, and to whom) to disclose SI has significant ramifications for a person's life. This grounded theory study was conducted as a preliminary investigation into SI disclosure. Eighteen women with a history of SI participated via in- person interviews or an online open-ended surveys. The study addresses participants' reasons for and against disclosure and experiences with seeking medical or therapeutic treatment: immediate reactions to and long-term outcomes of their disclosure are also discussed. Shame and stigma were found to play a significant role in SI disclosure. Based on these findings, participant's disclosure experiences are categorized based on the degree to which they disclosed their SI, and a grounded theory of self-injury disclosure is presented. Findings suggest the need for increased disclosure at the societal level, as overcoming shame and stigma to disclose SI not only empowers the one who discloses but may also empower others by creating a space for disclosure.

ACKNOWLEDGEMENTS

I would like to express my gratitude to all those who provided feedback and support for this thesis. Special thanks to my partner Sarah Reed, my committee, and the webmaster and moderators of the BPD Families online forums. Finally, I would like to acknowledge Alison, Ann, Bella, Casey, Courtney, Greylin, Jenny, KLH, KM, losingmyself, Nicole, P. E., P. N., P. S., P. T., Rose, Seppie, and Sol.

TABLE OF CONTENTS

List of Tables

List of Figures

Self-injury (SI) is a complex and troubling behavior. Since the 1990s, SI has received increasing attention in scholarly, professional, and popular media. As a result, scholars and practitioners (and to some degree the public) now have a better understanding of the phenomenon. We know which factors contribute to SI, the average age of onset and duration of the behavior, which groups are most likely to engage in SI, and their motivations for doing so. Despite the exponential increase in attention given to SI in recent years, there is still a large gap in the literature. Previous research has focused primarily on the SI itself (examining why, when, and how people self-injure) or (rarely) on treatment options. Of course, none of this research would be possible if there were not people willing to step forward and speak about their experiences. For many people who self-injure, the decision to disclose their SI is a serious one, a decision that may have a dramatic impact on their life. Surprisingly, an examination of what goes into that decision, and how people who self-injure make sense of that decision and the resulting experiences, is conspicuously absent in the literature. The aims of this study are to gain a better understanding of the factors that influence disclosure of SI and the effects of disclosure or nondisclosure. It is my hope that, with a more complete picture of SI disclosure experiences, we can reduce the stigma of SI and encourage PSI to come forward, share their experiences, and seek the help they need.

Definitions

At this point, it is necessary to define some key concepts: SI, disclosure, secrecy, stigma, and stigmatization. Intentional harm inflicted upon oneself is described using a number of different labels, including self-harm, self-mutilation, self-abuse, self-injury and parasuicide. Throughout this paper, self-injury, or SI, will be used to describe “the direct, deliberate destruction or alteration of one's body tissue without conscious suicidal intent" (Favazza, 1998, p. 260). The term SI is preferred because, unlike the term parasuicide, it does not imply a desire or attempt to die, and very few people who self-injure intend to kill themselves through their injury. It also does not carry the same pathologizing, negative connotations as the terms self-abuse and self-mutilation; it simply describes the behavior. Those who engage in this behavior will be identified as "people who self-injure," or PSI, because PSI, unlike commonly used terms such as "cutter," avoids describing people in terms of one dimension of themselves and instead recognizes them as people that happen to engage in a certain behavior. PSI also is a gender-neutral term that challenges the common assumption that only women engage in SI. SI most often takes the form of cutting or burning, (Abrams & Gordon, 2003; Suyemoto, 1998) but encompasses a wide range of behaviors, including slapping, punching, hair-pulling, head-banging, wound interference, ingesting sharp objects, and biting (Connors, 1996).

For the purposes of this paper, disclosure is defined as "an interaction in which one person deliberately and voluntarily reveals significant, personal information about himself or herself to one or more others". This means that not only is the shared information something important- i.e., not trivial-it relates to the person sharing it. It also must be information that the person sharing intentionally chooses to share; thus, if someone is outed, that is not a true disclosure. Bok (1989) and Finkenauer (1998) defined a secret (that which is maintained through the process/act of secrecy), as "information that (at least) one person actively and consciously withholds from (at least) one other person" (as cited in Finkenauer & Hazam, 2000, p. 247). Because actively withholding information from one or more others may be seen as the inverse of disclosure, the terms "secrecy" and "nondisclosure" will be used interchangeably throughout this paper.

For the purposes of this paper, stigma will be defined in accordance with Goffman's definition of “an attribute that makes [one] different from others . . . and of a less desirable kind” so that person is “thus reduced in our minds from a whole and usual person to a tainted, discounted one” (Goffman, 1963, p. 3). Stigmatization will be considered as occurring when a stigma (physical or otherwise) results in the negative social perception and treatment of the person who bears it.

These concepts, having been briefly introduced here, will be discussed in more detail later. Having presented them, we will turn now to a consideration of the aims and inquiries of the study at hand.

Theoretical Frameworks

This study considered women’s experiences with disclosure and nondisclosure of self-injury and their reasons for choosing to disclose or not disclose, as well as the role of power, shame, and stigma in disclosure, to propose a theoretical model of self-injury disclosure. The present study incorporated two theoretical frameworks: feminist and human ecosystems. A feminist approach was appropriate for several reasons. First, feminist scholarship accepts that there are often multiple points of view- or many voices- on an issue and all of them are valid. Feminist research also “argue[s] for the importance of including personal experience as a way of legitimating what were often women’s private, unnoticed or invisible subjective experiences as a woman” (Daly, 2007, p. 189). Stewart “suggests that researchers need to look for what has been left out in social science writing, and to study women’s lives and issues” (as cited in Creswell, 2007, p. 26). I share these sentiments, believing that these post-positivistic views are not only especially well suited to an exploratory study of a sensitive topic, but are essential to a complete understanding of the issues being investigated in the present study. I incorporated reflexivity into this study, enhancing my ability to respond to participants with sensitivity, tact, respect, and self-awareness. The study is also feminist by virtue of the attention given to issues of power and oppression implicit in experiences with disclosure of SI. As Daly explains, “at the root, feminist inquiry is built on the common cause of . . . eradicating women’s oppression in the home and beyond” (Daly, 2007, p. 119). That statement captures the ultimate aim of this study. Because women who engage in SI are in fact doubly disempowered, by their gender as well as by their SI, I hope that this study empowered women at a personal level by hearing and validating their experiences; as Shulamith Reinhartz (1988) states, “to listen to people is to empower them” (as cited in Fine, 1992, p.20). This study was also intended to be empowering at a political level by taking the first tentative steps toward an understanding of why frank discussion of SI is so taboo and breaking the taboo by encouraging women (and perhaps, indirectly, men as well) to speak openly about their experiences. In order to accomplish this goal, however, both sources of disempowerment (gender and SI) must be addressed. SI will be discussed later: let us begin with an examination of the connections between gender and power.

Kimmel (2000) proclaims that “gender is about difference and also about inequality, about power . . . It is impossible to explain gender without adequately understanding power . . . because power is what produces those gender differences in the first place” (p.92). Power (or, more specifically, power differentials) invades heterosexual relationships of all sorts, from the corporate boardroom to the marital bed. This is arguably due in part to gender differences, constructed through a complex process involving “identity, interaction, institution”- people develop a gender identity (largely through interactions with other gendered people) in settings (institutions) that serve to both shape and reinforce gender roles (Kimmel, 2000).

The social construction of gender is especially apparent when using gender as a lens through which to study mental illness. The relationship between gender and views of mental illness goes back to Victorian times, when most psychiatrists believed, despite their awareness of other influences (including physical and socioeconomic factors), that "women were more vulnerable to insanity than men because the instability of their reproductive systems interfered with their sexual, emotional, and rational control" (Holmshaw & Hillier, 2000, p. 41). This belief led to "the close association between femininity and pathology [becoming] firmly established in scientific and popular thinking" (Ibid.).

The link between femininity and pathology persists, albeit in different forms, to this day. The diagnostic process itself illustrates this link. Holmshaw and Hillier (2000) point out that, when identifying or diagnosing mental health issues, medical professionals "rely upon their judgments about coping, the extent to which someone's ability to carry out their role is affected by their mental state" (p. 46). A woman's role is often considered to be "putting others first, taking primary care and responsibility for children, home, spouse and dependent relatives" ((Holmshaw & Hillier, 2000, p. 48); the medical field is largely "male dominated and underpinned by stereotypes of female inferiority" (Ibid.). Thus, it seems likely that, in many instances, a diagnosis of mental illness is essentially a judgment by the (likely male) doctor as incapable of carrying out her "proper role" as caretaker.

In addition, Haw (2000) points out other possible sources of gender bias in diagnosing mental illness. Diagnostic sex-bias is gender bias related to the clinician's gender, while construct or criterion bias occurs when the diagnostic criteria themselves are biased, representing either "male" or "female" characteristics (such as a woman with multiple sex partners being diagnosed with Borderline Personality Disorder, while a man with multiple sex partners receives no diagnosis).

Gender differences persist after diagnosis. Holmshaw and Hillier argue that "women's feelings and behaviours [*sic*] are more likely to be diagnosed as psychological symptoms than are men's . . . due to both the general sexism in society as a whole, and also the sexism of professional attitudes" (2000, p. 48). They cite several studies illustrating the differential treatment women receive, in part because men's psychological problems are considered less likely to occur and more serious when they are diagnosed, so women's mental health concerns may be treated dismissively. Thus, gender and power have a strong bearing on the discussion, diagnosis, and treatment of mental health concerns.

The present study also included elements of a human ecosystems perspective. Ecology is "the study of the interrelationship between organisms or life and the environment" (Bubolz & Sontag, 1993, p. 419). Human ecology is the study of humans interacting with their environment. Though environments may be physical (either natural or human-built), this study will focus on the intangible environment, which is often called the socio-cultural environment (Bubolz & Sontag, 1993).

A human ecosystem, as Bronfenbrenner (1981) explains, can be "conceived as a set of nested structures, each inside the next, like a set of Russian dolls" (p. 3). He identifies the various "structures" as the microsystem, the mesosystem, the exosystem and the macrosystem. The innermost structure is the microsystem, which is "a pattern of activities, roles and interpersonal relations experienced by the developing person in a given setting" (Bronfenbrenner, 1981, p. 22). Bubolz and Sontag (1993) identify the family as "the principal microsystem context in which development takes place (p. 423)"; the family is the first and the most important socio-cultural environment in which a person participates, and thus has a fair amount of influence over human development. Moving beyond the family, the next "level" of environment is the mesosystem, composed of "the interrelations among two or more settings in which the developing person actively participates". It can also be described as "a system of microsystems" (Bronfenbrenner, 1981, p. 25). A commonly given example of a mesosystem is a young child starting school- the child is then participating (at minimum) in the family and the school. Exosystems, the next level, are settings that "do not involve the developing person as an active participant, but in which events occur that affect, or are affected by, what happens in the setting containing the developing person" (Bronfenbrenner, 1981, p.25). In other words, exosystems are settings in which a person has indirect involvement (for a child, this may include a parent's workplace). The final, outermost "level" of the human ecosystem is the macrosystem. A macrosystem encompasses "the broad ideological values, norms and institutional patterns of a particular culture that make up the 'blueprints for the culture's ecology of human development" (Bubolz & Sontag, 1993, p. 423) - the macrosystem helps to provide a context for the micro-, meso-, and exosystems.

An ecosystemic framework was appropriate in this study because of the exploration of how participants interact with the various individuals (e.g., family, friends, colleagues, therapists, doctors) in their socio-cultural environments, as well as a possible examination of various inputs, outputs, and feedback loops (such as knowledge and information, support systems, values and beliefs).

Research Questions

This study aimed to answer two research questions. The central question was essentially descriptive: What factors facilitate or hinder disclosure at the individual level? In this study, I also explored the personal and interpersonal consequences of disclosure and nondisclosure for PSI. Though complete answers to these questions are beyond the scope of this project, I hope that this study will serve as a preliminary exploration of these issues and will provide a springboard for further research.

In order to address the research questions, it is necessary to begin with a more complete understanding of the phenomena of SI and disclosure, as well as a consideration of the issue of stigma (in this case, the primary mechanism by which power is exercised or denied).

Self-Injury

Risk Factors

SI has been called "the anorexia of the 90's" (Edwards, 1998, p. 93) because the incidence of the two in the general population is similar and because both were "invisible" and heavily stigmatized before receiving increased attention in scientific research and mainstream media. Both persons with anorexia and PSI are often thought of as being only middle or upper class, white, teenage females, but this is not accurate. People of all ages, races, genders, and social classes self-injure. About one percent of the population has engaged in SI at some point in their life (AHSIC, 2007).

Research has suggested a variety of factors that may increase the likelihood of SI. Studies consistently indicate the strong correlation between SI and a history of physical and/or sexual abuse (Abrams & Gordon, 2003; Chapman et al., 2006; Connors, 1996; Favazza, 1998; McDonald, 2006; White, Trepal-Wollenzier, & Nolan, 2002). Family structure and relationships are also predictive. These include loss of or separation from family (Connors, 1996; Storey, Hurry, Jowitt, & House 2005; Suyemoto, 1998), childhood neglect (Favazza, 1998; Suyemoto, 1998), family trauma and stress (Abrams & Gordon, 2003), and parental alcoholism or depression (McDonald, 2006). Other social factors include low levels of social support (Storey et al., 2005), violence in society, curiosity and peer pressure (McDonald, 2006). Personal factors have also been linked to SI. These include depression, a history of chronic illnesses with childhood hospitalization (McDonald, 2006); a lack of coping mechanisms associated with stress

(Abrams & Gordon, 2003; Connors, 1996; McDonald, 2006; Suyemoto, 1998); low self-esteem (Chapman, Gratz, & Brown, 2006; Heath, Toste, & Beettam, 2006; Shapiro, 2008), lack of ability to self-soothe (Chapman et al., 2006), and poor impulse control (Favazza 1998; McDonald, 2006). In addition, Tantam and Huband (2009) propose another possible contributor: the existence of a psychological "safety catch" to aid in self-preservation, which PSI are able to temporarily or permanently disengage or "override". Despite some misconceptions that SI always starts in response to peer pressure or "fads," an exploratory study disproves this notion, finding that although about one-third of participants had been exposed to the idea before they began engaging in SI (often through media or friends), most were "self-learners" (Hodgson, 2004).

SI Motivations

Connors (1996) proposed four general motivations for SI: emotional expression, re-enactment of trauma, managing or maintaining dissociation, and self-organization and the return to homeostasis. In one small qualitative study, Abrams and Gordon (2003) found that the primary motivation for SI differed based on the respondent's environment. Participants from urban areas listed anger as their primary reason for SI, while suburban respondents were more likely to identify pain, depression, or emotional turmoil as their reason. In many studies on SI, "release" or "catharsis" emerges as a major motivation for SI (Abrams & Gordon, 2003; Chapman et al., 2006; Connors, 1996; McDonald, 2006; Suyemoto, 1998). PSI frequently perceive the act of SI as an effective method for alleviating guilt, shame, or anxiety.

Over the past few decades, scholarly research has provided a better understanding of SI-what it is, who does it, and how and why they do it. Despite a more complete theoretical knowledge, however, research suggests that, out of the lab and in the real world, it is still widely misunderstood by many, including the very people who attempt to treat it.

Knowledge Of and Reactions to SI

Heath et al. (2006) studied attitudes toward and knowledge of SI among high school teachers. Results were mixed. Forty-eight percent of respondents were “horrified” by the idea of SI, 78% underestimated the prevalence, and only 20% felt knowledgeable about SI. However, 62% said they would be comfortable if a student approached them to discuss their SI, 46% felt they would know how to respond to such a situation, and 52% felt able to identify self-injurious behaviors. Though male teachers felt more knowledgeable than did female teachers, female teachers had more positive attitudes toward SI than male teachers did. One noteworthy finding was that, though the teachers in this study were highly educated (60% had earned a graduate degree), there was a consensus that further training and information on addressing SI in a school setting was necessary.

Those in educational settings are not the only ones feeling ill prepared to respond effectively to SI. Friedman et al. (2006) surveyed staff in the Accident and Emergency ward of a British Hospital regarding their attitudes about PSI via laceration (cutting). The most common reason given for self-laceration, cited by 98% of respondents, was “to relieve tension:” desires “to punish themselves” (83%) and manipulative efforts “to get attention” (77%) were also frequently cited. When asked about their own response to patients who presented due to self-laceration, 69% of staff stated they were “concerned for [the] patient” and 50% reported feeling “sympathetic”: however, 51% were “frustrated,” and 35% felt “inadequate professionally” in such situations. Though 92% of staff perceived training in managing self-laceration behavior as “very” or “moderately” important, only 9% had received any form of training on the issue.

A New Zealand study of healthcare staff's attitudes toward SI (Gibb, Beautrais, & Surgenor, 2010) reported similar findings. Though nearly three-fourths (73.3%) of respondents agreed that "I can understand a patient who has attempted suicide or harmed themselves," almost as many (69.5%) reported that "self-harm patients are difficult to work with," and 51.8% were "frustrated" or "irritated" by them. Staff also acknowledged the need for further training, with less than one-third feeling they were "adequately trained to deal with self-harm patients," and 87.1% stating, "ongoing training in [addressing] self-harm would be useful for me."

Taylor, Hawton, Fortune, and Kapur (2009) conducted a review of the literature on PSI's views of clinical services in Australia, Europe, New Zealand, and North America. Though experiences varied widely, recurrent themes included poor patient-staff communication and a perceived lack of staff knowledge of SI. Five areas for service improvement were identified: "increased and improved communication between service staff and those who self-harm," "greater staff knowledge of self-harm and how to deal with people after a self-harm episode," "increased sympathy towards those who self-harm," "improved access to local services and after-care," and "provision of better information about self-harm for patients, carers, and the general public".

Overall, the literature suggests a gap in knowledge about SI, a lack of adequate training on addressing the issue, and a desire among staff for more training. Adolescents and adults who do engage in SI are often reluctant to seek help or medical treatment because the behavior is so highly stigmatized. As Walsh (2007) explains:

> Favazza has written that the treatment literature on self-injury 'is basically one of countertransference' (1998, p. 265). This statement is hopefully somewhat of an exaggeration; nevertheless, there is little doubt that self-injury can produce extreme

> reactions in caregivers. Many authors (e.g., Simeon & Hollander, 2001; Walsh, 2006) have discussed the negative reactions of treatment professionals to encountering self-injury in clients, such as shock, disgust, recoil, pejorative judgments, anxiety, fear, anger, and confusion. It is hard to imagine that any of these responses have therapeutic utility (p. 1060).

Klonsky and Olino (2008) classified PSI into four subgroups according to the method and function of their SI. Approximately 11% of the study sample engaged in multiple means of SI (e.g., cutting, hitting, burning) and endorsed social (e.g., interpersonal influence, peer bonding) as well as automatic (e.g., affect regulation, self-punishment) functions. PSI in this group had early onset of SI behaviors and displayed more symptoms of anxiety than those in other groups. The authors reported that “from a treatment perspective, the early age of onset and over-determined nature of the [SI] suggest that treatment of [SI] could be particularly difficult” (Klonsky & Olino, 2008, p.26).

In order to deal effectively with SI, there must be collaboration between mental and medical health services to treat those who currently engage in SI as well as to provide outreach and educational services. There also must be a concerted effort to raise awareness of the problem among the public to increase knowledge and, in turn, decrease stigma.

Medical and mental health practitioners are not the only ones who are sometimes ignorant when it comes to issues of SI. In a study of 71 mother-adolescent pairs, between 27% and 38% of adolescents reported engaging in less visible means of SI, including wound interference, head-banging, self-hitting and self-scratching (Sansone, Weiderman & Jackson, 2008). However, mothers greatly underreported these behaviors; the greatest concordance in reported SI behaviors was in the most severe SI behaviors (i.e. cutting, burning). It is possible that mothers were more likely to be aware of severe SI because of its “graphic nature . . . the adolescent’s possible need to be discovered, and/or the need for acute first-aid or more advanced care because of the act” (Sansone et al., 2008, p. 25). Though this study has several potential limitations, it suggests that often even those closest to PSI are unaware of the behavior.

SI is a maladaptive coping mechanism with a variety of factors contributing to this behavior. Because relatively little is known about SI, it is widely misunderstood and frequently feared. Unfortunately, far too many are unaware of this growing problem, in large part because of the secrecy that surrounds the behavior.

Secrecy versus Disclosure

Perspectives on Disclosure and Secrecy

Secrecy and disclosure occur in various contexts and in multiple relationships. In considering disclosure and nondisclosure of SI, the first issue to consider is what makes something a disclosure. In the views of early psychologists, such as Chelune (1979), self-disclosure required only that a disclosure contain personal information about the speaker verbally communicated to a target person (as cited in Antaki, Barnes, & Leudar, 2005). However, Antaki et al. (2005) argue that a true self-disclosure must be a significant, personal, and voluntary sharing of information, beyond what the context of the situation requires. Others take a simpler view, arguing that a self-disclosure need only involve “an interaction between at least two individuals where one intends to deliberately divulge something personal to another” (Greene, Derlega, & Mathews, 2006, p. 411). A similar definition is proposed by Finkenauer and Hazam, who cite Jourard in stating that “disclosure is. . . the process of revealing self-referring information, such as internal states or past events, to others” (Finkenauer & Hazam, 2000, p. 247). The common threads in these definitions relate to issues of information sharing, communication and relationships and, perhaps, a willingness to place oneself in an emotionally vulnerable situation. However, these varying perspectives on the nature of disclosure suggest that disclosure is a complex phenomenon that must be considered from a variety of perspectives.

These considerations become especially salient when (current, former, or ongoing) SI is the topic of the disclosure or nondisclosure. SI, as previously discussed, is a frequently misunderstood behavior, one that even educators, medical and mental health professionals often do not know how to respond to effectively. Thus, it is not surprising that SI is such a taboo topic that is only recently being acknowledged, studied and discussed. The highly sensitive nature of SI requires PSI to consider carefully the possible consequences of admitting to engaging in such behavior, while the intensely private nature of SI makes it quite likely that, absent such active disclosure, even their most intimate confidants will remain perpetually unaware of any past or present problem.

Making Decisions about Disclosure

The next consideration in examining self-disclosure is how people decide whether to disclose. Omarzu (2000), who studied the factors that help people to decide whether to disclose, proposes a model for determining whether self-disclosure occurs: the attainment of reward(s)- intimacy, social control, identity clarification, social approval, or distress relief- motivates disclosure. If disclosure is seen as a way to gain the reward, the subjective benefit of disclosure is weighed against the subjective risk of disclosure to determine whether or not disclosure will occur and, if it does, the “depth, breadth, content and duration of disclosure” (p. 174). As this model applies to SI, because of the high degree of social stigma it would likely create, a disclosure of SI would likely tend to decrease, rather than increase, social approval and social control (and by extension, would be likely to decrease power and increase social marginalization). Thus, the most pertinent factors are likely to be intimacy, identity clarification, and distress relief. Disclosures of SI may help foster intimacy and distress relief by allowing PSI to reveal something hidden and be acknowledged, accepted and validated for doing so (see also Farber, Khurgin-Bott, & Feldman, 2009). Distress relief also may be found in the abatement of physical and psychological difficulties (e.g., headaches, stomachaches, guilt, and anxiety) associated with the maintenance of a secret (Farber et al., 2009; Finkenauer, Engels & Meeus, 2002; McKillop & Kelly, 1996). Such a disclosure also may contribute to a view of oneself as a person who self-injures (identity clarification), and, because people cannot seek help for a problem they do not realize they have, this self-concept may encourage PSI to seek the treatment they need.

The intended audience for the disclosure is frequently cited as a factor in the decision of whether or not to disclose. The quality and nature of the relationship between two people often has a strong influence on the likelihood of one person disclosing to the other. In one study of victims of childhood sexual abuse (Petronio, Reeder, Hecht & Ros-Mendoza, 1996), participants limited disclosures of abuse to people who were perceived as trustworthy and responsive (part of what the authors describe as “boundary protection). Similarly, McKillop and Kelly (1996), as part of their decision disclosure model, suggest that disclosures should be made only to people who can be trusted to keep the secret, who will be supportive and non-judgmental, and who might be able to offer new insights. The authors point out that the timing of a disclosure is also an important factor, as disclosures early in a relationship may alienate others, while disclosures much farther into the relationship may be seen as a betrayal. Another model suggests that whether disclosure will occur in a given situation depends on a number of factors, including the availability of a person to receive the disclosure (henceforth referred to as a target of disclosure, or TOD) and the quality of the relationship with that person (Greene et al., 2006). The TOD's anticipated reaction to the disclosure and the existence of conditions (conversational flow, privacy) conducive to disclosure are also cited as factors in disclosure (Ibid). First, disclosure can only occur when there is one person to disclose and at least one other to receive the disclosure, and the relationship between the people often has a strong influence on whether or not disclosure occurs. Disclosure is less likely to occur if the person disclosing anticipates a negative reaction to the disclosure, and is more likely if circumstances allow comfort, privacy and discussion. These findings all suggest that a positive relationship with a trustworthy, supportive, and non-judgmental other and the existence of a comfortable, private setting are strong contributing factors to disclosure.

The Act of Disclosure and Its Consequences

Once the decision to disclose to a certain person is made, there are still a number of factors to consider, pertaining both to the actual act of disclosure (how, when, where, and how much to disclose) and to the potential consequences, or "aftermath," of the disclosure. A study of young victims of sexual abuse (Petronio et al., 1996) proposed that, when decisions to disclose are being made or considered, "boundary access" (in conjunction with boundary protection; see above) provides a framework for disclosure. Boundary access is comprised of three facets: "tacit permission," "selecting the circumstances," and "incremental disclosure". Tacit permission occurred when a child interpreted an inquiry into his or her well being or an expression of concern as an invitation to reveal the abuse. Selecting the circumstances was a tactic for reducing the anxiety associated with the disclosure- disclosures occurred in such everyday situations as washing dishes, playing softball, and watching TV. The authors suggest that the familiarity of these scenes creates a sense of safety and comfort for the child who is considering a disclosure. Another tactic used for reducing the anxiety of disclosure is incremental disclosure, in which the abuse is “hinted at,” or disclosed in stages, such as one child who began the disclosure by stating, “Sometimes I don’t like Dad”. Though childhood sexual abuse is not, of course, an identical issue to self-injury, there are some similarities between the two. Both are mental health issues that more often affect women than men, that are to some degree “taboo” topics, and that may cause great anxiety, fear, guilt, and shame in those that must cope with their effects. These similarities suggest that the “boundary access” framework may be applicable to disclosures of self-injury.

The act of disclosure itself carries both social and psychological consequences. Greene et al. (2006) posit seven dimensions of disclosure: reward value, informativeness, accessibility, truthfulness, social norms, effectiveness, and transactional. Reward value considers the positive and negative consequences of disclosure, similar to Omarzu’s (2000) model. Informativeness and effectiveness pertain to the disclosure itself, including how much it reveals about the person who discloses and how well it accomplishes the goal of both the discloser and the recipient(s) of the disclosure. On a deeper level, one must consider how difficult the disclosure is (accessibility) and the extent to which the disclosure relates to the speaker’s true self (truthfulness). Taking a broader view, one also must consider the broader social environment (social norms) and the extent to which the disclosure conforms to or deviates from the accepted standards and processes for disclosure and nondisclosure. In this model, disclosure is viewed not as a singular event, but as a dynamic and ongoing process (transactional), a belief echoed by other researchers (Farber, et al., 2009; Finkenauer & Hazam, 2000; Petronio et al., 1996).

Disclosure may carry with it severe consequences that many PSI take into account before making a decision to disclose (Berman & Wallace, 2007; McKillop & Kelly, 1996; Petronio et al., 1996). Petronio et al. (1996) suggest that consequences may include strained or damaged relationships, the possibility of the information getting out, and even reprimand (1996). Another study of survivors of childhood sexual abuse (Farber et al., 2009) suggests that, in a therapeutic setting, disclosure of the abuse may bring both risks and benefits. Disclosure may bring a variety of benefits to the client, including validation, affirmation, intimacy, catharsis, differentiation, authenticity, and self-awareness and identity formation. Risks include a possibility of the therapists' censure or disapproval of the client, the client's awareness of his or her emotional vulnerability, and, perhaps most significant, a temporary increase in depression or other forms of distress in the client, which increases the likelihood of discontinuing therapy. Berman and Wallace (2007) point out that the act of disclosure may be "risky" and carry heavy consequences, including shame, fear, anger, depression, anxiety and social censure, for both the person disclosing and the TOD. It is possible that some PSI may be hesitant to disclose their SI because they realize that, in doing so, they will be forced to give up the behavior and may feel threatened by this realization because they do not feel ready or able to stop self-injuring. By maintaining secrecy about their SI, PSI retain their ability to continue engaging in SI until they feel ready to stop.

McKillop and Kelly (1996) argue that in many cases, nondisclosure is actually beneficial, as it may help to maintain appropriate relational boundaries and a sense of privacy. Privacy may be especially important to PSI, because they are aware of the negative responses SI may invoke in others (including the possibility of being stigmatized), because they do not yet have more effective coping mechanisms to replace their SI, or both. In some cases, however, disclosure can bring rewards, including the alleviation of negative emotions and the gaining of new insights into an issue (McKillop & Kelly, 1996). The authors suggest that secrets should be revealed only when they cause physical (e.g., headaches, stomachaches, backaches) and/or psychological (e.g., guilt, stress, anxiety) harm.

Another study, which focused on secrecy and disclosure in adolescent-parent relationships, reached similar conclusions. Adolescents who kept secrets from their parents were more likely to report minor physical issues (i.e., headaches, stomachaches), but also reported a higher degree of emotional autonomy (Finkenauer et al., 2002). In contrast, a study of adolescents with mental health problems in “wraparound” treatment programs revealed that, though 70% of participants felt that receiving treatment for mental health issues was not something that must be hidden from others, 60% stated that they would not disclose their own treatment to someone unless they knew the person well (Moses, 2009). Such guarded secrecy, however, did not correlate significantly with scores on self-concept or depression scales.

A survey of high school freshmen and seniors and their parents on issues of parental authority and “right to know” about a variety of issues, as well as adolescents’ secrecy or disclosure and parents’ perceptions of their child’s disclosure (Smetana, Metzger, Gettman, & Campione-Barr, 2006) revealed some interesting findings. Both adolescents and parents felt that parents had more legitimate authority over prudential issues (with the potential for long-term harm or benefit) than over social (peer/moral), personal or multifaceted issues, and therefore both adolescents and parents felt that adolescents had more of an obligation to disclose prudential issues (see also Sansone et al., 2008). Interestingly, mothers overestimated their daughters’ degree of disclosure. Adolescents’ trust in parents and parental warmth, support and acceptance (see also Petronio et al., 1996) correlated strongly with adolescent disclosure. Disclosure of personal issues was viewed as more discretionary, making support and acceptance even more vital for open communication.

Parent-child relationships, furthermore, were not the only ones in which secrecy had both positive and negative consequences. A study of the influence of secrecy and disclosure on marital satisfaction and commitment considered both dispositional (factors relating to the person themselves) and contextual (factors relating to the relationship) disclosure and secrecy within the relationship (Finkenauer & Hazam, 2000). Results indicate that dispositional disclosure and secrecy were unrelated and did not significantly predict marital satisfaction. However, contextual disclosure and secrecy, namely "openness about conflictive issues, avoidance of difficult topics, and suspicion that partner keeps information from oneself" (Finkenauer & Hazam, 2000, p.253), were found to be significant predictors of marital satisfaction.

The process of disclosure, especially as it relates to the sensitive topic of SI, must be carefully considered and constantly negotiated. Relationships with trustworthy, supportive others help ease the anxiety that frequently accompany such personal disclosures. While disclosure may bring various benefits to PSI, it also may bring serious negative consequences. One of the major negative consequences that PSI must take into account when contemplating disclosure is the potential for stigmatization.

Stigma

Defining Stigma

Since Goffman's (1963) seminal work on stigma, scholars have struggled to define and understand stigmatization. His frequently cited definition of stigma considers a person's stigma to be "an attribute that makes him different from others . . . and of a less desirable kind" so that person is "thus reduced in our minds from a whole and usual person to a tainted, discounted one" (Goffman, 1963, p. 3). Others have argued that "stigma . . . is a social construction that involves at least two fundamental components: (1) the recognition of difference based on some distinguishing characteristic, or ‘mark,’ and (2) a consequent devaluation of the person” (Dovidio, Major, & Crocker, 2003, p. 3). Link and Phelan (2001) offer a slightly more complex definition, “apply[ing] the term stigma when elements of labeling, stereotyping, separation, status loss and discrimination co-occur in a power situation that allows the components of stigma to unfold”. For the purposes of this paper, stigma follows Goffman's (1963) definition, while stigmatization occurs when a stigma (physical or otherwise) results in the negative social perception and treatment of the person who bears it. This process implicitly considers issues of power and privilege, as it is the “privileged few” who define what makes someone “different from others . . . less desirable . . . tainted, discounted”.

The Process of Stigmatization

Like the process of disclosure, stigmatization is properly viewed as a dynamic process. Link and Phelan (2001) present one account of the process by which stigmatization occurs. The process begins with an observation that another person or group is different, and the identification and labeling of that difference (e.g., one’s skin color or sexual orientation). The identified difference is associated with some trait or characteristic generally seen as negative (e.g., laziness or promiscuity). Eventually, society is divided into groups according to the labels applied to its members (“Black,” “gay”), and negative treatment (such as discrimination) is made possible by power differentials among the various groups (e.g., Black/White, gay/straight). Smith (2002) offers a very similar explanation of the stigmatization process: observable differences are linked to undesirable traits, creating stigmatized out-groups lacking in power, and this recurrent process eventually leads to a “vicious cycle” of stigma.

Unfortunately, not only is stigma imposed upon one by others, it also may be self-imposed, as Watson, Corrigan, Larson, & Sells (2007) demonstrate in their study of self-stigma among persons with mental illness. The process starts with stigma awareness, a knowledge of the negative beliefs about people belonging to a certain group or possessing a certain characteristic held by society (e.g., people with mental illness are dangerous, weak, incompetent, and at fault for their illness). Stigma awareness gradually becomes stereotype agreement, or endorsement of the beliefs held by society about members of a certain group (e.g., people with mental illness are weak). Eventually, this morphs into stereotype self-concurrence, the belief that the person himself or herself in fact possesses or demonstrates the traits or characteristics commonly assigned to him or her by the general public (e.g., I am weak). Stereotype self-concurrence leads to reduced self-efficacy and a drop in self-esteem. Thus, whether the process of stigmatization is self-imposed or other-imposed, the result for the stigmatized person is the same: a loss of agency and self-efficacy and a decline in mental health and well-being.

The Role of Blame in Stigma

Frequently, there is an element of blame in the process of stigmatization. Society often views stigmatized persons as having some role in, and responsibility for, their circumstances. Chapple, Ziebland, & McPherson (2004) conducted a study in Britain in which they interviewed 45 people with lung cancer. Because of the strong association between lung cancer and smoking, even non-smoking participants often reported being blamed or held responsible for their disease. This blame, perpetuated by the media as well as by those in the medical professions, may be so severe and pervasive that it deters those with lung cancer from seeking the help they need or prevents them from receiving treatment when they do seek medical attention. The study points out that older people with lung cancer, who grew up at a time when smoking was socially acceptable and the health risks unknown, were seen as less at fault than younger patients who were aware of the risks.

In a study investigating the stigma of physical and mental health conditions, Stewart, Keel, and Schiavo (2006) conducted a study to investigate perceptions of a healthy individual, an individual with asthma, an individual with anorexia nervosa, and an individual with schizophrenia. Overall, participants perceived the individual with anorexia nervosa the most negatively of the four individuals described. Of the three individuals with a physical or mental health concern, he/she was perceived as the most able to "pull [him/her]self together if they wanted to," the most likely to be "acting this way for attention," and the least likely to have their issue attributed to biological factors. These findings suggest that people perceived as having a higher degree of control or choice are seen as more to blame for their condition and are therefore more likely to be stigmatized.

In their research on adolescent perceptions of the stigma of mental illness, Corrigan et al. (2005) found that, unlike adults, adolescents who reported more contact with people with mental illness tended to view people with mental illness as being *more* responsible for their illness and *more* dangerous than did adolescents who reported less contact. Viewing persons as responsible for their illness decreased feelings of pity for and the desire to help them and increased participants' anger toward them (Corrigan et al., 2005).

The frequency with which stigmatized persons are seen as playing a part in their circumstances may cause not only society, but also the persons themselves, to blame and view themselves as responsible for their situation and the resulting stigma. One study of overweight adults in a weight-loss support group asked participants about the most common stereotypes of overweight people, as well as their perception of the truth or falsity of those stereotypes (Puhl, Moss-Racusin, Schwartz, & Brownell, 2008). The most commonly cited stereotypes viewed overweight people as responsible for their weight, perceiving them as being lazy, overeating, and lacking self-discipline and willpower (among other negative stereotypes). Though most participants challenged these views, about 15% (primarily Caucasian females) endorsed them.

As the previous studies indicate, stigmatized persons are often perceived as responsible for their condition and, by extension, the resulting stigma. This is especially problematic because feeling responsible may actually prevent people from seeking help. In the case of PSI, in particular, feeling that they are at fault for engaging in SI or being ashamed of their SI may discourage them from seeking the treatment they need.

The Role of Power in Stigma

In examining the process of stigmatization, we must also consider the role of power. Power is an essential component of stigma: as Link and Phelan (2001) state, “stigma is dependent on power” (p. 376). To illustrate their point, they give an example of a group of staff and patients at a mental health treatment facility. The patients may stereotype and label the staff in various ways (e.g., “pill-pusher”) and treat them differently based on these labels. However, the patients cannot truly stigmatize the staff because “the patients simply do not possess the social, cultural, economic, and political power to imbue their cognitions about staff with serious discriminatory consequences” (Link & Phelan, 2001, p. 376).

True stigmatization involves the ability to exert some influence on the lives of others. This influence may include “[controlling] access to major life domains like educational institutions, jobs, housing, and health care,” (Link & Phelan, 2001, p. 376), having one’s “worldviews of what is right versus wrong or healthy versus sick [be] influential,” (Hinshaw, 2007, p. 25), or “[ensuring] that the culture recognizes and deeply accepts the stereotypes they connect to the labeled differences" (Link & Phelan, 2001, p. 376). Thus, true stigmatization perpetuates prejudice and discrimination at the macrosystem level.

Part of what makes the determination of "right" and "wrong" or the cultural recognition of stereotypes and discrimination possible is the ways in which society explains deviance. Hinshaw (2007) explains that perceptions of deviance may come from several sources, including statistical rarity and social deviance. Statistical rarity, as one may expect, views mental health as represented by a bell curve and considers deviance "statistical rarity, constituting extremes of behavior that seldom occur in the general population," with the small numbers of people at either end " literally 'ab-normal'-that is, far from the statistical norm or average value of the population" (Hinshaw, 2007, p. 8). Social deviance, in contrast, occurs when behavior in violation of established social norms is seen as threatening group cohesion. Such behavior is therefore labeled "unhelpful and atypical, with strong social pressure to identify the offenders and relegate them to the subgroup of individuals who do not belong in the mainstream," further reinforcing social norms (and perhaps resulting in stiffer penalties for those who violate them) (Hinshaw, 2007, p.9).

Whether defining deviance in terms of social norms, statistics, or in other ways, it is clear that the concept of "deviance" generally involves a separation from the mainstream. This separation creates an automatic minority, reducing the group's power and further increasing the odds that group members will be subject to poor treatment.

Perhaps surprisingly, stigmatized people themselves may help to perpetuate prejudice and discrimination against them by recognizing that there are situations in which conforming to stereotypes is to their advantage (Miller & Major, 2003). Heller (2009) discusses the status of lesbian, gay, bisexual and transgender (LGBT) asylum seekers as an example of such a situation.

Frequently, LGBT asylum seekers must support the legitimacy of their asylum claim by "reverse-covering," or conforming to stereotypical traits attributed to sexual minority and gender non-conforming individuals. Reverse-covering, however, may also lead to stigma and prejudice, as it is beneficial in certain situations to de-emphasize one's gender identity and sexual orientation ("cover"): for example, a lesbian female asylum seeker with children may be torn between reverse-covering to support her claim for asylum and covering to "prove" her fitness as a parent in a child custody hearing.

In summary, the power of stigmatization is the ability to single out groups that do not fit one's perception of how people should be, and to shape society's expectations, views, and treatment of these groups and even, perhaps, the behaviors and views of the groups themselves.

The Stigma of Mental Illness

Possible Origins

Though there are many stigmatized groups, this paper will focus on the stigma associated with mental illness. Several studies (Corrigan, Watson & Ottati, 2003; Herek, 1999; Martin, Pescosolido, & Tuch, 2000) have investigated the potential origins of the stigma of mental illness. Corrigan et al. (2003) examined three possible theoretical frameworks for explaining the source of mental illness stigma and stereotypes of persons with mental illness as either dangerous or incompetent: the "normal reaction" theory, the "kernel of truth" theory, and the "system justification" theory. The "normal reaction" theory argues that what appears to be stigmatizing views and behaviors toward persons with mental illness are in fact a legitimate and reasonable response to bizarre behaviors (thus viewing persons with mental illness as "dangerous"). The "kernel of truth" theory posits that mental illness stigma is a result of the partial truth of the stereotype; namely, the "truth" that persons with mental illness are inherently more dangerous and less competent than are those without mental illness. The "system justification" theory states that stigma is an attempt to draw on historical events in an effort to maintain the status quo-for example, using the historical fact of slavery to justify views of African-Americans as inferior. After reviewing a number of studies pertaining to each of the three frameworks, they conclude that system justification is the most likely source of the stigma of mental illness.

Herek (1999), in the context of his research into the stigma of persons with AIDS, outlines four factors that make an illness or condition more likely to be stigmatized. First, stigmatization is more likely when the cause of the disease "is perceived to be the bearer's responsibility" (Herek, 1999, p. 1104) (see also Chapple et al., 2004; Puhl et al., 2008**).** **"**Illnesses and conditions that are unalterable or degenerative" also are highly stigmatized, as are "conditions that are perceived to be . . . contagious or to place others in harm's way" (Herek, 1999, p. 1104-1105). Finally (and not surprisingly), "a condition tends to be more stigmatized when it is readily apparent to others" (Herek, 1990, p.1105).

Although these factors initially applied to the stigma of AIDS, they pertain similarly to SI. First, SI is often perceived as "attention seeking behavior," and thus as a conscious choice and PSI's responsibility. Some consider SI "unalterable," partly because the average time from onset to treatment is so long- an average of ten to 15 years (Favazza, 1998) -and partly because SI is often associated with Borderline Personality Disorder (BPD) or other personality disorders, often leading to the assumption that SI is "part of" PSI and thus PSI cannot stop their SI. Additionally, SI is often incorrectly viewed as a sign that PSI are violent and pose a hazard to others, or is wrongly interpreted as a failed suicide attempt. The various marks and scars that tend to result from SI are frequently “readily apparent,” unless great care is taken to conceal them. Finally, PSI are a subcategory of a larger stigmatized group: people with mental illness(es). For this reason, they may be doubly stigmatized.

Martin et al. (2000) conducted a secondary data analysis using a special module of the 1996 General Social Survey on mental health. The module described people meeting criteria for schizophrenia, depression, alcohol dependence and drug addiction, as well as a “troubled” person who did not satisfy any diagnostic criteria. Respondents were asked a series of questions about the person, including questions about the cause of their illness (biological causes, personal weakness, God’s will), how willing they would be to have various relationships with this person (friend, coworker, or neighbor), whether the person was dangerous or incompetent, and whether or not the person had a mental illness. Results indicate that people had the most desire to avoid persons with drug or alcohol dependence; however, 48.4% would avoid a person with schizophrenia, and 37.4% would avoid a person dealing with depression. Additionally, the majority of respondents reported that people with schizophrenia, drug or alcohol dependence were “dangerous,” and about a third felt those with depression were dangerous**.**

A related study conducted in Jamaica examined the effects of internalized stigmatization, hypothesizing that participants would adopt a negative view of family members with a mental illness (Gibson, Abel, White, & Hickling, 2008). Though overall this hypothesis proved incorrect, almost half of respondents felt afraid of or disgusted by their relative with mental illness (43.8% and 43.1%, respectively), and over a third (36.9%) felt angry with their relative. These findings reinforce those of earlier research (Herek, 1999; Martin et al., 2000) suggesting that fear and beliefs that persons with mental illness are violent or dangerous are strong factors in the stigma of mental illness.

Fear, however, is only one facet of the stigma of mental illness. Several studies (Corrigan et al., 2005; Jason, Taylor, Plioplys, Stepanek, & Shlaes, 2002; Rosenfield, 1997) have suggested that the language used to describe mental illness influences how people perceive it. Corrigan et al. (2005) conducted a secondary data analysis of a study that used vignettes to assess students' reactions to persons with mental illness, including pitying the person, fear of or anger towards the person, feeling that the person was responsible for his or her circumstances, and desiring to help or avoid the person. The study used four vignettes describing four adolescents, including one with a mental illness and one with a brain tumor that mimicked symptoms of mental illness. The student whose mental illness symptoms were caused by a brain tumor was seen as "less dangerous, less likely to be feared, more worthy of help and less likely to be avoided" than the student with mental illness, suggesting that it was the label given to the behavior, not the behavior itself, that was judged negatively.

In a similar study, Jason et al. (2002) presented medical students with one of three case studies, in which the patient's symptoms were identical but the names varied, and asked the students to answer various questions about the patient. The case studies described the patient's illness as Chronic Fatigue Syndrome (CFS), Myalgic Encephalopathy (ME), or Florence Nightingale Disease. Results indicated that the "medicalized" name (ME) made respondents more likely to attribute illness to medical causes and less likely to use psychiatric treatment methods and to assume the person was "faking" or exaggerating symptoms. The reverse was true for CFS: students were more likely to assume the patient was "faking" and to use psychiatric treatments, and less likely to attribute a biological cause to the patient's symptoms.

A study by Mann and Himelein (2004) however, suggests that labels are not the only factor in determining societal perceptions of persons with mental illness. Mann and Himelein surveyed 116 undergraduate students to ascertain whether the stigma of mental illness is a result of the person's behavior or of the label given to him or her. The surveys included vignettes of "Adrian," who had depression, and "Tony," who had schizophrenia, and asked respondents to complete a series of scales rating their level of comfort interacting with Tony and Adrian in various capacities (e.g., neighbor, friend). Half of the vignettes for each person contained diagnoses and medical terminology; the other half used lay terms and described only behaviors. Respondents expressed less stigmatizing attitudes toward Adrian than toward Tony. The descriptive language (medical, diagnoses/ lay, behaviors) used in the vignettes did not have a significant effect on respondents' level of stigma. However, the nature of the behaviors depicted in the two vignettes ("hallucinations"/ "sees things that are not there" versus "decreased appetite"/ "rarely feels hungry") likely also played a role in students' willingness to interact with "Adrian" and "Tony". These findings suggest that the stigma of mental illness is a result of both behaviors seen as bizarre or threatening and of the labels applied to those behaviors.

Rosenfield approached the issue of the stigma of mental illness by applying a labeling theory perspective. Labeling theory argues that the act of labeling is destructive to persons with mental illness because it "[creates] chronic mental illness or [compromises] the life chances of those so labeled," interfering with life satisfaction and well-being (Rosenfield, 1997, p.660). Opponents of this view, taking the so-called psychiatric perspective, argue that labeling mental illness is beneficial because it allows persons with mental illness to receive needed services. In this article, Rosenfield proposed that both mental illness stigma resulting from labeling and the receipt of mental illness services have an influence on the quality of life of persons with mental illness. She conducted interviews that addressed subjective quality of life, services received, perceived stigma, self-esteem, mastery, and mutual empowerment (addressing decision-making skills and “supportive interactions”) with clients of a “clubhouse” program providing mental health services. Results indicated that both perceived stigma and mental health services correlated significantly (negatively and positively, respectively) with clients’ reported quality of life. Perceived stigma resulted in clients’ more negative self-concept, and consequently in reduced life satisfaction. Mental health services, however, benefitted clients in the form of improved self-confidence and an increased sense of being in control of their lives. In this way, the labeling of mental health issues is a sort of “double-edged sword” for those labeled, producing both positive (assistance) and negative (stigma) outcomes simultaneously.

Experienced, anticipated, and perceived stigma of mental illness.

As we have seen, sources of the stigma of mental health are largely subjective and comparative, relying on the perceptions of the societal “other” in defining what constitutes “normal” and “acceptable” behavior. Such societal definitions may carry heavy penalties for those whom society deems “different,” “less desirable,” and “tainted.”

Moses (2009) applied Modified Labeling Theory (MLT) to investigate adolescents’ experiences with and perceptions of the stigma of mental illness. MLT, posited by Link and colleagues, proposes that “all individuals internalize cultural prejudices” against mental illness, that people with mental illness face negative treatment in society, and that “the societal devaluation of [mental illness] becomes personally relevant” for persons who are labeled as having a mental illness” (Moses, 2009, p. 262). Moses conducted interviews with 60 adolescents involved in “wraparound” programs, a mental health treatment approach in which treatment professionals from various agencies collaborate to develop and deliver a personalized treatment plan for children and adolescents at high risk of institutionalization. Few participants felt that children with mental health or behavioral issues are generally feared, rejected, excluded, blamed, mistrusted, or assumed incapable of improvement or self-care. However, many felt that youth with mental health or behavioral issues were likely to be teased, harassed, or looked down on by peers. One-fourth of participants reported never having experienced any of the negative treatments listed. Of the remaining participants, the majority reported on average two or three (of the six) types of negative experiences. The most commonly cited negative experience was feeling disrespected by peers (55%), and slightly more than one-fourth (27%) reported having been rejected outright. In terms of self-stigmatizing, almost one-third of participants (32%) admitted a fear of being disliked if others knew of their mental health issues; about one- fourth felt embarrassed by their mental health issues.

Angermeyer, Beck, Dietrich and Holzinger (2004) conducted a study in Germany that analyzed anticipated and experienced stigma among persons with depression and persons with schizophrenia. They asked participants about anticipated or experienced stigma along four dimensions: “interpersonal interaction, public image of mentally ill people, access to social roles and structural discrimination”. For each dimension of stigma, participants were asked two questions, one about what they believed would happen (answered on a Likert scale) and one about what they had experienced (answered in terms of yes/no/don’t know). The most commonly anticipated stigmatizing experiences were in relation to access to social roles (such as friend or employee), followed by negative public images of persons with mental illness. The most common types of experienced stigma reported concerned social interactions, with experiences of contact with negative media portrayals of people with mental illness also frequently reported. Results suggest that persons with mental illness anticipate stigmatization significantly more often than they actually experience it, especially in relation to access to social roles. Consistent with earlier findings (Mann & Himelein, 2004; Martin et al., 2000), participants with schizophrenia experienced stigmatization more often than did participants with depression, lending further support to the theory that labels are an important factor in the stigmatization process. Interestingly, however, the study found no difference in the frequency of anticipated stigmatization experiences based on diagnosis. This may be due in part to the higher frequency of depression compared to schizophrenia as well as to the negative media portrayals of persons with mental illness.

Unfortunately, being labeled is not the only possible negative consequence of mental health issues. Markowitz (1998) conducted a longitudinal study of stigma and life satisfaction among people with mental illness, collecting a second wave of data 18 months after the initial data collection. The sample included people in self-help groups as well as people in outpatient therapy. Questionnaires addressed self-efficacy, self-esteem, symptoms of mental illness, interpersonal and economic life satisfaction, and anticipated and experienced rejection. Results for both groups were similar. Seventy-two percent of respondents agreed or strongly agreed that people with mental illness are stigmatized (or “devalued and discriminated against,” p.339) ; about half reported negative treatment in the prior six months, including employment issues (17%), “social exclusion” and “verbal derogation” (14% each), “denial of rights (6%), and “adverse treatment by service providers”(3%)(Markowitz, 1998, p. 338). These findings suggest “anticipated stigma is related to depressive-anxiety symptoms and life satisfaction” (Markowitz, 1998, p.341). Anticipated stigma was unrelated to psychotic symptoms. Results also suggest that experienced stigma may have a significant impact on the effects of anticipated stigma. Self-efficacy and self-esteem (self-concept) influenced economic and interpersonal life satisfaction, although life satisfaction affected only self-esteem. Symptoms of depression and anxiety were more stigmatizing than symptoms of psychosis.

A similar study by Yanos, Rosenfield and Horwitz (2001) focused on the influence of social interactions on perceived quality of life among a sample of 104 clients of an inpatient treatment program (the majority of whom were middle age white males, unemployed, high school graduates, and diagnosed with schizophrenia). The interview consisted of measures assessing participants' number of supportive and negative social interactions, subjective and objective quality of life, perceived experiences of stigmatization, and psychiatric symptoms. Negative social interactions predicted lower subjective QOL scores, especially in relation to overall satisfaction with life, satisfaction with one's financial situation, and satisfaction with leisure activities, but they had no significant effect on objective quality of life scores. Supportive interactions, however, influenced both subjective and objective QOL, including frequency of contact with friends and family, leisure time activities, and current employment status (after controlling for psychological symptoms and demographics). Only two types of negative social interactions- being treated "like something is wrong with you" and being criticized by others- were significantly correlated with QOL scores. However, after controlling for demographic information and psychological symptoms, experiences of criticism by others were not a significant predictor of satisfaction with life. The number of negative interactions did have an influence on the amount of perceived stigma, which, in turn, had a significant negative correlation to satisfaction with life. Stigma was a mediating factor in the relationship between negative interactions and QOL, accounting for about one-fourth of the variance. Thus, for those with mental health issues, a variety of objective and subjective factors influence their quality of life.

Social stigma surrounding those with mental illness is pervasive; in some cases, not even those with mental illness themselves are immune to the strong cultural messages and may come to view themselves negatively in accordance with prevailing social views of people with mental illness (see “The Process of Stigmatization”). However, Watson et al. report that some people with mental illness appear energized and empowered by their stigma. In their study of the process of self-stigmatization among persons with a serious mental illness, the authors found that identification with persons with mental illness as a group served as a buffer against stereotype agreement and stereotype self-concurrence. Increased awareness of public stigmatization of mental illness was correlated with a decreased acceptance of this stigmatization as legitimate, while increased acceptance of the legitimacy of mental illness stigma increased the likelihood of self-stigmatization.

An old children’s rhyme claims, “sticks and stones may break my bones, but words can never hurt me”. As previously shown, however, it seems that words can indeed cause harm, and may often lead to more severe consequences that ultimately affect many areas of a person’s life. It should not come as a surprise, then, that many PSI, who are often labeled, blamed, feared, rejected, and viewed as dangerous, are reluctant to speak openly about their struggles and seek the help that they so desperately need.

Though SI has now become a relatively common topic of scholarly interest, research conducted on the issue has been largely from a clinical standpoint, resulting in a pathologized view of SI and a narrow focus on the behavior itself. This study attempted to fill a gap in the literature by focusing not on the behavior itself, but on how, when, and why people talk about it to others and their experiences with doing so.

Methods

The current study utilized data gathered from in-depth interviews and an online mixed-methods survey with the goal of gaining a better understanding of women's experiences with disclosure and nondisclosure of SI. The option of participating via online survey had the advantage of increasing the pool of potential respondents, as well as allowing people not comfortable with a face-to-face interview to participate. Interview topics included experiences with disclosure and nondisclosure in various relationships (e.g., family, friends, classmates, colleagues), experiences with seeking or avoiding medical or therapeutic treatment because of SI, and perceptions of experiences with stigmatization or discrimination (See interview protocol and online survey, Appendices D and G). Taken together, this information provided a more complete understanding of the perceptions and experiences of PSI relating to disclosure, nondisclosure and stigmatization. Recruitment for the study began in April 2010.

Setting

Four face-to-face interviews were conducted in a private location of the participant's choosing. Due to the sensitive nature of the research, it was imperative to create conditions to facilitate participants’ comfort, and allowing them to select the location of the interview while ensuring that the location was private helped to put participants at ease and showed respect for their privacy. Interviews locations included a private room at a local coffee shop, a private study room in Michigan State University’s main library, the participant’s place of employment, and the participant’s home. Every effort was made to ensure a quiet, private environment free of disruptions. The remaining 14 participants completed the interview via online survey.

Sample

The sample consisted of 18 participants who fulfilled eligibility criteria. Eligible participants were at least 18 years of age and identified as female. They were not enrolled in an inpatient or intensive outpatient mental health treatment program. Eligible participants had a history of episodic or repetitive SI, which for the purposes of this study included two or more episodes of "direct, deliberate destruction or alteration of one's body tissue without conscious suicidal intent" (Favazza, 1998, p. 260). Individuals who had self-injured because of a developmental issue (often referred to as stereotypic SI), compulsion (compulsive SI), or schizophrenia were excluded from this study. To reduce the potential for participation to create negative consequences (including causing urges to self-injure, or “triggering,”) participants who had self-injured in the previous six months were also excluded.

Procedures

In-person interviews. Approval of the Michigan State University Institutional Review Board was obtained prior to data collection. Participants were recruited through flyers (see Appendix A) hung in various locations on MSU's campus and in various locations in the surrounding communities, including coffee shops, a beauty salon, a women’s resource center, and the offices of several mental health services providers.

Recruitment flyers contained a brief description of the study and contact information (name, phone number, and email address) for those interested in participating. Every person who called or emailed was prescreened (Appendix B) to determine eligibility (see above). All eligible respondents were invited to participate in an interview at a convenient time and location. Before the interview began, the participant with a copy of the informed consent form (Appendix C). The key points of the form were verbally summarized, and the participant was permitted to read over the form if desired. If the participant voluntarily agreed to participate in the interview and to be audio recorded, she indicated her willingness by signing the consent form. Once informed consent was obtained, the audio recorder was turned on and the interview began. Participants were given the opportunity to ask questions or share their comments. At the conclusion of the interview, all participants received $20 to compensate them for their time and a list of mental health resources in Ingham County.

After the interview was completed, the audio file was downloaded from the digital recorder to a secure, password-protected folder on a password-protected computer. The audio file was then deleted from the recorder. Signed consent forms were stored in a locked safe in a home office. All interviews were transcribed, and any identifying information removed. Transcripts were stored electronically as password-protected files in a separate password-protected folder. Backup data were also stored in the locked safe on a password-protected external hard drive. Though the data were stored in a home office due to lack of on-campus office space, all necessary precautions (locked safe, password-protected computer, individually password-protected backup, folders and files) were taken to ensure the highest possible level of data security and participant confidentiality.

Online surveys. The Michigan State University Institutional Review Board approved the online survey, which was developed using SurveyMonkey. To recruit participants for the online survey, emails (see Appendix E) were sent to webmasters of several SI related online support groups, information centers, and local and regional mental health organizations to ask if they would be willing to link to the survey on their websites. Recruitment for the online survey was primarily through a post on a message board for family and friends of people with Borderline

Personality Disorder (see Appendix F); however, due to the nature of the Internet, it is impossible to know how individual participants heard of the survey.

The protocol was modified slightly for the online survey. Rather than prescreening potential participants for eligibility, the questions from the prescreening form appeared on individual screens before the consent screen. Participants were required to answer each question to determine their eligibility. If any of their responses made them ineligible, the survey was programmed to take them to a screen thanking them for their time, explaining they were ineligible, and providing contact information in case of questions. The in-person consent form was used, with slight modifications to the wording (e.g., "survey" rather than "interview"). The primary change was that, rather than signing a paper consent form, there was a statement at the bottom of the consent screen explaining that, by clicking the "yes" button, the participant voluntarily agreed to participate in the survey.

At the conclusion of the survey, participants were offered the opportunity to share any comments they may have had. Due to confidentiality concerns, individual participants were not identifiable and therefore could not be compensated for their participation. However, the final two screens of the survey provided my contact information and a list of national mental health resources. All responses were copied verbatim into a template, and analysis then proceeded as in the in-person interviews. Though the majority of participants chose how they would like to be identified in this study, the ninth, thirteenth, seventeenth and eighteenth participants in the study declined to provide a name and are identified as “P. N.,”“P. T.,” “P. S.,” and “P. E.,” respectively. No identifying information is included the transcripts. Quotations are included verbatim and may contain spelling and grammatical errors; however, obvious typos were corrected when required to make the meaning clear (e.g. “gold a lot of friends” corrected to “told a lot of friends”).

Measures

In-person interviews. In-person interviews followed a semi-structured interview protocol (Appendix D) which inquired about participants’ experiences with disclosure and nondisclosure of their SI to family members, friends, classmates, colleagues, and others. Participants also were asked about any experiences of seeking or avoiding treatment (physical or psychological) associated with their SI, and the interview concluded with a series of questions about perceived instances of stigmatization or other negative experiences related to SI.

First, participants were asked to discuss experiences with, feelings about, and reactions to disclosure and nondisclosure among the people they identified (via the ecomap diagram) as part of their social network. This included how others found out about the participant’s SI and how they reacted when they did, how the participant felt about them finding out, and, in instances in which the disclosure was intentional, how the participant decided to disclose and how she felt about her decision to disclose.

Participants also were asked questions about their experiences with treatment providers, including doctors, nurses, counselors, and therapists. These questions inquired about participants’ experience with seeking medical treatment for self-inflicted injuries, instances in which they may have refused or avoided medical attention and their motivations for doing so, and any experiences they may have had with mental health treatment providers. The interview concluded with a brief section on negative consequences of SI, such as instances in which participants felt stigmatized, discriminated against, or limited by their SI or resulting scars, and any experiences in which they were asked about a scar or wound from a self-inflicted injury.

Online survey. As explained previously, slight modifications to the in-person protocol were made for the online survey. To simplify data collection, the ecomap exercise from the in-person interview was replaced with four closed-ended questions, each one listing various categories of people (e.g., parent, friend, and neighbor). The first asked participants to indicate whether they are very close, close, or less close to the person(s) in that category (among those they considered part of their social network). The second asked participants to indicate how long they have known the people in their social network. The third asked them to indicate the people who know about their SI, and the final question asked them to indicate the people who do not know about their SI. The remainder of the survey questions followed the interview protocol, with the addition of questions to serve as "probes" where needed. These adjustments also served to increase the accuracy and completeness of data collected, as they addressed aspects of the in-person protocol that participants occasionally found confusing (i.e., the ecomap).

Analysis

Though this study was originally intended as a phenomenological study, changes in recruitment procedures necessitated a methodological shift to grounded theory. A phenomenological study "describes the meaning for several individuals of their lived experiences of a concept or phenomenon . . . and what all participants have in common as they experience a phenomenon" (Creswell,2007, p. 57-8). In this case, the phenomenon was SI disclosure. Such a study requires incredibly rich data from all participants to gain a thorough understanding of how participants make meaning of their experience. However, the necessity of modifying the study design to an online survey limited the richness and detail of data for a number of participants. In addition, participants reported incredibly diverse disclosure experiences, and choosing to focus on the "essence" of their experience would result in the omission of a great deal of data with the potential to provide valuable insights and a more complete understanding of SI disclosure. For these reasons, a phenomenological approach was abandoned and a grounded theory approach was employed. Grounded theory, like phenomenology, is well suited to exploratory studies. Glaser and Strauss have argued, “this is where grounded theory is most appropriate- where researchers have an interesting phenomenon without explanation and from which they seek to ‘discover theory from data’” (as cited in Suddaby, 2006, p.636).

Though the term “grounded theory” is often incorrectly applied to studies which merely describe data and fail to generate theory (Corbin & Strauss 2008; Suddaby, 2006) one of the intentions of this study was to propose a theory of SI disclosure, as the topic is largely ignored in the scholarly literature. The analytic procedure advocated by Corbin and Strauss (2008) was followed to generate a theory of SI disclosure. As they point out, “theories can't be built . . . from ‘raw data’. The incidents, events, happenings are taken as, or analysed [*sic*] as, potential indicators of phenomena, which are thereby given conceptual labels” (Corbin and Strauss, 1990, p.7). Thus, the process began with line-by-line open coding, “naming segments of data with a label that simultaneously summarizes, categorizes and accounts for each piece of data” (Charmaz, 2007, p.43). Axial coding followed and involved “relating concepts to each other” (Corbin & Strauss, 2008, p.195), a process which entailed collapsing a large number of codes into categories.

Initial coding was performed using a three-column Microsoft Word coding template as described by Hahn (2008), including the original text and applicable code(s). Axial codes were organized using a Microsoft Excel spreadsheet. Categorization involved the use of “constant comparison,” in which “each incident in the data is compared with other incidents for similarities and differences [and] incidents found to be conceptually similar are grouped together under a higher-level descriptive concept" (Corbin & Strauss, 2008, p.73). From this process, several negative cases (Ann, Alison, and Greylin) which did not fit the general pattern were identified (see "Establishing Trustworthiness"), and it was determined how and why their experiences varied from the norm. Integrating these cases and their correlating axial codes into a cohesive whole led to the identification of a "selective code" (Corbin &Strauss, 2008), a central code which subsumed all axial codes. Because the axial codes related to various factors which influenced SI disclosure- reasons for and against disclosure, prior experiences with disclosure, and previous experience seeking therapeutic or medical treatment- the representative selective code chosen was "how PSI make decisions about disclosure".

Establishing Trustworthiness

I employed numerous strategies to enhance the credibility of my findings. First, when possible, in vivo codes were used to keep themes rooted in the participants' own language. For example, I anticipated that some participants may discuss instances in which they attempted to downplay the severity of an injury or avoided discussing their SI. As several participants referred to these experiences as "blowing it off," I adopted their language and "blowing it off" became an in vivo code. Second, I conducted member checks with various people in my social network, including one therapist trained in treating SI, one person with scholarly knowledge of SI, and one person with a personal history of SI. These conversations helped ground the data and at times provided me with additional clarity and insight into the data. Third, I examined negative cases, described by Patton (2002) as those that do not seem to fit the emergent coding scheme, which contributed to trustworthiness by providing an opportunity to expand the analysis and ensure that all participants' experiences were represented. Fourth, after data analysis, I connected participants' responses to existing literature to show how findings were supported by existing theories about disclosure. Fifth, I engaged in reflexive memoing throughout data collection and analysis and responded to my own survey to remain conscious of any possible biases that may occur. These measures allowed me to remain conscious of how my personal experiences, beliefs, and expectations may have influenced the analysis and interpretation of the data. Thus, reflexivity helped serve as protection against attempting to fit the data to a preconceived hypothesis. This introspection and self-awareness is consistent with a feminist approach to research (Charmaz, 2006), as feminist methodology suggests that understanding of and receptivity to participants' experiences must be preceded by understanding of our own. Therefore, though it is impossible for my perspective to be completely absent in the data, it was not deterministic of my findings.

Additionally, my tacit knowledge, gained through scholarly research and personal experience, also enhanced trustworthiness. I have studied SI from multiple disciplinary perspectives (including psychology, sociology, and women's studies). I have also struggled with periods of self-injury since age 15, and have witnessed friends and family dealing with SI. My desire to study SI was a result of these experiences, most notably of the difficulties of choosing either to disclose or not to disclose my SI. This tacit knowledge and personal history were assets in this study, as they allowed me to more fully understand both the behavior itself and the issues accompanying it, and to respond to the need for a high degree of sensitivity surrounding these issues.

As a final means of enhancing credibility, I examined my experiences with the data collection process and considered how these experiences aligned with my findings. In the discussion, I will explain how the insights I gained as part of the data collection process substantiate my findings.

Overview

This chapter will summarize and synthesize participant's experiences with disclosure and nondisclosure of SI. The chapter begins with a brief summary of participant demographics. It proceeds with a presentation of participants' reasons for and against disclosure, types of disclosure, reactions to disclosure, and long-term outcomes of participants' disclosure of their SI.

Overall, participants reported that trust in the TOD, a desire to help other PSI, tacit permission, and the knowledge that the TOD also engaged in SI facilitated SI disclosure; shame, fear, judgment and prior negative reactions to disclosure hindered disclosure. Across participants, three categories of disclosure- voluntary disclosure, involuntary disclosure, and nondisclosure- emerged, with voluntary disclosure further categorized as full disclosure, selective disclosure, and/or delayed disclosure. Though participant's experiences with therapy varied, the few participants who had sought medical attention for self-inflicted injuries reported the experience(s) as overwhelmingly negative. These findings are discussed in further detail below.

Participant Demographics

All participants in this study fulfilled eligibility criteria (see "Sample" above). Participants' ages ranged from 18 to over 55. Among the four participants interviewed in person, two were non-White: one participant referenced her female partner in the online survey. Participants also were diverse in their experiences with therapeutic or medical treatment. Of the 18 participants, four spoke of their experiences seeking medical attention for a self-inflicted injury and the majority (13) had sought treatment from a therapist or counselor at some point in their lives. There also were differences in the number of people to whom participants had disclosed and the number of people who were and were not aware of their SI. These differences will be discussed in detail in the following sections. The following table (Table 1) summarizes participants' relevant demographic information.

Table 1. Summary of Relevant Participant Characteristics

Name	Age	Disclosure type(s)	Medical Treatment/ Disclosure	Therapy/ Disclosure	# who know	# who don't know
Sol	18-23	V-S	No	Yes/N	1	3
Rose	18-23	V-S; I	No	Yes/N	4	8
Alison	35-40	I; N	No	Yes/I	4	3
Courtney	30-35	V-S; I	Yes/NA	Yes/V	4	13
Casey	18-23	V-S; I	No	Yes/I	6	14
KLH	18-23	V-S; I	Yes/N	Yes/V	6	8
Nicole	55+	V-S	Yes/NA	Yes/V	3	2
Ann	41-45	V-F; D	Yes/N	Yes/V	9	3
P.N.	30-35	V-S; I	No	Yes/I	3	10
KM	30-35	V-S; D; I	No	Yes/I	5	14
Greylin	55+	N	No	No	0	6
Losing-myself	18-23	V-S	No	Yes/N	1	6
P.T.	51-55	V-S; D	No	No	2	13
Seppie	30-35	V-S; D; I	Yes/N	No	6	5
Jenny	18-23	V-S;I	Yes/NA	Yes/V	6	3
Bella	41-45	V-S	No	Yes/NA	4	19
P.S.	18-23	V-S; D; I	No	Yes/D	5	6
P.E.	18-23	V-S	No	No	4	8

Note: The "# who know/don't know" refers to the different relationships participants listed: some groups (e.g., friend, sibling, colleague) may include multiple members. The following abbreviations are used throughout the table, D=delayed, I=involuntary, N=nondisclosure, NA= not available, S=selective, V=voluntary

Reasons For and Reasons Against Disclosure

Throughout the interviews, participants referred to factors that motivated their disclosure, as well as factors that discouraged disclosure.

Reasons for Disclosure

Participants cited many reasons for their decision to disclose their self-injury, including emotional reasons, an opportunity to disclose, trust in the other person and the belief that they would be supportive and nonjudgmental, a desire for insight into their SI, the other person's own SI, and a desire to help or educate others.

Sometimes, their decision was emotionally driven. Several participants (P. S., P. E., and Bella) cited their "closeness" to the people to whom they disclosed as facilitating disclosure. Nicole, who had a distant relationship with her adoptive family growing up, said, "I think I was looking for attention, but I was looking for negative attention". Seppie's disclosure to her mentor was "because I needed him to know how much I'd been hurting". P. S. disclosed to a close friend "becuase [*sic*] i needed someone to confide in purely out of exhaustion from keeping up the act around everyone and having no one to trust," and Casey "told the people I told because I didn't want to be alone and feel so ashamed". P. E. commented, "I wasn't going to keep it a secret from my boyfriend, and I just felt like telling my friends". Rose's reason for disclosing to her friends "was just to confide in them . . . you know, high school girls, they talk". Another participant (P. N.) disclosed to her significant other in "a moment of vulnerability," in part out of a desire to explain "my sometimes confusing behavior when I was young". P. S. expressed a similar thought, saying "if they were a friend i didn't want to block out a part of [my] past and also a part of myself to them because then how could they ever truly know me". These responses suggest that disclosure may be motivated by a desire for connection and a need to have their emotions and struggles understood and validated. In one case, fear was a motivating factor: Seppie explained, “I told my parents because I was afraid I might kill myself by accident”.

Other participants disclosed simply because they had an opportunity to do so. As Sol explained:

> I told them about it, but it was because of, like, them noticing that . . . like something was wrong . . . like they’re like, ‘Hey, are you okay?’ or like ‘What’s going on? Do you want to talk about anything?’ or kind of thing. And then, like, usually when that happens it’s really hard for me not to, like, disclose, or something, where there’s like, an issue.

KM agreed, stating that, “If the situation arises where it makes sense to disclose it -- e.g. the subject of SI comes up independantly [*sic*] -- I have no hesitation in admitting I did it.”

Trust and perceptions of the TOD as understanding and nonjudgmental facilitated disclosure as well. Nearly half of participants cited their trust in those to whom they disclosed as a reason for disclosure. KLH reported that “the level of trust I had with the person had an influence on how willing I was to tell them”. Nicole echoed this sentiment, explaining how, for her, disclosure was because of “my-my trust in them . . . Trust with me has always been an issue, you know? And I could trust them with my life”. Participants also were more likely to disclose to those whom they believed were likely to be understanding: in the words of P. N., her disclosure was facilitated “definitely by my ability to trust someone's compassionate understanding”. Jenny also disclosed to those she did “because I knew I could trust them and they would be supportive”. Expecting the other person to be nonjudgmental was another factor in choosing to disclose. As Sol explained:

> When I do tell them it’s because I know that I can like, trust that person in the sense to, like, understand and be open enough to, like, hear what I’m saying without jumping to, like, ‘But you can’t do that!’ or ‘Why would you do that?’

When deciding whether to disclose her SI to someone, P. E. considered “how I felt they might react”. P. S. disclosed to others only if she “thought that they wouldn’t freak out”. Seppie stated simply that she is “more willing to disclose to someone who understands that this doesn't make me crazy”. Finally, Sol explained the potential for new insight as a motivation for disclosure, saying “when I feel . . . like there’s something to be gained from it . . . like, I might learn something from you . . . those are the opportunities I took . . . to really . . . to open up about it or whatever”. Bella agreed, explaining, “it felt good to tell someone and get help”.

Two parallel themes that frequently emerged were a desire to educate others on SI and a willingness to disclose to help other PSI. Several participants commented on how SI is often misunderstood and suggested their disclosure was motivated in part by a desire to rectify this lack of understanding. Notably, six participants stated that they would be more likely to disclose if they could help or educate someone else by doing so. As Ann stated, “I choose to [disclose] because [SI] is misunderstood . . . I choose to tell them in the hopes of educating people”. KM remarked that she would be “willing to disclose [her SI] if someone else is struggling and, by sharing my own story of struggle, they won't feel so alone or "bad" for doing it”. Ann expressed a similar thought: “I choose to [disclose] because I see that I can help people by doing so . . . Many people feel so alone. It helps them to see others suffer from it and have overcome it.” Sometimes, the desire to help may even trump all one’s reasons against disclosure. Alison, for example, had never willingly disclosed to anyone, but speculated that there may be one thing that would convince her to do so:

> My girlfriend from a group, she had a daughter that cut herself. Maybe to help somebody-a younger teenager or something-so that they wouldn’t do that, maybe. Try to say that . . . to tell them that I have the same issue, maybe they could relate, so that they didn’t feel so-stupid about it . . . and [would understand] that it can happen to anybody at any time . . .

Thus, for PSI, the desire to help or educate others can serve as a powerful motivation for disclosure.

A final theme that emerged as a facilitating factor was the TOD’s own experience with SI. Five participants relayed experiences in which someone had disclosed to them, prompting them to reciprocate. Losingmyself disclosed to a friend “to comfort them” and “because I wanted them to know they weren't alone”. P. T. learned from her son’s classmate that her teenage son had engaged in SI and “in the process of addressing that issue I told my husband then my son that I had self injured myself [*sic*] at around the same age (15 years)”. Her disclosure helped her “connect,” with her son, and “as he has grown older we are able to converse somewhat about his continuing self injury upfront”. Rose described how her own experiences with SI gave her new insight into her friends’ experiences. She explained:

> Almost half my friends had done it themselves . . . most of my friends that had done it had done it before I had ever had and I thought ‘oh, that’s disgusting, that’s gross’ . . . And then once I had done it, I saw why they did it. So that was part of the reason I told them.

Courtney commented, “once I found out my girlfriend was a cutter herself, it made it so much easier to tell her”. However, shared understanding did not necessarily make the decision to disclose easy. Losingmyself admitted, “if my friend was not in such a low state I wouldn't have said anything," and Casey confessed that "I really only told them [because] they told me first. Even when they told me, it took a lot of convincing myself to tell them too." No matter what prompted the decision, disclosure remained difficult for many participants. In the words of P. N., "it is certainly a taboo subject".

Reasons Against Disclosure

Participants gave multiple reasons for choosing not to disclose their SI: embarrassment or shame, fear of judgment, not feeling comfortable disclosing, prior negative experience, and concern for how their disclosure would affect others. Almost all participants identified embarrassment and/or shame as deterrents to disclosure. As Greylin put it, "If anyone were to find out that I self-injured . . . I would feel very embarrassed and ashamed". For that reason, several participants commented that they would feel "uncomfortable" or "yucky" about disclosing, especially if their SI was in the distant past. Several participants admitted that having engaged in SI made them feel "stupid" or "foolish". Bella felt that her SI was private and "not their business". Alison summed up the general feeling among participants, stating that SI "isn't something you're proud of".

In addition to the self-induced shame, participants often dreaded the judgments of others. As Seppie explained, "if I was going to be judged, I didn't want to disclose". Worries about being seen as "crazy" or "insane" as well as "what people will think of me" were common among participants. In high school, Casey and her best friend, both PSI, kept their SI secret from other students because "we didn't know that others did it too and worried that other people in school would judge us or think we were freaks". KM avoided disclosing to others because she "feared they would see it as a shameful, stupid thing to do". Rose noted that disclosure may have changed how others perceived her, because "when you say . . .'Oh, I cut myself,' . . . that leads into the whole, you know, other thing, and it's just- then people might view me differently . . . and then they wonder, "oh you still cut yourself?' and 'What's this?,' you know- 'that's gross'". P. S. expressed a similar thought, explaining that:

> When someone finds out that . . . you have self harmed they make instant judgements [*sic*] about you. if it's a stranger on the sidewalk you[r] daily life isn't affected much as long as your [*sic*] able to brush off the glances however, if your co-workers know that you actively SI or your friends or school or boss alot [*sic*] of dangers start to occure [*sic*].

Courtney confided that she felt it was "actually a positive thing that I don't disclose to people out of my circle--my co-workers or boss—[because] if they knew I'd worry more about what I think of me" which in turn may lead her to engage in SI.

Many participants commented on how misunderstood SI is, and how people often have inaccurate assumptions about PSI. Casey commented, "I just think most people don't understand. They think we're all crazy, or have been abused, or are violent". Alison expressed a similar thought, saying:

> People don't understand why you do it. It's like, 'why would you do something like that? . . . if you're going to try to kill yourself, why didn't you slice your wrist differently' or something like that. And you're really not trying to kill yourself. They don't understand that . . . they just don't understand.

Even people participants viewed as generally non-judgmental may react negatively to SI. As Sol explained:

> Some of my friends, um, who . . . who are really open-minded on a lot of things at times are not open-minded when it comes to like, um, like, sort of emotional or like, mental

> hardships kind of stuff, so they're not very sensitive to those things. And so, to them it's more like, 'Well, you're just not trying hard enough'.

Others' ignorance about SI and the potential for judgment and stigma caused several participants to cite the fear of being "outcast" as an additional reason against disclosure.

Though many participants were concerned about the potential social and emotional ramifications of disclosure, others cited pragmatic reasons for their nondisclosure. Courtney remarked that if her boss found out about her SI, "I'd be worried he would think I was a nutcase and let me go". P. T. felt that "any situation where it Important [*sic*] to be seen as normal or competitent [*sic*] or professional would be the kiss of death to disclosure". P. S. agreed, explaining how she was currently out of work and looking for a job and would conceal her scars during interviews because she is:

> Very fearful of people in power over me finding out . . . you are always aware that if someone knows about this they can forget everything they already know about you and everything you are telling them and all the see is an unstable human being not fit to be in a workplace or possibly in a relationship. if you decide to disclose it can sometimes make people afraid of you. which is dangerous in a work setting because they can fire you or decide wether [*sic*] to hire you or not on that small detail.

Sol described how "the idea of sharing this would be for me to, like, be able to either help myself or have somebody help me, so if they're not going to be able to do either of those things, why would I even . . . you know, go through the trouble of telling them". In one case, she chose not to disclose to another person who engaged in SI because "I didn't feel like it would also help her either, if I was like, 'Oh yeah, I'm doing this too' . . . so I never told her about it".

Past experiences also influenced several participants' willingness to disclose. Greylin confided that her mother, who had been diagnosed with a mental illness:

> Would shame me and humiliate me whenever I would become ill or injured as a child . . . tell me that I was stupid or clumsy or thoughtless, and make me feel guilty for causing her extra work. If I received a wound that needed stitching, she would tell me that I was ugly, that the scar was ugly and made me unattractive.

Casey had a more recent experience that made her reluctant to disclose. In high school, her decision to disclose "backfired when I told my aunt. I think it was [because] of how she responded that I hesitated to tell other people." Casey and Greylin's prior negative experiences suggest that even one negative experience with disclosure may hinder future disclosure. In sum, participants' restriction of disclosure to those whom they perceived as trustworthy and understanding emerges as a protective strategy for minimizing the risk involved in disclosure that may also serve to decrease PSI's shame about their SI.

Many participants also avoided disclosure for reasons related to the potential target(s) of disclosure. Rose portrayed her mother as "just a really 'don't ask, don't tell' kind of person. She doesn't want, you know, her life to be more complicated than it needs to be . . . she didn't want to ask questions, it was just she turned a blind eye." Nicole described how:

> My mother only wants to talk about pleasant things, even if it's not true, you know- you can wrap it in a pretty piece of paper and put a bow on it- that's what she wants to talk about … There might be a bomb inside, but she would just look at the paper and the bow.

Perhaps not surprisingly, neither felt comfortable disclosing to their mother.

Several participants chose not to disclose out of concern for the other person and concern about how disclosure may affect the TOD. Losingmyself avoided disclosing because "I have never wanted to do serious harm to myself and don't want anyone to worry about me". Sol added that if she told someone about her SI, "they'll always be worried about it. There'll be no way to, like, ever take that out of their mind again." She also was concerned that disclosing may negatively affect someone else because:

> Maybe that person might not be able to handle it . . . maybe they're just not ready, maybe they're not at a point in their life where they can handle something like that. 'Cuz, you know, that is also . . . not a burden, but it's something heavy to take on, just to even know about something . . . it may reduce them to feeling really helpless. And their relationship with me as like a friend or a family member, and either not being able to help me or not having been there, or maybe they should have known something.

Courtney also considered how her disclosure may affect someone else, explaining, "I always worry about telling my girlfriend [because] she is still a self injurer and deals with her own issues". Overall, participants reported a number of considerations that influenced their willingness to disclose and thus reported varying degrees of disclosure.

Types of Disclosure

Several different categories of disclosure emerged across the surveys and interviews: nondisclosure, involuntary disclosure, and voluntary disclosure. Voluntary disclosure was further divided into full, selective, and/or delayed disclosure.

Nondisclosure

Nondisclosure applied to cases or instances in which participants chose not to reveal their SI to others, or lied about it when asked. Two participants (Alison and Greylin) had never voluntarily disclosed their SI to anyone prior to their participation in this study. Other participants had disclosed to a select few but as Courtney explained, “typically do not intentionally disclose”. KM stated that her SI “is not something I broadcast or feel the need to tell everyone”. P. N. agreed, remarking that she “keeps it private” because “I don't think it's something that needs to be shared”. Casey also shared how she “[doesn't] want a lot of people to know. I make efforts to hide it. I hide all my scars and try to get rid of them with different creams”. Sol explained that, though she may talk to people about her life and her “bad days,” she wouldn’t often disclose her SI to them because keeping her SI private was “what’s most comfortable, it’s just that way,” adding, “I don’t bring it up for sure. Um, just because . . . like, there’s not really a time or place for it.” KM expressed a similar thought, commenting, “mostly it has not come up as a concern”. Sol’s and KM’s comments suggest that perhaps they may be more likely to disclose in the right conditions: if, for example, someone else broached the subject in a private, relaxed setting.

Concealing and covering up SI. Nondisclosure also occurred when a participant hid or lied about her SI. Eleven participants admitted that they made a conscious effort to conceal scars and injuries. Many of them dressed in ways that would hide their SI. Seppie commented, “I didn't want anyone to know when it was going on. I kept my body covered.” Greylin agreed, explaining, “I made a conscious decision to conceal my self-injuries. They were . . . small and in places covered by clothing.” Jenny, whose scars were on her wrist and legs, described how:

> I do make a conscious effort to conceal it . . . I wear a watch around people that I don't want to know. I am constantly adjusting it to make sure it's covering most of the scars . . . I can't wear shorts or short skirts. It's kind of awkward to go swimming too because the scars on my legs are pretty obvious and I can't wear a watch in the water.

Rose discussed how clothing affected her SI, explaining:

> It was really in the wintertime anyway when I did so you could never see it anyway. I remember [a friend] telling me something like, ‘you need to stop, because we’re going on spring break soon, you’re gonna be wearing a bathing suit,’ and then it kind of occurred to me I should probably stop, because . . . spring was coming, and I didn’t want people to see- I didn’t want to be one of those girls that had to, like, hide her cuts. I guess I eventually stopped doing it for reasons like that.

Alison, who frequently dressed to conceal her scars, said of SI:

> You wish you hadn’t done it, but the scars are still there. And you know, it’s pretty difficult when you have to be somewhere and it’s really hot out . . . You get the questions, and you get the stares.

Casey was concerned about other people seeing her scars, and reported that “I do cover my scars with clothing and spend a lot of money on creame [*sic*] and oils to try and make them less obvious to people”. P. E. also concealed her SI by wearing long sleeved shirts. P. S. explained how:

> After i had stopped [self-injuring] i got a job later and because i was working next to ovens all day long sleeves weren't an option . . . i had already taken measures during the interview and whenever [my boss] was around me to hide any scars becuase [*sic*] i was worried she would fire me . . . after wearing long sleeves every single day for 6 years on end i finally became comfortable enough to start wearing t-shirts and eventually tank top and short [sleeve] or sleeveless shirts.

These comments suggest that participants often chose to wear or not wear certain clothes based on how comfortable they were with other people seeing their scars.

Lying about SI. Despite their efforts to conceal scars and injuries, participants generally were not entirely successful in avoiding questions about "what happened". Of the 12 participants who reported having noticeable scars, all but one stated that they had been asked about a scar or injury and lied about how they got it. Jenny, the only participant who had not been asked directly about her scars, believed people did not ask because they assumed what happened, saying, "I think from the number of scars it's pretty easy to tell that I do it on purpose". When asked about their scars, participants utilized a variety of avoidance strategies to avoid explaining their self-inflicted injuries, including feigning ignorance, "blowing it off," and making an excuse. Losingmyself and P. N. both reported having told someone they "didn't know" or "didn't remember" when asked about an injury. Sol tried to "blow it off [and] make it so that whatever I'm blowing off really isn't important so you don't have to pay mind to it kind of thing". Alison took a similar approach, saying "Well, I'm not going to say 'I took a knife and cut myself all up because I was depressed,' and I'm going to blow it off as quickly as possible . . . and keep a smile on my face and act normal". Sol explained the different ways she would "blow it off," explaining:

> I was very nonchalant about it . . . I also used humor and storytelling also to kind of pull it off, because the more I engage with them on it, the less that they seem to be concerned about it, 'cuz like, why would I engage with you on something that I'm clearly, like, trying to hide?

In other cases, she would:

> Try to bring the attention to me in . . . a different way. So instead of attention on my injury, attention on me as like a clown and like, 'I remember this happened' and like,

> engage them that way and we laugh about . . . whatever. So, I do that, I guess- I redirect the conversation.

Most participants avoided questions by making an excuse for the injury. Courtney, who had a noticeable scar on her arm, reported, “I tell people, when they ask, that I burnt myself taking something out of the oven”. P. S. admitted that, when asked, she would:

> Always lie in a sarcastic way to let them know to back off. like ‘oh i was attacked with a cheese grater’ . . . i only use those responses for my arms becuase [*sic*] there is nothing i could say to explain it away and all i can do is make a snarky response to get them to stop asking questions . . . with small more isolated [injuries] i explain them away as accidents or animal attacks or warning to not cook on a stove when your [*sic*] so tired because [*sic*] it might result in injury.

Rose commented that once “my dad saw it, but I told him it was, like, the creases of my bed sheets, ‘cuz I had just woken up”. KLH would “usually tell them a story I made up . . . and they seem to believe me”. Sol also made up stories, such as when she told people, “Oh yeah, I fell” or “this bug-” or “we were like, playing sports and I collided with that guy in first”. Alison and Courtney would sometimes claim, “the cat scratched me”. Rose was sometimes asked about a scar on her shoulder and admitted that “because it’s on my shoulder, I just say like, ‘Oh, I had a pet rabbit and she scratched me’. . . But I did have a pet rabbit, and she’s just- she used to scratch me a lot, so I don’t really feel like I’m lying (sheepish chuckle).” Ann, who was more averse to lying about the cause of her injuries, explained how she:

> Consciously hurt myself in multiple ways to keep people from guessing that I did self-injure. I wasn't actually lying when I said that I spilled hot tea on myself, shut my hand in the door, hit my thumb with a hammer, burnt my hand on the stove, or broke my toe

> when a bowling ball fell on it. I did not want to have to lie, so I devised ways of injuring myself where I did not have to.

These comments suggest how stigmatized SI really is, as well as how far participants were willing to go to conceal their SI from others.

Participants cited several reasons for concealing or lying about their SI. Alison commented that, when asked about SI, lying is “just the easiest way to get out of it. And some people believe it, and go on their own way and don’t ask more questions.” Losingmyself agreed, commenting, “I lied . . . because it was the easy way out”. KLH explained that “the reason I would lie was because the stigma attached to injuring yourself brings such a burden sometimes and sometimes harsh words/actions from others. Plus, it was easier than explaining and answering, "Why would you do something like that? That's dumb.” Jenny too cited the fear of judgment as a reason for nondisclosure, saying “I just don't want people to judge me for it. I already judge myself enough, and have to see the scars everyday [*sic*].” P. S. lied because she “did not want the looks of sympathy or the interventions that i knew would come along with anyone finding about such a harmful thing i was doing to myself”. She also lied because “you either don't want the person to know becuase [*sic*] you don't know them that well yourself and it is such a personal topic, or your [*sic*] just scared of what could happen if they find out”. P. E. also was concerned about the potential consequences of disclosure, remarking, “I don't know what I would do/ what would happen if they found out. It would be an incredibly uncomfortable situation”. Courtney commented that she lied about her SI “because I felt I have to lie about it. People are not understanding.” Seppie took a slightly different approach to questions, saying: “about my scars, unless it was inappropriate I have always toldsome [*sic*] version of truth. About wounds, no never . . . I had great stories about them though.” Casey confessed, “I've flat out lied about it a couple of times . . . I guess that means I am still ashamed and afraid how they will react." Thus, the reasons participants gave for lying about their SI echo the reasons given for nondisclosure: shame, fear, the possibility of judgment, not wanting to bring it up, and others' lack of understanding.

Involuntary Disclosure

Involuntary disclosure occurred when a participant's SI was discovered by another person without them intending to reveal it.

Being Caught. Several participants had been "caught" engaging in SI or, as KLH put it, "they would find evidence of it". Alison, for example, reported how "my daughter caught me with a knife . . . blood everywhere," and Nicole described her last incident of SI, explaining how her husband had "come home, and . . . [there] was so much blood in the, um, tub, I got up out of it and thought I was gonna be sick . . . He cleaned it up, 'cuz I- I couldn't look at it." Courtney revealed that sometimes someone else would "see me do it". These graphic scenes of involuntary disclosure were likely highly traumatic for the person who was "found out" and the person who discovered the other's SI. Other instances of involuntary disclosure, though perhaps less dramatic, were also deeply troubling for all involved. P. S. described how "my parents found out throught [*sic*] finding razor blades i had kept in my room," and how "my school did find out" as well. Many participants had experiences in which their SI was discovered when others noticed a scar or injury: as Seppie said of her experiences with disclosure, "most of the time people see my scars," and Jenny explained how "my Mom found out that I SI when she saw the cuts on my legs". Finally, Casey related an upsetting incident in which "a co-worker found out recently, but not [because] I told her. She overheard a conversation I was having."

However, P. S. suggested that involuntary disclosure is not always such a negative experience, explaining how people sometimes "[do] a double take on my arms or there [*sic*] eyes linger long enough that i know they have noticed [my scars]. However, she rarely has people ask about her scars, and "on the rare occasions i do it is always a fellow SI'er looking to connect with me".

Being outed. Outing was another form of involuntary disclosure, in which one person disclosed someone else's SI to a third person without permission. Six participants (Seppie, Casey, KM, Jenny, P. N., and P. S) reported being outed, and all described it as a terrible experience. P. N. "showed my therapist who reported it to my parents. I was angry. They were angry. It was terribly embarrassing for me and I definitely felt like there was a stigma engulfed by a complete lack of understanding." KM described similar feelings, reporting how her mother mother "discovered it by seeing it on my body. She told my father about it. She was very angry. I felt shame, confusion, and hurt. I felt frustration that I couldn't make her understand that I wasn't trying to commit suicide." Jenny's experience paralleled KM's; her mother told her father after noticing the scars on her legs. When her brothers somehow learned of her SI, "they managed to berate me about it and it made me feel terrible". P. S. related how:

> My parents found out throught [*sic*] finding razor blades i had kept in my room. they were very upset and immediately insisted i see a counselor and start therapy and meds. i felt very ashamed and guilty that i was upsetting them so much.

Seppie shared how:

> My parents, when they first learned of my SI [told a] lot of there [*sic*] friends so they could 'pray for me'. This was disclosure I'd [*sic*] did not want and in a way made me feel ashamed of my SI inaway [*sic*] I never did when I self disclose.

Casey shared her experience with being outed, saying:

> Toward the end of high school, I told my aunt. I thought I could trust her and she was worried about me . . . She told my mother, though I asked her repeatedly not to. She wanted me to get help, which I now appreciate. At the time, I felt betrayed, angry, embarrassed and ugly.

P. S also related a second experience with being outed: she was the only participant to report being outed to someone other than a family member. As a younger student, though she was careful to conceal her scars at school, somehow:

> My school did find out and the the [*sic*] administration there was shocked and outraged at my behavior and kicked me out. i feel very hurt and that event made me feel even more ashamed of myself and stronger in my beleif [*sic*] that i was a freak and if anyone found out it would either result in them running away from me and forcing me to go somewhere to get 'fixed'.

These painful experiences suggest that any unintentional disclosure of SI is deeply upsetting for everyone involved. These participants' stories suggest that in at least some instances, people outing PSI do so out of a sincere desire to help, like Casey's aunt who reported Casey's SI because she "wanted [her] to get help". The reactions of the people who learned secondhand about another's SI - anger, sadness, rejection, ridicule, reaching out to others for help- underscore the public's lack of understanding of SI and how to respond to a disclosure of SI in an effective, supportive and respectful manner. Finally, participants' stories of being outed illustrate the potential negative effects of unintended disclosure- increased shame, loss of trust in the person who outed them, and feelings of anger, hurt, isolation, and betrayal, all of which may damage relationships and reduce the available sources of social support and understanding PSI so desperately need.

Experiences with involuntary disclosure were common among participants, with a majority (14) reporting at least one instance of involuntary disclosure. Whether the incident is as dramatic as Nicole and Alison’s SI scenes or as seemingly innocuous as Casey’s overheard conversation, involuntary disclosure can always be viewed as a potentially traumatic violation of a person’s autonomy in deciding whether to disclose.

Voluntary Disclosure

The majority of instances of disclosure reported by participants were voluntary. In other words, participants made a conscious decision to disclose their SI. Voluntary disclosure could be full, selective, and/or delayed disclosure.

Full disclosure. Full disclosure occurred when a participant made no effort to conceal her SI from others, and actually made a point of talking about it. Full disclosure was the least common type of disclosure in this study, reported by only one participant (Ann). Ann explained her reasons for speaking so openly about her SI, saying:

> As a nurse, I also think it is part of my professional responsibility to inform people about illnesses they may not be aware of or may misunderstand. I make it a point to talk openly about it because I think it is really misunderstood.

Ann also stated that “so many people know about it now because I make a point to tell them”. For example, during a class discussion on Borderline Personality Disorder, someone commented that s/he did not understand how people could purposely hurt themselves, and Ann took the opportunity to explain and share her experience.

Selective disclosure. Other participants were more reticent, engaging in selective disclosure-, as they disclosed their SI to certain people while concealing it from others. Selective disclosure was the most common form of disclosure in this study, practiced by 14 of the 18 participants. Many participants made comments identifying people who were aware of their SI and people who were not. P. T., for example, commented, “my older child knows but my younger child does not”. Rose remarked, “really the only people I flat-out told were my friends”. KM had “disclosed it to a few close friends and family (spouse)” as an adult. Nicole and P. N. also both reported having disclosed to their husband. Courtney reported that “I typically do not intentionally disclose but when I do it is to my best friend or to my therapist”. For P. S., “my biggest fear is rejection so i am very careful about who i talk to my past with SI about . . . i rarely tell anyone out and out what the scars are from.” All of these comments suggest PSI may be significantly more likely disclose to the people closest to them, including family members, close friends, a spouse or significant other. Jenny commented that “if they were just close enough to care but not much closer I didn't want to tell them because I feel like that's when someone is most judgmental”. As Sol said of the people to whom she had not disclosed, “there’s just, I guess, like, different forms of levels of relationships, friendships, whatever, so . . . And these particular ones, there’s no need for me to go to that point or really bring it up.”

Delayed disclosure. An emergent sub-category of voluntary disclosure was delayed disclosure. Delayed disclosure occurred when a long time lapse occurred between SI and the time when PSI first disclosed it: five participants described incidents of delayed disclosure. P. T. admitted, “it was 25 years before I could even name what I felt and tell my husband”. Seppie described a similar experience, saying, “In the beginning I didn't know what to say . . . and felt uncomfortable. But the further away from SI I get the more matter of fact [I] become about it." P. S. also "told friends later on in life". Thus, a participant's distance from her SI was related to the amount of shame she felt about it, so that shame tended to lessen with time. As KM explained:

> I don't remember the exact time I first disclosed my SI intentially [*sic*]. However, I do know it was many years after the fact. I held onto residual shame about it for a very long time. I probably did not let that go and come to terms with it for 15-20 years . . . [and] I was reluctant to disclose [my SI] until it was in the very distant past and I had come to terms with it myself. After coming to terms with [my SI], I have no problem admitting to it. Before then, it was sort of a 'shameful secret' from my childhood that I rarely, if ever, admitted to.

Because participants' shame and the need to "come to terms" with their SI before disclosing it often hinders disclosure, these comments may help to explain why it is not uncommon for PSI to engage in SI for an average of 10 years before receiving treatment. As the old cliché goes, admitting you have a problem is the first step in seeking help.

Reactions to Disclosure

Other People's Reactions

People to whom participants disclosed had various reactions to the disclosure; some were positive, some were not. Two participants reported that those to whom they disclosed their SI did not react strongly to the news. P. E. stated that "my friends didn't have a particular reaction," either positive or negative. P. S.'s coworkers noticed her scars, "but never addressed it directly or brought it up . . . [they] never made me feel uncomfortable." Her boss "at one point directly asked me" about her scars, but did so mostly out of "couriosity [*sic*] for why i participated in such an extreme behavior".

Ten participants reported at least one positive reaction to their disclosure. The most common positive reactions participants experienced were compassion, sympathy, understanding, concern, and support. P. S. stated simply, "when i have told friends later on in life i have usually had a positive experience". Three participants reported that others were concerned for them. Nicole's friends "all wanted me to get- get better, I know that, they all wanted me to get better . . . they would discourage me from that type of behavior," and KLH remarked that others' reactions were "mostly shown by fear/worry for my safety". Casey's mother, when she found out about her daughter's SI from someone else, "was really worried I had been molested or something [because she read somewhere that] a lot of people who cut have been assaulted. I told her over and over that I wasn't."

A majority of participants reported that others were supportive and nonjudgmental, reacting to the disclosure with understanding, sympathy, and compassion. Nicole described one friend as having "had nothing but compassion for me" and another "hasn't judged me either," adding that she believes her disclosure to two other friends helped make them more aware of SI, and "I think they knew I was in pain and I was crying out, you know?" Jenny's friend "was very supportive. It made me feel like I could talk to her." P. N. commented that her husband reacted to her disclosure with "compassion and understanding". Bella's friends were also "compassionate". KM reported that "the reactions to [my] adult admissions have generally been sympathy and understanding, often with surprise . . . [My SI] was the action of a confused, hurt child and I think most people understand that. So, if anything, they feel sympathy and understanding for me." Losingmyself's disclosure also came as a surprise to someone. After her friend admitted to SI, she disclosed her SI, and “they were shocked and we cried together”. Casey’s mother, after learning about Casey’s SI from someone else, “tried to understand. She read up on self injury online and bought a book to read.”

Ann described how “years ago as part of my recovery process, I began to tell people . . . Some just hugged me and told me that they loved me.” She also discussed a time she disclosed to her classmates and professor and how:

> Some of the students talked with me about it more after class. The professor said he appreciated my frankness and candor and was glad that I had received the help I needed. After the class ended, one of the students in that class also approached me and confessed to self-injuring. I was one of the few people she had told.

P. S. related her experience disclosing to a close friend, and how her friend:

> Was very calm about it and tried to help my not by constantly pestering/forcing my into treatment but by trying to [be] there to talk if i needed to and she supplied [me] with any medical bandages and things i needed but couldn't get openly . . . she was a great help and . . . is one of the major reasons i stopped [self-injuring].

Sol also reported that the people she told were supportive and nonjudgmental, saying:

> I think most of them were just, like, trying to understand what I meant, and trying to understand the severity of how I was feeling . . . once they understood that . . . they’d be like, ‘Okay, well, how does that . . . why does that happen?’. . . and just seeing if I even wanted to talk about it . . . but yeah, they’re pretty supportive, they’re like, trying to help me understand.

She also talked about her disclosure to one person in particular, describing her reaction as:

> You know, she just wanted to make sure I was okay and then she’s like, ‘Well, I understand. Like, I get it. Like, you just needed to do this to be like, okay, well, everything else is going crazy but I have power over this one thing, and I’m going to take advantage of it’. . . And it wasn’t like she was encouraging it, it was just more like, ‘I get what happened, like, and I’m glad you’re talking to me about it’. . . And, like, her empathizing that strongly with it really, like, helped me to like, calm down immensely . . . it wasn’t like I had to explain the whole thing, kind of thing, you know? She just knew.

Not all participants had others respond to their disclosure in such a nonjudgmental, affirming manner. Alison (who had never voluntarily disclosed) commented, “there’s been friends in the past that demonized later on” after somehow learning of her SI. P. S. shared how, when she was a younger student, other students “made fun of me and it was a regular event to . . . hear 'hey why don't you just kill yourself already' or something of that sort”. Casey’s aunt also “didn't respond well. She didn't understand. She asked me 'what is wrong with you?' and wondered how someone so beautiful could make themselves [*sic*] ugly. She cried.” Jenny’s parents “were very upset. They didn't understand why I was doing that to myself.” P. N.’s family, unlike her husband, reacted to her disclosure “with anger and not understanding”. P. E.’s boyfriend, after she disclosed to him, “cried and said that he had lost respect for me”. P. S. reported that she has “had people stop talking to me because of [my SI] or avoid my eye if they catch sight of my scars”. She offered her interpretation of their reaction, saying “some people as soon as they find out treat you like a rabid animal as if at any moment you might break loose of your composure and attack either yourself or them, and it frightens them”. Jenny felt that she might have been discriminated against because of her SI, remarking that “I think someone saw my scars during a job interview and I definitely didn't get that job, so yeah”.

Ann and Nicole also reported negative responses to their disclosure, both from their husbands. Nicole described her husband’s response to times he would “come home and find out I’d cut,” saying:

> [He] would be very upset with me. He would forgive me, but in the moment it was occurring . . . he felt sad. He would, you know, be in one room and I . . . would be in another room, and I would- I would feel real bad.

Ann described the only negative effect of her disclosure, commenting:

> For a short time, I think that it may have hurt my husband, largely because he blamed himself and did not like the thought of me in pain. He thought it was all his fault that I was unhappy. I know he feels guilty about it and about not ever having realized that I was doing it. When I first told him, I think it caused a rift between us.

PSI’s Reactions

Twelve participants reported diverse reactions to and feelings about their disclosure. In addition to the six participants who shared their overwhelmingly negative experiences with involuntary disclosure (see “Involuntary Disclosure”), Courtney also reported feeling negatively when she disclosed her incidents of SI, explaining that when she discloses to someone close to her, “I always feel guilty and worry that they will be mad at me”. P. E. admitted that she was “apathetic” about her decision to disclose to her friends after they showed little reaction to the news, though it “hurt me a lot” when her boyfriend reacted negatively to her disclosure.

Four other participants reported that they felt positively about their disclosure. Ann stated that “deciding to be open about my struggles with self-injury is one of the things I am most proud of”. Rose “was a little nervous, but I – I guess I felt better,” and Jenny said of her decision to disclose, “I was very nervous about how they would react but it turned out okay”. P. S. felt “intense relief that there was someone i did not have to hide around anymore”. Bella reported that after her disclosure, she felt “less lonely”.

Several participants had mixed feelings about their disclosure. Losingmyself remarked, “I felt better after the fact knowing I wasn't alone . . . I felt guilty for saying something but I know it was for the better.” P. E. stated, “I feel fine” about her initial decision to disclose and that “my only regret is that I have to confess every time I do it now, and hurt my boyfriend in the process”. Both Seppie’s and KLH’s feelings about disclosure varied according to the recipient of the disclosure. KLH commented, “depending on who it was, I was either ashamed (parents) or felt like I could show someone (boyfriend for example) a bit of my ‘darker side’”. Seppie reported that:

> I told my mentor, because I needed him to know how much I'd been hurting. I felt fine about it. I told my parents because I was afraid I might kill my myself [*sic*] by accident, and I felt a lotof [*sic*] shame. Now, that it has been years since I SI'ED AWhen [*sic*] I disclose it is for the purpose of helping others. And I feel empowered by what I have over come [*sic*].

KM expressed similar feelings, explaining that she had disclosed to a few people close to her as an adult “because I no longer feel shame about it. I understand it as a mal-adaptive coping mech[an]ism of a young child trying to deal with overwhelming difficulty at home.” These responses suggest that a person’s feelings about (voluntary) disclosure may be influenced in part by their reasons for disclosing, as the trust implied in feeling able to “show someone . . . a bit of your darker side,” understanding, validation, connection, and a sense of empowerment resulted in more positive feelings about disclosure.

Disclosure Timelines

As we have seen, reactions to a disclosure of SI- one’s own as well as those of others- may have a significant impact. Both Casey and Greylin suggested (directly or indirectly) that experiences in which they were judged, blamed, criticized, or felt their trust in another had been betrayed discouraged them from future disclosure. The inverse also may be true: experiences in which others react to a disclosure of SI with compassion and understanding may increase the likelihood of future disclosure. Participants’ experiences support this theory. All ten of the participants who cited positive reactions to their disclosure had disclosed to at least a few people; neither of the participants who had never voluntarily disclosed cited a positive experience with disclosure; and Ann, the only participant to disclose fully, reported overwhelmingly positive reactions to her disclosure. Also notable was the fact that five of the participants (Jenny, Casey, P. N., KM, and P. S.) reporting a positive experience with disclosure also reported a very negative experience in which they were outed. The following timelines (Figures 1, 2, and 3) illustrate the chronological order of Casey’s, KM’s, and P. N.’s disclosure experiences discussed as being either positive or negative experiences. Disclosure timelines for Jenny and P. S. are not included because, though both reported positive as well as negative experiences with disclosure, they did not specify the order in which these experiences occurred.

Figure 1. A summative timeline of positive and negative reactions to P. N.'s disclosure

Note: dots represent instances of disclosure to those named (with the most recent to the far right) and space between dots represents the passage of time. The spaces between dots are not to scale and provide only an approximation of the length of time that passed between these experiences with disclosure. A (+) indicates a positive experience; a (-), a negative experience.

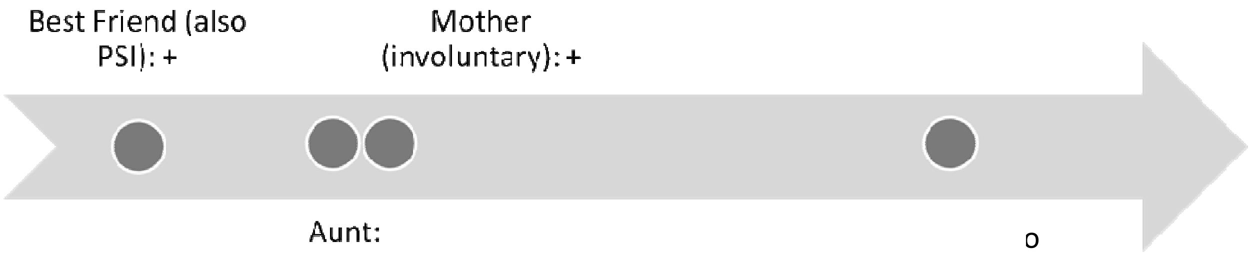
P. N.'s timeline represents all the people whom she reported as being aware of her SI. Because she commented that her disclosure was facilitated by her "ability to trust someone's compassionate understanding," we can surmise that her first disclosure was most likely because she trusted the therapist and felt safe disclosing. When the therapist reacted negatively and told her parents, she found the situation "terribly embarrassing". It was not until years later that she confided to her husband about her SI, and then only after initially lying to him when he asked her about a scar "because that's what I do when I think someone will judge the answer". Her experiences support the idea that prior negative reactions can significantly limit or delay disclosure of SI.

Figure 2. A summative timeline of positive and negative reactions to KM's disclosure

Note: dots represent instances of disclosure to those named (with the most recent to the far right) and space between dots represents the passage of time. The spaces between dots are not to scale and provide only an approximation of the length of time that passed between these experiences with disclosure. A (+) indicates a positive experience; a (-), a negative experience.

KM's first experience also was both involuntary and negative. Her mother's negative reaction contributed to her "residual shame," which lasted for over 15 years before she came to see her SI as a coping mechanism to help her deal with "overwhelming difficulty at home". After coming to terms with her SI, she eventually disclosed to her husband and a few close friends, all of whom reacted with sympathy and understanding. Later, she also disclosed to several members of online discussion forums she frequented: they reacted similarly. It is plausible that her first negative experience and the resulting shame she felt contributed to her delayed disclosure, and that the supportive reactions to her later disclosure and her decreased shame increased her willingness to disclose to others.

Figure 3. A summative timeline of positive and negative reactions to Casey’s disclosure



Note: dots represent instances of disclosure to those named (with the most recent to the far right) and space between dots represents the passage of time. The spaces between dots are not to scale and provide only an approximation of the length of time that passed between these experiences with disclosure. A (+) indicates a positive experience; a (-), a negative experience.

Casey’s first disclosure was to her best friend, who also engaged in SI. Her friend’s reaction was supportive. Casey later disclosed to her aunt, who reacted negatively and told Casey’s mother, who in turn was supportive. Later, Casey disclosed to her classmate Ann after Ann disclosed her SI to the class. Ann also was supportive. Casey’s experiences also suggest that other PSI are more likely to be a TOD, as they are thus more likely to be understanding and less likely to react negatively. Disclosure is also more likely to occur when the TOD is perceived as trustworthy and nonjudgmental (like Casey’s aunt). It is possible that Casey’s first positive disclosure experience increased her willingness to disclose to her aunt. Her aunt’s reaction likely made her more hesitant to disclose initially, but her mother’s supportive reaction (the only person who found out secondhand about someone’s SI who did not react negatively) may have increased her willingness to disclose, especially after Ann disclosed her own SI (which suggests she would be less likely to react negatively).

Long-term Outcomes

Participants reported overwhelmingly positive long-term outcomes of their disclosure, with only five participants (Alison, Casey, Jenny, P. S., and P. E.) reporting one or more undesirable long-term effects. The most common long-term outcome of disclosure related to a participant's relationship with someone to whom they had disclosed. Alison described how her relationship with her daughter was affected by her SI, explaining:

> I think it hurt my daughter and I . . . [My SI] didn't just happen once, and I think the last time, when she saw that . . . her trust factor went down. She, like, was really upset. Because once it's over for me, it's over, really, and they have to see the-they have to, like, go through it more.

Alison described her SI as impulsive and did not dwell on an incident of SI. Her comment here suggests that it may be more difficult for those closest to PSI to move on from a loved one's incidences of SI. She also felt that her relationship with her boyfriend was affected by his knowledge of her SI, saying that "it makes it hard to get out of the relationship, 'cuz . . . [it] makes it like, 'oh, he was there for me when I was doing weird stuff.' Makes it hard to obtain a healthy relationship." P. E. reported that her relationship with her boyfriend was negatively affected by "the aforementioned hurt" she felt after his negative reaction to her disclosure. Casey's disclosure also affected her relationships with her aunt and high school best friend, and she grew distant from them over time. She stated that she is "not that close to my aunt anymore. I still feel betrayed." Of her relationship with her high school best friend, she remarked:

> I don't see her much anymore. I think that is a good thing [because] we made it worse for each other . . . I would say it helped my relationship with her in the beginning [because]

> we could talk to one another. Later though, I think it has come between us [because] I stopped and she didn't.

P. S. sometimes had experiences in which she "disclosed my behavior to others who i thought were close to me and it has lead [*sic*] [to] them feeling disgust towards me and the relationship ending," although "this has happened rarely".

Other participants reported less of an effect on their relationships. Two participants reported that, though they felt their initial disclosure had not affected their relationships, there were some people with whom they did not discuss their SI further. Casey described how her past SI:

> Just became one more thing I don't talk about with my mother. She knows I don't do it any more [*sic*], so doesn't see a point in talking about it. I don't tell her I struggle with it a lot. I don't refer to when I was younger and did it. I don't mention my other friend [who still engages in SI] to her. I don't want to make her upset and she just wants to forget it and move on.

Ann agreed, saying of her initial disclosure to her husband, "I think it caused a rift between us. Now, it is a non-issue. I wish we could talk about it more, but I don't want to open old wounds, so to speak. It just reminds him of a painful time in my life and of what he perceives as his failings." In addition, five participants (Greylin, Jenny, KM, P. N., and P. T.) reported that they felt their disclosure (or nondisclosure) had not affected their relationships: as KM said of her disclosure, "I don't really feel it has had a big effect either way". Greylin, who had previously never voluntarily disclosed, said, "I do not think my nondisclosure has affected my relationships either positively or negatively. I suppose I am not a very open or trusting person to begin with. I never share everything that I am thinking or feeling, ever." Jenny remarked, "I don't really think it has affected my relationships with others very much. They love me and after they found out they still loved me."

Nearly all participants who felt their disclosure had a long-term effect (eight out of ten) reported at least one positive long-term outcome related to either a positive effect on their relationships. KLH commented that her disclosure had affected her relationships "mostly positively after a while". Rose remarked of the people to whom she had disclosed, "if anything it just made me closer to them . . . it definitely didn't hurt me". Bella expressed a similar view, stating that "disclosure has made me closer to people I care about". P. S. agreed, saying that for the people to whom she disclosed, "their knowledge of my past behavior and feelings usually strengthens whatever bond is between us already".

Ann described how her disclosure had benefitted others, saying, "I've been able to help other people who I care about … For others, my success in overcoming it has served as motivation and inspiration." Seppie said of her disclosure, "Sometimes it gives me a connection . . . like we are both from this darkness". Losingmyself stated, "I actually like the way things turned out . . . I have a better support system and can appreciate what I went through."

Aside from effects on their relationships, participants also reported other long-term outcomes of disclosure. Two participants reported that disclosure contributed to their recovery from SI. Alison shared how her boyfriend's discovery of her SI led to a turning point, describing how:

> He ended up throwing away my one knife, finally, so . . . really- I think that helped. I asked him to throw it away . . . and I watched him throw it away . . . I haven't really thought about it 'til now . . . It was about 7 months ago. Haven't done it since.

Ann's disclosure also helped her to overcome SI:

> Six years ago I would have said that the self-injury makes me feel secretive, alone, addicted, weak, and like a failure. Six years ago I was ashamed of it, disgusted with myself, full of self-pity. Now, I see myself as having suffered from a common mental condition that unfortunately has received a bad reputation. Now, I'm glad for the experience. It gives me a means of helping other people who do it. It makes me feel good to educate people and it gives my pain a purpose.

Others, however, did not feel as positively. Four participants commented on the ongoing potential for involuntary disclosure and the negative effects it had on their life. Alison worried that if people in her town found out, "word would spread that there was something wrong with me" and others would "talk behind my back". P. S. felt limited by her past SI and explained how she didn't "think i could ever be in any kind of public attention" because "anything from an actress to a politician [SI] limits you in some way. you could never hold a [*sic*] elected job because people view you as unstable." She also spoke about how she perceived her scars in particular as severely limiting, because:

> Anything that involves being able to reveal yourself in any way to the public, from hollywood [*sic*] to strippers, would be out of the question because of all these ugly scars you now carry around for the rest of your life. you would be constantly judged and scrutinized from every angle. it wouldn't work. even proffesional [*sic*] jobs such as bank managers or ceo's if you want someone to take you seriously as a person professionally [*sic*] you can't let them see.

Jenny also worried about the scars resulting from her past SI, saying, "now I wish I had never started [self-injuring] because I'll never be able to get rid of these scars. I mean, what am I going to tell my kids (If I ever have any) when they ask?"

Though several participants were concerned about the potential long-term effects of involuntary disclosure, Nicole took a different perspective on the issue, commenting:

> I just don't worry about it. There's too many other things in life to focus on rather than my past, 'cuz I can't change it, I only have the present moment to either go forward or, you know, go backwards, a- and you know, I hope I'm on the recovery path . . . to go forward in life. Let the past stay there, you know, and go forward . . . go forward in life.

Experiences with Counseling and Therapy

Disclosure and Nondisclosure in Therapy

Four participants - Greylin, P. E., P. T., and Seppie- never received counseling or therapy. Among the remaining 14 participants, three reported engaging in nondisclosure, four involuntarily disclosed, and six voluntarily disclosed. (Bella did not state whether her disclosure was voluntary.) Rose saw her therapist for approximately two years, but made a conscious decision never to disclose her SI because:

> I was doing better in the therapy and I didn't want to bring myself down or make her feel like, um, like I had fell back, and you know. Because we had made progress and . . . so I didn't want to bring it up, you know?

She also commented that it "felt kind of like I was holding something back by not telling her, but in the long run I didn't feel like it affected [my therapy] that badly". Sol also had "talked to counselors about different things," but not self-injury. Losingmyself also decided not to disclose her SI because she "did not want that hanging over my head. You know how it is always said 'everything said here stays here unless you intend to hurt yourself or someone else'?

Well that pretty much sealed the deal to not say anything," though she made it clear that "I didn't ever want to hurt myself in a suicidal way just did it for some relief".

Disclosure to a therapist, counselor or other mental health professional was divided between voluntary (Ann, Courtney, Jenny, Nicole, KLH, P. N, and P. S.) and involuntary (Alison, Casey, KM, and P. S.) disclosure. Ann confided that she "told my therapist after I had been seeing her almost a year. Even when I told her, I was nervous. I debated telling her for months before I decided to." Courtney stated, "I have often disclosed to my therapists over the years and my biggest concerns is that they will be mad at me or think I didn't try any other coping skills". KLH disclosed to her therapists "because I felt/knew that they were there to help me get better and wouldn't judge me (at least too much!) on what I did". The hesitance of these participants to disclose to their therapist suggests how taboo SI is and how difficult disclosure can be.

P. S. had sought therapy long after she was no longer engaging in SI and reported, "all the therapists i have seen i have told about my preivous [*sic*] self harm and they never really wanted to talk about it," although she also admitted that "i've never stayed with one that long so that might be the reason". P.N. also voluntarily disclosed to her therapist, but was angry and embarrassed when her therapist then told her parents about her SI. These responses to a voluntary disclosure of SI suggest that, in some cases, even trained mental health professionals may feel ill prepared to address SI and thus either avoid the issue or allow someone else to address such concerns.

Three participants did not voluntarily disclose their SI to their therapist. Alison, who had previously received more intensive therapy, explained that she had " cut myself in programs . . . just from being upset, and just finding something to cut myself with . . . [You get caught and you get] in trouble . . . And they take away your stuff." Both Casey and KM reported being "forced" to seek therapy, and both had their SI disclosed involuntarily. KM explained how:

> Because my SI happened when I was a pre-teen and my mother discovered it, I was 'forced' to seek treatment for it. She drug [*sic*] me into therapy. She therapist shopped until she found one that agreed with her 'take' on the situation

Casey had a similar experience- when her mother learned about her SI, " she insisted I go to therapy, but wouldn't come with me . . . My mom told the therapist I was there [because] I cut myself and 'needed help.'" P. S. did not seek therapy for her SI at first because at the time she:

> Was deathly afraid [*sic*] of any theripist [*sic*] or mental care provider because i was completely convinced that as soon as they found out what was going on they would lock me up somewhere and not let me come out until i proved my self [*sic*] to be a normally [functioning] human being (which at the time i never thought i could be).

However, her parents eventually discovered her SI and "insisted" she see a therapist and psychiatrist, "niether [*sic*] of which helped because [*sic*] i was so closed down at the time". Thus Casey, KM, and P. S. did not fondly recall their experiences in therapy, as they lacked both rapport with their therapist and autonomy within the therapeutic process.

Negative Therapeutic Experiences

Negative experiences with therapy were common among participants: of those who discussed their experiences in therapy, over half reported at least one negative experience. P. S. described her feelings about her experience as an outpatient in a psychiatric hospital, stating, "i just felt like i was another problem of theres [*sic*] to be fixed and prodded and expertly disassembled [*sic*]. it was like suffoctating [*sic*] in a test tube." Casey described her experience with her therapist, who specialized in working with adolescent women, saying:

> I didn't get a say in it and didn't like the therapist one bit. None of the books on her walls were about self-injury. She insisted at our first meeting that if I cut myself, I must do other things to hurt myself or other things I shouldn't be doing. She wanted me to get it all on the table upfront to 'know what were dealing with.' I didn't trust her. I kept going, but mostly sat on the couch with my arms crossed silently. I went for like a year before I told my mother I wasn't going to waste me [*sic*] time or her money anymore.

Casey was frustrated by her therapist because:

> I just felt she didn't understand and didn't have any experience with people like me. She treated people with anxiety, depression, [Attention Deficit Disorder], eating disorders, those kinds of things. She wanted to fit me into those boxes and was certain that there must be other ways I hurt myself too. She also thought I was suicidal . . . We never really talked about [my SI], we talked around it.

KM's experience was very similar, and she described it as:

> A terrible experience for me. I don't recall my SI being directly addressed -- I mostly recall the therapist suggesting a slew of oppressive rules and regulations to stop my 'acting out.' I don't recall him ever getting at the real problem -- a terrible and chaotic home life due to a mentally disordered mother.

Nicole also described aggravation over receiving ineffective treatment after a misdiagnosis years earlier:

> It wasn't until I took some tests at the psychiatric hospital that they realized I was borderline [Borderline Personality Disorder], they'd been giving me the wrong type of

> therapy for years and years-talk therapy, which made my situation worse rather than better. And it wasn't until I went on one of the newer medications Zyprexa and they took me off Prolixor- Prolixor didn't do anything for me, I'm walking the streets at night at midnight on Prolixor . . . half out of my mind-with the Zyprexa, I was able to find myself again.

Alison remarked on her prior experiences with clinicians in more intensive therapeutic treatment programs, saying, "they're mean. Some of them are mean to you. They- they have no sympathy. And they're treatment specialists. It's surprising . . . They're just mean." Jenny's experiences in more intensive treatment programs were also negative: she described the staff's frustration at her attempts at SI and that "I have had some nurses tell me it's really immature for me to still be cutting. They say 'Don't you think that's kind of a teenage thing to be doing?'"

Positive Therapeutic Experiences

Fortunately, not all participants' experiences were so negative. Nicole derived a great deal of benefit from her experiences in Dialectical Behavior Therapy (DBT), a skill-based treatment approach created to help people with Borderline Personality Disorder. She said of that experience:

> My life was pretty, uh, pretty painful, my life was, and I used the self-injury or the, or the cutting to kind of help the pain. That was the wrong way to go about healing pain, I realize that now, but . . . I didn't have the coping skills that I needed, and I did gain those skills through, um, a [DBT program] . . . and that's what helped me turn my life around, gave me a different way to think- and it changed my behavior: by thinking differently, my behavior changed. Without DBT I would probably still be, you know, doing the same

> old thing, ‘cuz I didn’t know any other way to cope. But DBT gave me another way to cope.

She also described how her therapist would help her develop effective coping mechanisms, saying “whatever I would bring to my counselor . . . she would tell me, ‘what skill? What DBT skill should you be using? . . . She always redirected me to these skills.” Other therapists also supported her use of alternative coping mechanisms when she disclosed her incidents of SI: as she commented, they:

> Appeared to me in the moment uh, to be, um, sympathetic. But they would encourage me not to do that kind of self-injury. They would say ‘well why didn’t you call emergency services at CMH?’ . . . ‘what could you have done instead of harming yourself?’ and, you know, stuff like that.

Alison also reported some more sympathetic reactions to her disclosure, saying of the therapists:

> Well, they always wanna see [the injury] . . . um, same question-‘did it make you feel better?’, then they give you the warning- ‘sometimes you could miss and actually hit a vein and die,’ give you the warning signs-which is good, to do it nicely, ‘cuz you can . . .
>
> I think they realize it’s more of an outlet. Better than killing yourself.

Jenny’s therapist “responded in a supportive way, but not too supportive. It was like she didn't want to make a big deal out of it so that I wouldn't do it just for the attention.” Bella reported that her experiences in therapy were “positive” and that she “did not feel stigmatized.” Ann’s experiences in therapy were perhaps the most positive. After her disclosure, “my therapist responded well. She was not judgemental [*sic*], was very understanding, and made me feel comfortable. I did not feel stigmatized. She even gave me a few books to read about [SI].”

Ann’s therapist also supported her in disclosing to others and “once called [SI] a 'silent epidemic' and said that I should be very proud of myself for giving it voice.” These comments suggest that therapists who are nonjudgmental and accept SI matter-of-factly and don’t “make a big deal out of it” were perceived by participants as the most helpful.

Factors Influencing Perceptions of Therapy

Overall, participants suggested a number of factors that may influence perception of therapy as either a positive or a negative experience. Participants who were forced to seek therapy rather than choosing to do so, lacked rapport with their therapist, felt that their therapist was unsympathetic, or viewed their therapist as lacking the understanding and skill to address their SI viewed therapy as both negative and ineffective. Participants whose therapists were knowledgeable about SI, sympathetic and nonjudgmental, and helped participants develop alternate methods of coping felt positively about their experiences in therapy.

Surrogate Therapists

Interestingly, two participants also shared experiences in which they sought help and support through alternate means. I have coined the term “surrogate therapist” to refer to these pseudo-therapeutic relationships. Casey described her relationship with Ann, saying:

> I think of her like a mentor. She has helped me more than the therapist ever did. She gave me some books and website support group information. We mat [*sic*] like once a week for lunch and she has helped me open up a lot. She listens, doesn’t [*sic*] judge and is the only person I knew at the time who stopped doing it. She was like a sponser [*sic*] like you hear about in AA. When I cut, [I] could call and talk to her and not be judged. When I wanted to, I could call her and we would do something else to take my mind off

> it. She taught me things to do to occupy my mind. It is [because] of her that I haven't cut in so long. She was a blessing.

P.S. also sought out additional support and resources, explaining how she:

> Did my own research online to try to understand what was happening to me and it led me to some very good sites with non harmful stress releif [*sic*] techniques and chat rooms where SI'ers could talk to each other, which was very important to me at the time because i was feeling so alone and cut off from everyone. everyone i met was very nice and open and non judgemental [*sic*]. online it was a good experience.

These comments suggest that some PSI, especially those who feel judged or misunderstood by trained therapists, may benefit from the support of others who can offer nonjudgmental advice and support based on their own personal experiences.

Experiences with Seeking Medical Attention for a Self-Inflicted Injury

The majority of participants-twelve out of eighteen-reported that they had never sought medical attention for a self-inflicted injury. Several of the participants who had never sought medical attention for a self-inflicted injury offered an explanation: all but one felt that there was no need because the injuries were “never that bad”. Only one participant (P. S.) explained that she declined to seek medical attention for self-inflicted injuries because she “was to [*sic*] afraid to go to an ER to [*sic*] and have them lock me up somewhere becuase [*sic*] i was a danger to myself”. Of the six who had sought medical attention for a self-inflicted injury, five reported at least one negative experience, generally a result of feeling that others were judging or stigmatizing them. KLH stated, “I always felt stigmatized, and have lied/created stories just so the doctors wouldn't try to treat me any differently”. Seppie agreed, saying, ”if I was going to be judged, I didn't want to disclose. This made me not want to tell doctors because I always felt judged by them," adding, "the first time I got stitches for a wound the doctor made me feel like a total idiot and was afraid I was suicidal. Which I wasn't." Nicole reported similar feelings, describing how:

> The last time I cut, I had to go the emergency room . . . I- I felt ashamed, and I could feel the personnel, the uh, nurses and the doctor were lookin' down on me because of what I'd done to myself. It wasn't an injury inflicted by someone else on me-it was an injury, a self-injury, and um, you know, I could tell they were, um, you know, not stigmatizing but, um . . . It was a- a shaming thing, you know. It was like a very negative bad thing to do to yourself, you know, for a person to harm themselves, their own flesh, is a very negative thing.

Courtney also felt stigmatized by medical personnel, reporting:

> On two occasions I had to visit the ER for my cuts . . . Then, when it was time to get the stitches out, I had to go see a friend of the family as to avoid embarrassment. People just don't understand.

Not all participants felt stigmatized or judged by medical personnel. Seppie described another instance in which she sought medical attention for a self-inflicted injury, saying "the next time there was no judgement [*sic*]. But that doctor knew me and knew who I was and my struggles and myself outside the struggle." Ann also did not feel stigmatized on the several occasions she sought medical treatment, explaining how:

> I always had a convenient excuse for them so no one ever suspected anything. Because I work at the hospital, I often had people I work with take care of me. They'd often just

> joke about how clumsy I was or make a joke about how my injury let me off the hook for some of the worst jobs.

Jenny's experiences with medical treatment were unique among participants. She reported that "I have had to get stitches and staples in my wrist before and the doctors that took care of me were generally understanding. I guess they see that kind of thing a lot."

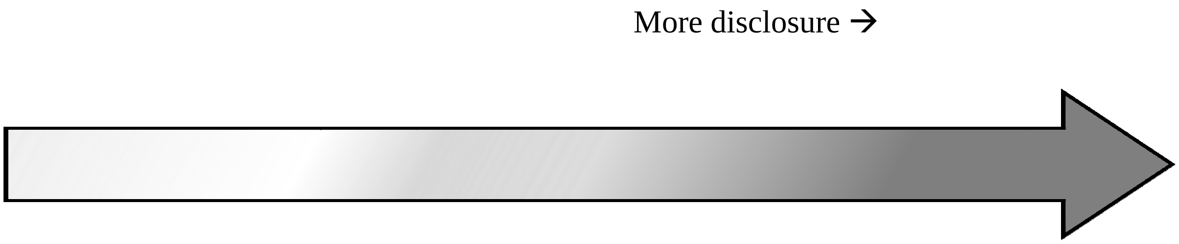
It is interesting to note that of the few participants who sought medical attention for self-inflicted injuries, most felt stigmatized by medical personnel. All but one participant who had received medical attention as a result of a self-inflicted injury reported that were not entirely truthful about the cause of the injury (Jenny did not say whether or not she lied), fearing or believing they would be treated poorly if they admitted the injury was intentional. Thus, though they may have suspected the truth, none of the medical personnel could be certain that the injury was intentionally self-inflicted. Therefore, the differences in treatment participants reported varied based on the provider's familiarity with and understanding of the person herself (Seppie and Ann) or of SI in general (Jenny).

This study examined the SI disclosure experiences of 18 women. A grounded theory approach was used to explore the socio-cultural context of disclosure and determine the factors that facilitate or hinder disclosure. Findings suggested that participants’ disclosure experiences were diverse and influenced by a multitude of factors.

The Spectrum of SI Disclosure: Avoiders, Accepters, and Advocates

I propose that the concepts of voluntary, delayed, and involuntary disclosure can be applied to describe a continuum of SI disclosure behaviors. In this study, PSI who (prior to this study) had disclosed only involuntarily or not at all (Alison and Greylin) were described as “avoiders,” because they went out of their way to avoid revealing their SI to others. The vast majority of participants (fifteen of eighteen) were “accepters.” Accepters frequently delayed disclosure until their SI was “in the past” and evaded questions from certain people (especially strangers and medical personnel) but would disclose to a select few. At the far end of the spectrum was Ann, the “advocate” who made a point of being open about her SI in an effort to educate and help others.

Figure 4. The spectrum of self-injury disclosure



Avoiders	Accepters	Advocates
Nondisclosure/ Involuntary disclosure	Voluntary delayed/ Selective disclosure	Voluntary full disclosure: may include delayed disclosure

Note: the terms “avoiders,” “accepters,” and “advocates” refer to *disclosure behavior at the present moment*. The terms do not refer to past disclosure behavior (e.g., someone who did not disclose as a teenager but discloses selectively now is considered an accepter, not an avoider), nor do they refer to acts of SI (i.e., advocates support not the act, but the disclosure of SI).

Ann, the sole advocate in this study, was unique in that her disclosure experiences were voluntary and overwhelmingly positive, and she received support from others in her disclosure. In contrast, Alison and Greylin, the avoiders, reported overwhelmingly negative experiences with involuntary disclosure. The majority of participants, as accepters, reported both positive and negative disclosure experiences, voluntary and involuntary.

Findings from the Ecomaps

These perspectives on disclosure were supported by the ecomaps. In analyzing the ecomap data, I collapsed the original 25 relationships described into nine categories: extended family, guidance relationship, immediate family, participant’s child, professional relationship, romantic relationship, social relationship, therapeutic relationship, and tentative ties. My decision to collapse these categories was based in part on the limited number of participants citing certain types of people as part of their social network (e.g., only two participants cited a religious leader). Though participants were asked how long they had known the people in their social network, I chose to exclude that data. Presumably, participants had known their immediate and extended family members for over 10 years (approximately 20% of the people cited were family) and there was little variation in the length of time they had known others in their social networks.

Parents and siblings were considered immediate family: aunts, cousins, grandparents, nephews, nieces, and cousins were categorized as extended family. Participant's children were categorized separately from other family because I thought that, due to their young age and immaturity, participants would be significantly less likely to disclose to their children than to others in their social network. Guidance relationships included mentors and religious or spiritual leaders; therapists and counselors were considered therapeutic relationships. Bosses, classmates, colleagues, co-workers, professors, supervisors, and teachers comprised the professional relationship category. A boyfriend, girlfriend, partner or spouse was considered a romantic relationship. Tentative ties included acquaintances, friends of the family, and neighbors. The remaining relationships were categorized as social relationships: these included best or close friends, coaches, friends, housemates, roommates, and teammates.

Participants were most likely to disclose to those with whom they had a therapeutic relationship and least likely to disclose to extended family members (see Table 2). Interestingly, both accepters and participants overall were more likely to disclose to a neighbor, friend of the family, or acquaintance than to members of their extended family. Rates of disclosure in guidance relationships did not vary significantly from rates of disclosure to immediate family: rates of disclosure to participants' children were slightly lower. Overall, findings suggest that a participant's level of intimacy with a TOD was more determinative of whether disclosure occurred than was the nature of their relationship. The people to whom participants were "very close" were more likely than not to be told of the PSI's SI: the opposite is true of those to whom participants were "less close" (see Table 3). Ann, the advocate, had disclosed to everyone in her social network to whom she was "very close," all but one person to whom she was "close," and all but 2 people to whom she was "less close". The influence of intimacy on disclosure was not as readily apparent among avoiders (Alison and Greylin), who had not voluntarily disclosed to anyone. However, it is interesting to note that they were more likely to report being "less close" than "close" or "very close" to those in their social networks.

Table 2. Disclosure by Relationship Type

	Percentage of each group told				**Fraction of each group told**			
	Accepter (N=14)	**Advocate (N=1)**	**Avoider (N=2)**	**Overall (N=17)**	**Accepter (N=14)**	**Advocate (N=1)**	**Avoider (N=2)**	**Overall (N=17)**
Extended Family	3.0%	50%	0%	5.6%	1/33	1/2	0/1	2/36
Guidance Relationship	33.3%	NA	NA	33.3%	2/6	0/0	0/0	2/6
Immediate Family	36.4%	100%	0%	33.3%	8/22	1/1	0/4	9/27
Child	20.0%	100%	0%	28.6%	1/5	1/1	0/1	2/7
Professional Relationship	10.7%	33.3%	0%	12.5%	3/28	1/3	0/1	4/32
Romantic Relationship	72.7%	100%	0%	60%	8/11	1/1	0/3	9/15
Social Relationship	43.6%	100%	NA	47.6%	17/39	3/3	0/0	20/42
Therapeutic Relationship	100%	100%	0%	85.7%	5/5	1/1	0/1	6/7
Tentative Tie	7.4%	NA	0%	7.1%	2/27	0/0	0/1	2/28

Table 3. Disclosure by Level of Intimacy

	Percentage of each group told				**Fraction of each group told**			
	Accepter (N=14)	**Advocate (N=1)**	**Avoider (N=2)**	**Overall (N=17)**	**Accepter (N=14)**	**Advocate (N=1)**	**Avoider (N=2)**	**Overall (N=17)**
Very close	56.0%	100.0%	0%	55.4.5	28/50	3/3	0/3	31/56
Close	25.0%	83.3%	0%	31.3%	10/40	5/6	0/2	15/48
Less close	11.4%	50.0%	0%	12.1%	10/88	2/4	0/7	12/99

Findings suggest that PSI frequently disclosed to romantic partners, some of whom (Ann's and Nicole's husbands) reacted negatively. These negative reactions differ from the negative reactions reported by other participants. Unlike other reported negative reactions, the husbands' negative reactions affected both the PSI and the target of their disclosure. Arguably, their reactions also were motivated not by anger or ignorance, but by love and concern; they did not condemn or blame their wives, but rather felt "sad" or "guilty" about their SI. We can speculate that perhaps Ann and Nicole's husbands reacted differently than Alison's friends, Casey's aunt, or P.N.'s family because of the nature of their relationship. Ann and Nicole presumably saw their husbands on a daily basis and most likely, participants did not have daily contact with, for example, an aunt or friend. Spouses generally share the most intimate parts of their lives, including their living spaces, their secrets, successes and sorrows, and even their sexuality. The intimacy and interdependence of marriage may make PSI's spouses feel partially responsible for the SI, because (as Ann's comments suggest), a spouse's disclosure of SI may make one feel that they somehow contributed to the behavior or should have known that it was happening. Other people in PSI's social networks, with whom their life is not as intertwined, would tend to feel less responsible for the PSI's behavior and are thus more likely to blame the PSI (rather than themselves) for their SI. Because SI is so commonly misunderstood, even among medical and therapeutic professionals (see e.g., Dennis et al. 1997, Crawford et al. 2003), PSI may be more likely to be blamed for their behavior than, for example, a person with depression or an eating disorder, potentially stigmatizing conditions which are more generally understood. As previous studies (see e.g., Chapple et al. 2004; Herek & Capitanio, 1993) have demonstrated that persons who are perceived to be responsible for their stigmatizing condition are more likely to be stigmatized, blaming PSI for their SI would increase the tendency for others to react with anger and judgment rather than support and compassion.

Participants' experiences revealed the existence of specific factors that serve to either facilitate or hinder disclosure and thus determine where on the spectrum of disclosure they fall.

Several facilitating factors aligned with existing models of disclosure. Petronio et al.’s (1996) concept of tacit permission, when a casual inquiry is seen as an invitation to disclose, applied to two participants. McKillop and Kelly’s (1996) decision disclosure model was found to be highly applicable to participants’ experiences. The decision disclosure model proposes that disclosure should occur only if the potential TOD is perceived as supportive and nonjudgmental and can be trusted to keep the disclosure secret: trust and perceptions of the TOD as supportive and nonjudgmental were the reasons most commonly cited as facilitating disclosure. The decision disclosure model also suggests that disclosure should occur if the potential TOD may be able to offer new insight into the issue. The potential for new insight was also cited as a reason for disclosure, albeit less frequently. Finally, Greene et al. (2006) proposed that disclosure is determined by factors including the quality of the person’s relationship with the TOD, anticipated reactions to the disclosure, and the presence or absence of conditions conducive to disclosure, such as privacy and conversational flow. Findings of the present study support this theory. Participants frequently cited “closeness” as a reason for disclosure, and often based the decision of whether to disclose largely on how they believed the TOD would react to such a disclosure. Conditions conducive to disclosure, though a less salient theme, also emerged as an influence on disclosure, as participants’ comments suggest that privacy and anonymity (e.g., via online chat) may facilitate disclosure (see **“**Reflections on Shame: Exposure versus Anonymity”) while disclosure is less likely when the topic “never comes up”.

Several unique factors were found to facilitate disclosure. A number of participants reported that they were more willing to disclose when they knew or suspected that the potential TOD also engaged in SI. Similarly, many participants (including Alison, an avoider) reported that they would be more likely to disclose their SI if doing so would help the TOD to address his or her own SI. The desire to educate others about self-injury was also cited (albeit less frequently) as a reason for disclosure. Education was a primary motivation for Ann's disclosure, as she was motivated by a desire to increase awareness of SI as well as a feeling of "professional duty" to educate others.

Multiple other hindrances to disclosure emerged in the findings. Many participants cited a general lack of understanding and a belief that "people don't understand" as reasons against disclosure. Others were discouraged by prior negative experiences with disclosure. Some were concerned about how their disclosure might affect those to whom they disclosed: others cited more pragmatic concerns, such as the potential for being fired from a job or "locked up" in a psychiatric facility. A few participants were simply embarrassed by their SI and did not want others to know about it.

Throughout the interviews, participants referred again and again to stigma: fears of being judged, experiences of being treated poorly, and shame about their SI, which was directly related to stigma. (The connection between shame and stigma will be discussed in further detail below).

Shame

In all participants' stories, shame emerged as a major factor in SI disclosure and nondisclosure. For these PSI, shame was a result of several factors, including harsh judgment, negative reactions from others, and an awareness of society's stigma of SI. Brené Brown (2007) argued that, "for many of us, shame is about exposure or the fear of exposure. This is why we work so hard to hide the flawed parts of ourselves that leave us open to being ridiculed or judged" (p.216). She explains that "we increase our shame by individualizing (I am the only one); pathologizing (something is wrong with me); and reinforcing (I should be ashamed)"

(2007, p. 100). This explanation aptly describes the shame of SI. Many participants at one point felt alone in their struggles, believing they were the only one engaging in SI (individualizing): they referred to their SI (and by extension themselves) using words like “foolish,” “crazy,” “stupid,” “shameful,” and “really weird” (pathologizing), and they often demonstrated an acceptance of the stigma placed on them as a result of their SI. Eleven participants referred explicitly to feeling “shame” or being “ashamed” of their SI at some point. Perhaps even more telling, two participants made comments that indirectly revealed their feelings about their SI. P. N., in speaking about her disclosure of SI and its effects, remarked that she did not feel her disclosure affected her self-image or her relationships. However, in speaking about these disclosure experiences, she remarked, “I feel ashamed”. Her use of the present tense rather than the past tense (“I *feel* ashamed,” rather than “I *felt* ashamed”) suggests that she too may be pathologizing her SI and reinforcing her shame. Alison confided that:

> If I knew that somebody did something like that [SI], I’d think it was weird . . . Yeah. I don’t know if I’d want to get very personal with someone who had a problem like that-there would be something deep-rooted, why somebody would be doing something like that.

Her comment suggests her (perhaps subconscious) condemnation of her own SI (a pathologizing behavior).

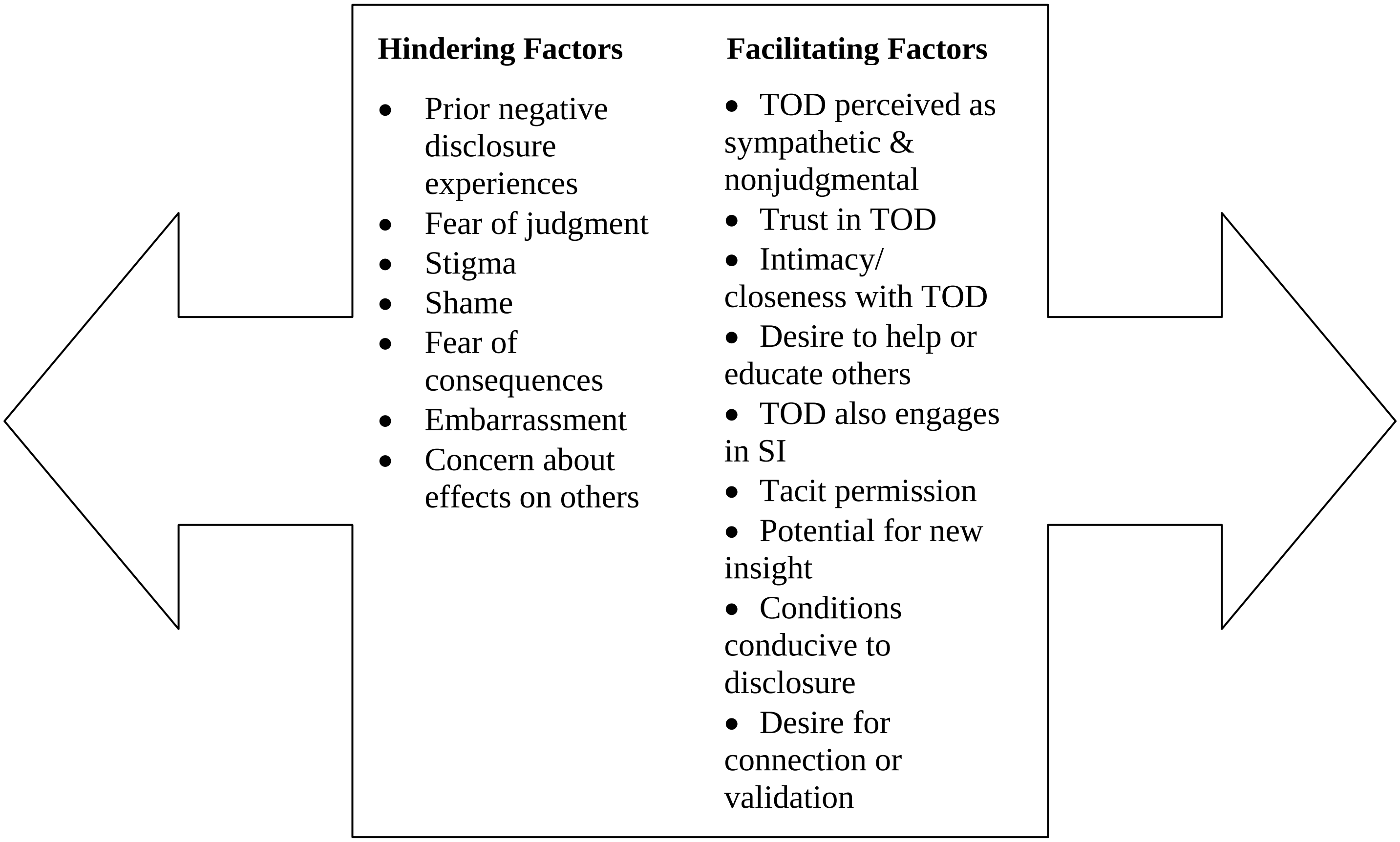
Both in-person and online, participants frequently (directly or indirectly) expressed feelings of shame about their SI. If, as Brown (2007) contends, shame is about “the fear of exposure,” it should come as no surprise that shame strongly influenced participants’ willingness to disclose. Participants who still felt a great deal of shame about their SI at the time of their interview were not likely to disclose. Those whose shame had abated over time and those who had not experienced stigma or judgment because of their SI were more willing to disclose. In light of these participants' experiences with disclosure and the prevalence of shame as an emergent theme, I posit that shame and SI are cyclically related, such that shame may increase SI and SI may increase shame. As shame increases, voluntary disclosure tends to decrease: involuntary disclosure also tends to increase shame.

A Grounded Theory of SI Disclosure

In summary, the extent to which PSI feel shame about their SI and their willingness to disclose in the future is affected by the nature and degree of others' reactions to the disclosure. Supportive, nonjudgmental reactions increase their willingness to disclose, while anger, blame, and judgment decrease willingness to disclose. PSI's relationships to TODs may also affect their willingness to disclose, as the ramifications of disclosure and its potential effect on a TOD vary greatly with the nature and intimacy of the relationship.

The following figure (Figure 5) summarizes the factors that facilitate and hinder disclosure and thus move PSI forward or backward along the spectrum of disclosure.

Figure 5. A summary of factors which facilitate or hinder SI disclosure



In summary, PSI disclose to varying degrees, which can be viewed as a spectrum of disclosure: avoiders as the most limited disclosure, accepters the greatest degree of disclosure, and accepters somewhere in between. PSI’s degrees of disclosure are influenced by a number of factors. Judgment, shame, stigma, embarrassment, prior negative disclosure experiences, and fear of the consequences tend to hinder disclosure. Trust, closeness, a desire to help or educate others, knowledge that potential TODs are also PSI, perceiving the potential TOD as supportive, and tacit permission tend to facilitate disclosure. Shame and intimacy emerged as the most salient factors influencing disclosure decisions.

Limitations and Strengths of the Present Study

Limitations

There were several limitations to this study. First, a few participants who completed online questionnaires rather than in-person interviews provided more limited responses to open-ended questions, and the nature of the online survey limited the ability to probe or clarify responses. To counteract this limitation, several probing/clarifying questions were incorporated into the online survey to elicit more detailed responses. A brief review of participants' responses suggests that the different levels of complexity and detail in responses- from a single word to an entire page-varied not by the method of data collection, but rather by participant. Both online and in person, some participants provided lengthy responses to each question, while others were much more reticent (see Appendix H, "Compiled responses to a single question"). Another limitation was that participants were self-selected, and thus may not represent the experiences of all PSI. However, because online recruitment was conducted primarily through an online message board with over 16,000 members, the message likely reached a large sample of eligible participants.

PSI, like many stigmatized groups perceived to be somehow to blame for their stigma, are a hard to reach population who may be reluctant to volunteer as research participants. However, because participants by definition were at least somewhat willing to disclose their SI, this limitation lends credence to the idea that shame is a significant factor in disclosure, as participants with a higher degree of shame and greater "fear of exposure" would most likely not volunteer to participate for a study on such a personal and taboo subject. Participants were much more likely to disclose in the context of an online survey, perhaps because the anonymity of the Internet helped mitigate some of the risk of disclosure: the influence of anonymity on disclosure will be explained in more detail below (see “Reflections on Shame: Exposure versus Anonymity”).

The present study included not only participants who spoke (relatively) openly about their SI but also those who had otherwise never voluntarily disclosed, thus representing a wider range of PSI’s disclosure experiences. However, as this study excluded PSI who were in an inpatient or intensive outpatient (“day”) mental health treatment program as well as those who had engaged in SI within the last six months, these findings may not be applicable to these populations. Because PSI in intensive therapeutic treatment are more likely to have recently engaged in SI and shame tended to decrease as disclosure tended to increase with time, it seems plausible that PSI with more recent episodes of SI may have disclosure experiences which differ from the PSI in the present study.

Strengths

Though the study sample may not include the perspectives of all PSI, it represents a number of diverse experiences and perspectives related to SI disclosure. Participants ranged in age from late teens to late adulthood, reported varying levels of disclosure (including two who did not choose to disclose), and may or may not have sought therapy or medical treatment for their SI. This study is the first in-depth analysis of SI disclosure, and it represents a starting place from which to understand the disclosure experiences of PSI. Many participants felt empowered by their involvement in this study and believed such work is necessary. For some participants, this study was the first time they were able to share their experiences without fear of judgment or reprisal, to be accepted as they are, and to know that they are not alone. PSI often use SI to express or manage their confusion, anger, shame, fear, and sadness. This study empowered participants by providing another means of witnessing and validating their experiences and making visible their triumphs and tragedies.

Insights and Observations

In this section, I will comment on the most significant insights and observations I gleaned through processes of data collection and analysis to facilitate a more complete understanding of my process, thus bolstering the trustworthiness of my research.

The Role of Iterative Interviewing

In grounded theory, data collection procedures evolve in response to previous experiences via a method known as iterative interviewing (Charmaz, 2006). Though I was unable to make significant revisions to my interview protocol, I did engage in some degree of iterative interviewing: for example, my online interview protocol was slightly revised from the original version to address a point of confusion related to the ecomap data. The most significant adaptation, however, was not in my survey, but in me.

It has been argued that, in qualitative research, the researcher functions as an instrument of data collection. My experience in conducting the initial interviews supports this view, as an observation early in the data collection process led me to modify my behavior to determine whether my perceived status as an insider or outsider may have influenced the data I received. The following is a reflexive memo I wrote following my interview with Sol.

> I noticed over the course of the interview that at times she seemed to be choosing her words very carefully and even seemed somewhat guarded, as if she were afraid of my reaction to what she was saying or afraid that I may be judging her. I also found it interesting that she only twice said self-injury” or “hurting myself,’ the rest of the time

> instead saying ‘it’ or ‘that.’ I realized that I happened to be wearing a shirt that covered my scars, and began to wonder if participants would act differently (more comfortable, more open, less guarded, et cetera) based on whether or not I had visible scars. I decided that, for the next interview I did, I would intentionally wear something that made my scars visible to see if the participant seemed to respond differently to that. Because self-injury is such a sensitive topic, I thought that perhaps I might get better data if it was apparent to participants that I am an insider.

To determine whether my perceived status as an insider or an outsider affected how participants responded to me, for my interview with Rose, I intentionally wore a short- sleeved shirt that revealed some of my scars, though I did not say or do anything to draw attention to them. I noticed that, during the second interview, Rose seemed more relaxed and open when discussing her SI than Sol had: though she also sometimes referred obliquely to her SI, unlike Sol, she also referred directly to her SI behaviors and even pointed out her scars. I interviewed Alison next, and again wore a short-sleeved shirt. As I later learned, I was the first person to whom Alison had voluntarily disclosed her SI. To my surprise, though Alison (understandably) seemed a bit hesitant throughout the interview, she also spoke openly about her SI: when asked whether she intentionally tried to conceal her SI, she responded, “Well, I’m not going to say ‘I took a knife and cut myself all up because I was depressed’”. Thus, it appears likely that my status as an “insider” may have improved data quality in these interviews by facilitating trust and presenting myself as a “safe,” compassionate, nonjudgmental TOD. Findings from the online surveys also support this possibility: a number of participants commented that they would be more likely to disclose to someone who had also engaged in SI and/or who was perceived as trustworthy, compassionate, and nonjudgmental.

Reflections on Shame: Exposure versus anonymity

Alison's interview was noteworthy for another reason: when given an opportunity to make a comment or ask a question, she asked whether her responses had been "sort of the norm of what other people have to say? Is this the same kind of feedback you get?" Her anxiety over whether her responses were similar to those of other PSI was noteworthy, particularly given that as an avoider, she had previously never voluntarily disclosed. She seemed relieved to hear that, though participants' experiences were diverse, there were some common themes. It seems plausible, then, that her inquiry represents more than simple curiosity, and in fact should be considered an attempt to reduce the shame she felt over both engaging in and later revealing her SI. Her desire to be reassured and to align her own experiences with those of other PSI may be viewed as attempts to resist individualizing and pathologizing her behavior and rather view it as something that "can happen to anybody at any time". This brief exchange was significant because (as previously discussed) findings suggest that early experiences with disclosure may have considerable influence on future disclosure behaviors: perhaps disclosure would be more common if all PSI were affirmed for having the courage to disclose and assured that they were not alone.

Though Alison's questions may be seen as one way of reducing the shame that often accompanies a disclosure of SI, other participants took a different approach, disclosing online in ways that made them unidentifiable to the TOD. The Internet affords many opportunities for connecting with others while maintaining complete control over what and how much a person reveals. In their study of disclosure via individual diary-style web logs ("blogs"), Qian and Scott (2007) found that in general, there was an inverse relationship between the amount of personally identifiable information on a blog and the blogger's level of disclosure on the blog, so that higher degrees of anonymity may be related to increased levels of disclosure. This finding helps explain why two participants suggested that they would be more likely to disclose their SI to someone known to them only over the Internet. As KM explained:

> Normally, the person (or forum) I disclose it on is aware that I had a difficult childhood . . . So, I have no problem in saying ‘I cut myself at one point when I was struggling with my difficult home life and in a particularly bad period of adjustment’ . . . The readers of these forums are known to me, but I have never met most of them other than online . . . I disclose . . . to very few people or in few places (I have disclosed it on public online forums but only under screen names that cannot be tracked except by those I would choose to share real personal identity with).

Casey also suggested that the anonymity of the Internet might encourage disclosure that would otherwise not likely occur, commenting, “I probably said more on here [this survey] about my cutting than I have to any one [*sic*] other than my mentor”. Thus, we can speculate that the ability to control the amount and content of disclosure, as well as the social distance implicit in online interactions (as opposed to relationships with those we see face-to- face on a daily basis), may make the possibility of judgment and/or the potential loss of a relationship less of a deterrent to disclosure.

Implications

Nondisclosure (or delayed disclosure) often has important implications for PSI and others. Many PSI avoid disclosing to medical and therapeutic professionals due to shame, stigma or fear of the potential consequences. In therapeutic situations, as PSI disclosing to mental health professionals may fear negative reactions as well as the possibility of being seen as a danger to themselves and thus made to seek more intensive treatment. Therefore, even when PSI do seek treatment, they may not disclose their SI to their therapist. In the present study, 14 participants had sought therapy: only about half voluntarily disclosed their SI. Concerns such as these may help explain why PSI delay seeking treatment for an average of ten to 15 years (Favazza, 1998). Delayed disclosure results in delayed treatment and may limit the effectiveness of therapeutic interventions. Shame, stigma and fear of the potential consequences may also deter PSI from seeking necessary medical attention for self-inflicted injuries. Failure to seek medical treatment for a self-inflicted wound creates the potential for complications, such as scarring, infection, or nerve damage.

When PSI do disclose, the TOD's reaction may have implications for SI. Previous research has found that PSI often engage in SI to relieve shame or anxiety (Abrams & Gordon, 2003; Chapman et al., 2006; Connors, 1996; McDonald, 2006; Suyemoto, 1998), to express emotions (Connors, 1996), or to cope with depression or emotional pain or turmoil (Abrams & Gordon, 2003). Negative reactions to disclosure may create feelings of shame, anxiety, depression, and emotional pain for PSI. Thus, negative reactions to disclosure may lead to further SI.

Disclosures to knowledgeable, nonjudgmental others may benefit PSI in helping to establish a network of both formal and informal supports to address their SI. Compassionate medical and therapeutic personnel with the skills to respond effectively to disclosures of SI facilitate treatment as well as future disclosure. Family, friends, and other informal supports, such as online support groups or "mentors" like Ann, are also beneficial. Thus, it seems plausible that people with a history of SI (but who no longer engage in SI) who have been formally trained in therapeutic techniques could be especially effective in responding to and treating SI.

Family, friends, peers, and professionals may all play a role in supporting individual PSI and, on a larger scale, helping reduce SI stigma. Efforts to increase dissemination of SI knowledge to medical and therapeutic personnel, as well as to the public, are a vital component in stigma reduction. As increased knowledge and understanding of stigmatized conditions tends to reduce stigma, we can posit that increased understanding, in decreasing stigma, may tend to increase disclosure and facilitate treatment for PSI.

Conclusions

Brown (2007) explained that “for most of us, reaching out to others results in tremendous individual change, and inspires some still further to engage in collective change.” PSI are often empowered by sharing their stories and having their experiences understood and validated. It is even more empowering to know that they are serving as an advocate in the fight against this “silent epidemic.” A cultural shift from viewing SI as a “taboo,” shaming thing . . . a very negative bad thing to do” to a “common mental health condition” requires two things: awareness and advocacy. Awareness entails not only a recognition that SI exists, but also an understanding of the nature of, prevalence of, and motivations for SI. Awareness also requires a common language for speaking about SI and a willingness to engage in frank discussion (for more on the role of language and labeling in stigma, see e.g., Corrigan et al., 2005; Jason et al., 2002; Rosenfield, 1997) on the issue. This level of awareness requires PSI to come forward, share their stories, and become advocates of honesty and opponents of shame and ignorance.

PSI who are willing to transcend their fear and shame to reach out to others are powerful advocates in the struggle for improved understanding and decreased stigma of SI. Shame and stigma flourish in an atmosphere of secrecy and ignorance; openness and awareness are their enemies. Brené Brown (2007) argues that "practicing courage, compassion, and connection in the face of shame is a political act" (p.132) which "creates the opportunity for both personal and social change" (p. 134). Participants' stories (especially Ann's) demonstrate how the decision to disclose empowers PSI to create powerful change in themselves and in those around them: to deepen intimacy with others through honesty and vulnerability, seek treatment, accept oneself, educate others, challenge stigma, and refuse to accept being seen and treated as "less than".

As this study shows and participants' voices attest, more such advocates are needed. When offered the chance to comment on the research, many participants (eight) demonstrated very positive feelings about this study and their participation in it. Several were pleasantly surprised to learn that such a study was being done. Many participants expressed appreciation of the fact that "there is someone who cares to hear their story without judgement [*sic*]" and gratitude for the opportunity to share their experiences. As Courtney commented, "Thanks for letting me talk about this. I don't get to talk about it often. It's nice to get things off my chest." Even Ann, who often took the opportunity to share her experiences with others, was "glad that I [participated in this study]. It has given me one more way in which to tell my story."

Several participants commented on the need for this study and others like it. Losingmyself remarked," I don't think there is any kind of education provided to children about the hard things they have to go through. There are some support lines set-up but if something more could be done, self-harm could be prevented," and Jenny stated that "I think it's really cool you're doing a study on this. It'd be great if some of the stigma of cutting could be reduced."

These participants' comments underscore the need for further research into SI disclosure. Perhaps with a better understanding of the factors motivating and inhibiting disclosure of SI, we can develop methods for encouraging PSI to reach out to others, speak out about their struggles, and seek the help they need without fear of rejection or rebuke.

Many participants seemed to recognize instinctively the potential impact of increased SI disclosure, as their comments also implicitly demonstrate that, though they themselves may not feel ready or able to act as SI disclosure advocates, they recognize the need for PSI willing to speak openly about their SI and disclosure experiences. In providing an opportunity for PSI to share their experiences without fear of judgment, I served (and was often implicitly acknowledged) as an "advocate by proxy," in much the same way as Ann's disclosure gave Casey the courage to share her experience. Thus, an advocate, in overcoming one's shame and breaking the SI taboo, not only empowers the one who discloses but also may empower other PSI by creating a space for them to disclose. As Brown (2007) writes, "it has been said that real freedom is about setting others free. In the spirit of that powerful definition, my greatest hope is that we will reach out across our differences and through our shame to share our stories and to connect with those who need to hear 'you are not alone'" (p. xxvii).

APPENDICES

Recruitment flyer (Appendix A)

Women Needed For Study of Self-Injury Disclosure

Who can participate in the study?

Women who:

- are 18 years of age or older
- have a history of more than one episode of self-injury not related to a developmental issue
- currently reside in Ingham County
- are not in a residential psychiatric treatment program
- have not self-injured in at least 6 months.

What is the project about?

The goal of this research project is to gain a better understanding of and women's experiences with disclosing (and not disclosing) self-injury. **No questions directly addressing self-injury methods or other potentially "triggering" questions will be asked.**

What do I have to do, and why should I participate?

If you are eligible to participate, you will be asked to participate in **one interview**, lasting approximately 60 minutes. You will also be asked to **complete a diagram** showing your relationships to various people in your life-family, friends, and others. You will be **compensated $20** for your time. This information will help to provide a better understanding of why people do or do not disclose their self-injury. It is hoped that this information may help to reduce the stigma of self-injury and encourage others to speak out and seek help.

How do I sign up or get more information?

Please call Meagan Hubbard at 630 740 4687 or email hubbar92@msu.edu to see if you are eligible to participate or to get more information about the study. Meagan will return your call as soon as possible and ask you a few questions to see if you are eligible to participate. If you are eligible, you will be invited to participate in an interview at a time and place that is convenient for you.

Prescreening form (Appendix B)

PRESCREENING FORM TO DETERMINE ELIGIBILITY FOR SI DISCLOSURE STUDY

1. How old are you?
    a. 17 or under-NOT ELIGIBLE
    b. 18 or older-CONTINUE TO QUESTION 2
2. What city do you live in? ____
3. Have you ever intentionally injured yourself, for example, by cutting yourself, burning yourself, hitting yourself, picking at your skin, or swallowing an object or toxic substance?
    a. YES-CONTINUE TO QUESTION 5
    b. NO-NOT ELIGIBLE
4. Have you intentionally injured yourself on more than one occasion?
    a. YES- CONTINUE TO QUESTION 6
    b. NO-NOT ELIGIBLE
5. Were these injuries intended to result in your death (in other words, were you suicidal at the time of the injury)?
    a. YES-NOT ELIGIBLE
    b. NO-CONTINUE TO QUESTION 7
6. Have you ever been diagnosed with any of the following conditions: mental retardation or developmental delay, autism, schizophrenia, or Tourette's syndrome?
    a. YES-NOT ELIGIBLE
    b. B. NO- CONTINUE TO QUESTION 7
7. Are you currently involved in any form of therapy, on an inpatient, outpatient or intensive outpatient basis?
    a. YES, INPATIENT/INTENSIVE OUTPATIENT-NOT ELIGIBLE
    b. YES, OUTPATIENT-ELIGIBLE
    c. NO-ELIGIBLE
8. Have you intentionally self-injured within the past 3 months?
    a. YES-NOT ELIGIBLE
    b. NO-ELIGIBLE

*Are you willing to participate in a face-to-face interview? _____________

INTERVIEW LOCATION: ____

INTERVIEW DATE/ TIME:____

PARTICIPANT'S NAME ____

PHONE #/EMAIL: ____

Consent form (Appendix C)

1. Explanation of the Research

You are being asked to participate in a research study of experiences with disclosure and nondisclosure of self-injury (SI).You will first complete an “eco map,” a diagram demonstrating your relationship to various people and groups. You will then be asked questions about whom you have told about your SI and your feelings about telling them, times you have sought or not sought treatment as a result of your SI, and times you may have felt that you were treated poorly as a result of your SI. You WILL NOT be asked any questions that directly address your experiences with SI. You must be at least 18 years old to participate in this study.

2. Your Rights to Participate, Say No, or Withdraw

Your participation in this study is completely voluntary. You have the right to say no and refuse to participate. You may at any time change your mind about participating and withdraw from this study. You may decline to answer any question or questions in the interview. You may also decline to have this interview recorded.

3. Costs and Compensation for Being in the Study

There will be no financial cost to you as a result of participating in this study. Your participation in this study will consist of one interview, which will last approximately 60-90 minutes. To compensate you for your time, you will be paid $20 at the conclusion of your interview (even if you do not answer every question). You will also be provided with a list of resources at the conclusion of the interview.

4. Contact Information for Questions and Concerns

If you have any questions or concerns about this study, please contact Meagan Hubbard by email (hubbar92@msu.edu), phone (630 740 4687) or mail (2904 Taylor St., Lansing, MI 48906). You may also contact Dr. Marsha Carolan via email at carolan@msu.edu. If you have questions or concerns about your rights and role as a research participant, would like to obtain information or offer input, or would like to register a complaint about this study, you may

Consent Form, cont'd.

contact, anonymously if you wish, the Michigan State University's Human Research Protection Program at 517-355-2180, fax 517- 432-4503, or email irb@msu.edu or postal mail at 207 Olds Hall, MSU, East Lansing, MI 48824.

5. Documentation of Informed Consent: Your signature on the line below indicates that you voluntarily agree to participate in this research study. You will receive a copy of this form for your records.

______________________________ _________________________

Signature Date

In-Person Interview protocol (Appendix D)

I. *Secrecy, Disclosure and Your Social Network*

1. ***Explanation of ecomap exercise***

Interviewer: "Before we begin the interview, I'd like you to take some time to complete an ecomap. Ecomaps are diagrams that show the various parts of an ecosystem: in this case, people interacting with their environment. In this study, ecomaps will be used to facilitate data collection and organization, and to help ensure that the data is accurate. I would like you to fill out this diagram with the first names, nicknames or initials of people you interact with. Please write the names of people who know about your previous self-injury in red ink, and the names of those who do not know in blue ink. Take your time, and let me know when you are finished so we can continue."

2. Tell me about the people in your ecomap: what is their relationship to you and how long have you known them? (If not mentioned: Are any of them in a position of authority over you, like a professor or a boss?)

3. Of the people that know about your SI, how did they find out? (Probes: Tell me about when they found out. What happened? How did they react? How did you feel?)

4. If you intentionally disclosed, why did you choose to do so, and how did you feel about it?

5. Of the people who don't know about your SI, did you make a conscious effort to conceal it from them? How and why? How would you feel if they were to find out about your SI now?

6. Do you feel that your disclosure or nondisclosure of your SI has affected your relationships with others, either positively or negatively? If so, how?

In-Person Interview Protocol cont'd

7. What things made you more willing to disclose to someone? What made you more reluctant to disclose?

II. PERCEPTIONS OF/EXPERIENCES WITH STIGMA OF SI

A. Health Care Experiences

1. Did you ever seek treatment from a doctor, nurse, therapist or other professional as a result of your SI (for example, to have a wound stitched or to address your concerns about your SI)? If so, did you ever feel stigmatized by them because of your self-injury?

2. Did you ever disclose your SI to any health care providers (including mental health care providers, like therapists)? If so, what was that experience like? If not, why not?

C. Other Possible Perceptions of Stigma

1. In your opinion, have you ever experienced prejudice or discrimination as a result of self-inflicted injuries, or scars or other marks resulting from self-inflicted injuries? (If so, please tell me about it.)

2. In your opinion, does your SI or the resulting marks/scars limit you in any way? (For example, can't do certain activities, can't hold certain kinds of jobs, or can't wear certain kinds of clothing)?

3. Has anyone ever asked you about a self-inflicted injury, or about a scar or other mark resulting from a self-inflicted injury? (e.g. "What happened to your arm?") If so, what was your response? If you lied about what happened, why did you lie?

4. Has your SI or resulting injuries affected the way you feel about yourself, either positively or negatively? If so, how?

Appendix E. Initial Online Recruitment Message

To Whom It May Concern,
I am currently a Master's student writing my thesis on women's experiences with disclosure and nondisclosure of self-injury, and wondered if you might be willing to help me. As part of my research, I am conducting an online survey and hoped you might be willing to share a link to the survey on your web site. If not, would you please forward this message to anyone else who might be willing to help?

The survey can be found at http://www.surveymonkey.com/s/7CSZKHM, or you can use the following code to create a link on your web site:
`<a href="http://www.surveymonkey.com/s/7CSZKHM">Click here to take survey</a>`

Eligibility criteria for the survey are as follows:
- 18 years of age or older
- Self-identify as female
- Intentionally self-injured on at least two occasions
- Have not self-injured within the past 6 months
- Not currently in an inpatient or intensive outpatient (day) mental health treatment program (those in outpatient mental health treatment are eligible)
- Not have been diagnosed with schizophrenia, autism, Tourette's syndrome, or a developmental delay.

If you have any questions or would like more information, please do not hesitate to contact me at hubbar92@msu.edu. Thank you for your time.
Sincerely,
Meagan Hubbard

Appendix F. Online Recruitment Message

Online Survey Opportunity-Posted with Permission
Experiences with disclosure and nondisclosure of self-injury

Participants are wanted for the Women's Experiences with Disclosure and Nondisclosure of Self-Injury online survey. The purpose of this research study is to learn about the various factors influencing self-injury disclosure. Your participation in this study will consist of one online survey, which will take approximately 30-45 minutes. You will be provided with a list of resources at the conclusion of the survey.

Please note that no questions directly addressing acts of self-injury will be asked.

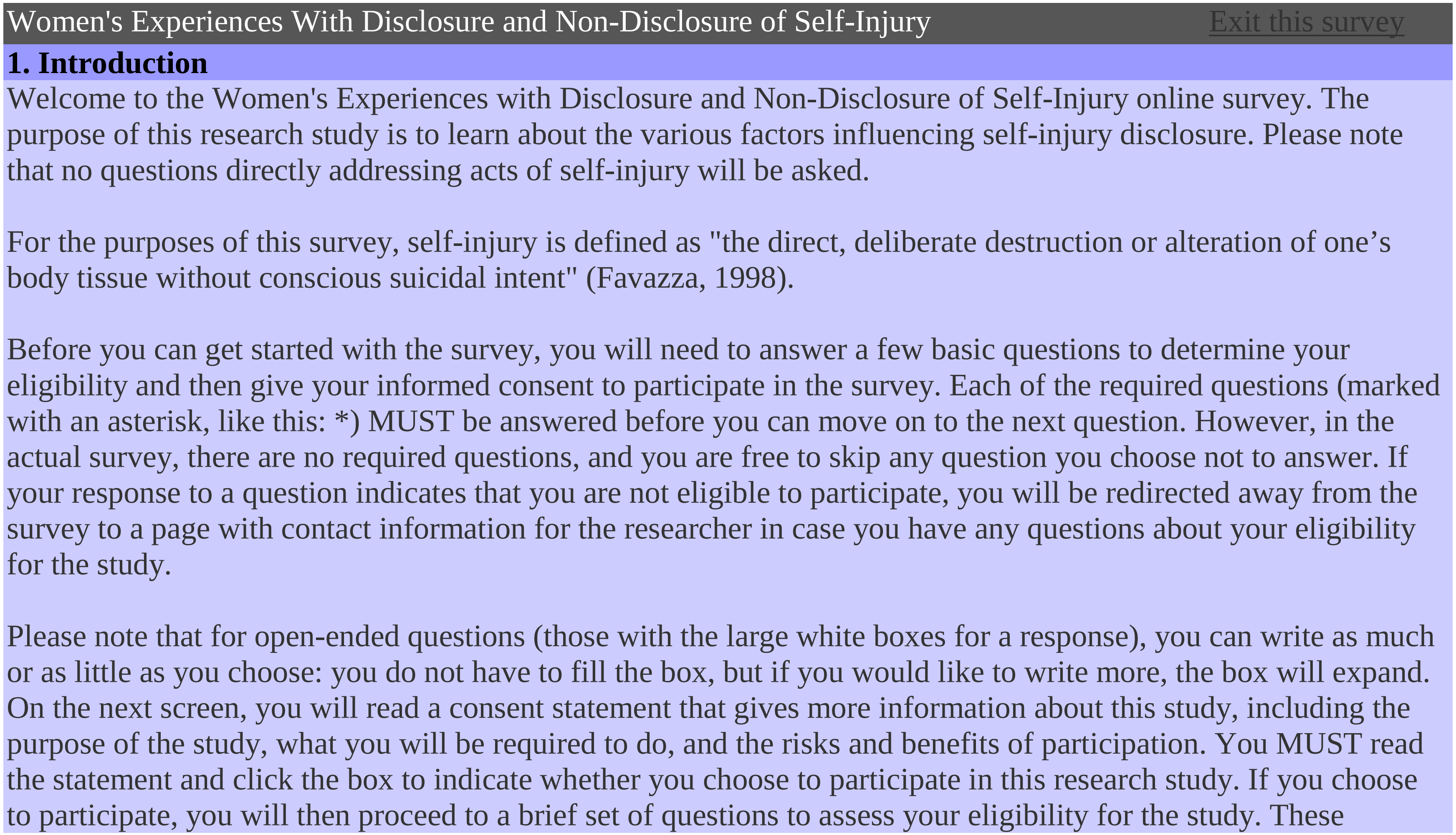
Eligibility criteria for the survey are as follows:

- Self-identify as female
- Intentionally self-injured on at least two occasions
- Have not self-injured within the past 6 months
- Not currently in an inpatient or intensive outpatient (day) mental health treatment program (those in outpatient mental health treatment or therapy are eligible)
- Not have been diagnosed with schizophrenia, autism, Tourette's syndrome, or a developmental delay.
- 18 years of age or older

The survey can be found at http://www.surveymonkey.com/s/7CSZKHM

Appendix G. Online Survey Protocol

For interpretation of the references to color in this and all other figures, the reader is referred to the electronic version of this thesis.



Women's Experiences With Disclosure and Non-Disclosure of Self-Injury

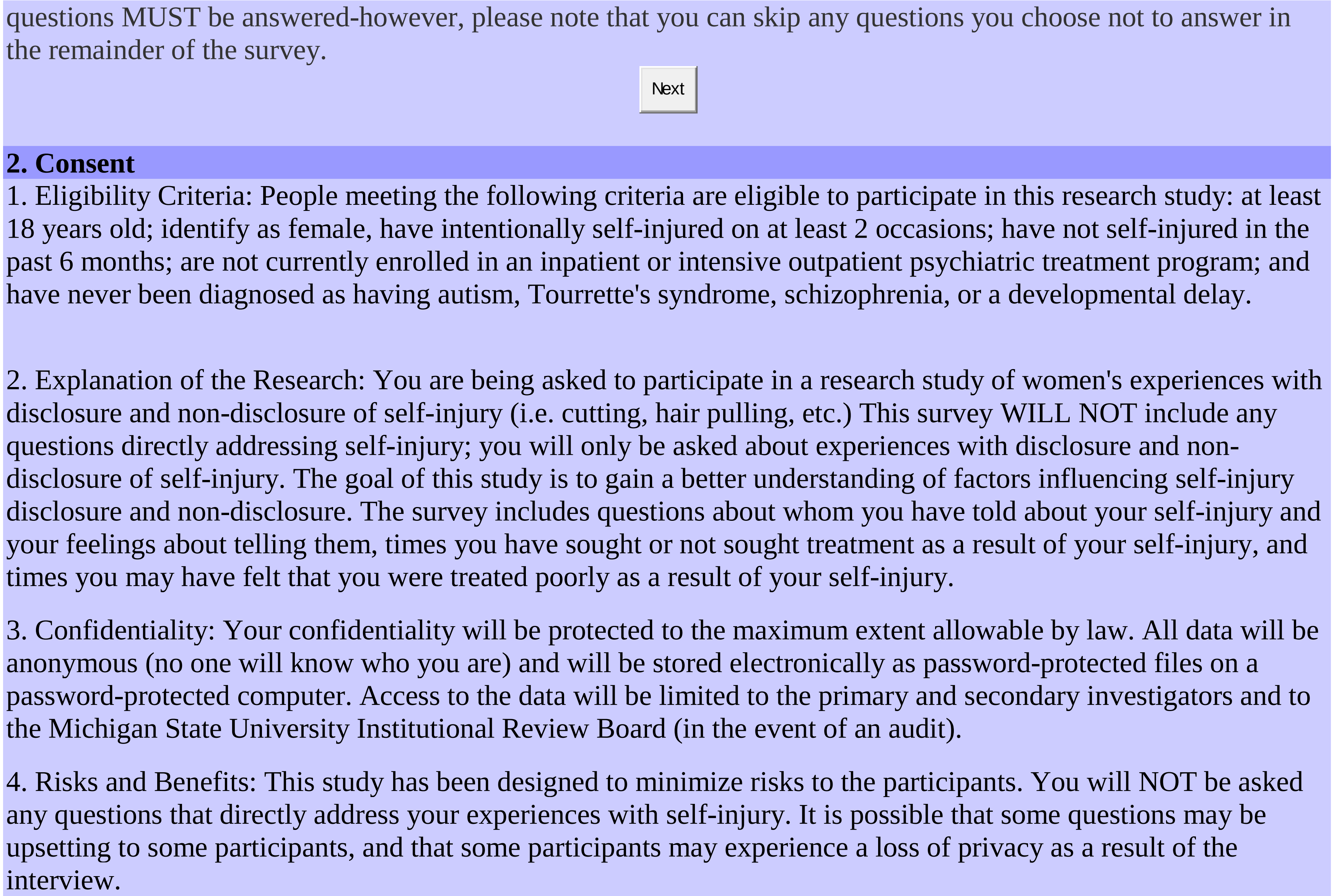
1. Introduction

Welcome to the Women's Experiences with Disclosure and Non-Disclosure of Self-Injury online survey. The purpose of this research study is to learn about the various factors influencing self-injury disclosure. Please note that no questions directly addressing acts of self-injury will be asked.

For the purposes of this survey, self-injury is defined as "the direct, deliberate destruction or alteration of one’s body tissue without conscious suicidal intent" (Favazza, 1998).

Before you can get started with the survey, you will need to answer a few basic questions to determine your eligibility and then give your informed consent to participate in the survey. Each of the required questions (marked with an asterisk, like this: *) MUST be answered before you can move on to the next question. However, in the actual survey, there are no required questions, and you are free to skip any question you choose not to answer. If your response to a question indicates that you are not eligible to participate, you will be redirected away from the survey to a page with contact information for the researcher in case you have any questions about your eligibility for the study.

Please note that for open-ended questions (those with the large white boxes for a response), you can write as much or as little as you choose: you do not have to fill the box, but if you would like to write more, the box will expand. On the next screen, you will read a consent statement that gives more information about this study, including the purpose of the study, what you will be required to do, and the risks and benefits of participation. You MUST read the statement and click the box to indicate whether you choose to participate in this research study. If you choose to participate, you will then proceed to a brief set of questions to assess your eligibility for the study. These



questions MUST be answered-however, please note that you can skip any questions you choose not to answer in the remainder of the survey.

2. Consent

1. Eligibility Criteria: People meeting the following criteria are eligible to participate in this research study: at least 18 years old; identify as female, have intentionally self-injured on at least 2 occasions; have not self-injured in the past 6 months; are not currently enrolled in an inpatient or intensive outpatient psychiatric treatment program; and have never been diagnosed as having autism, Tourrette's syndrome, schizophrenia, or a developmental delay.

2. Explanation of the Research: You are being asked to participate in a research study of women's experiences with disclosure and non-disclosure of self-injury (i.e. cutting, hair pulling, etc.) This survey WILL NOT include any questions directly addressing self-injury; you will only be asked about experiences with disclosure and non-disclosure of self-injury. The goal of this study is to gain a better understanding of factors influencing self-injury disclosure and non-disclosure. The survey includes questions about whom you have told about your self-injury and your feelings about telling them, times you have sought or not sought treatment as a result of your self-injury, and times you may have felt that you were treated poorly as a result of your self-injury.

3. Confidentiality: Your confidentiality will be protected to the maximum extent allowable by law. All data will be anonymous (no one will know who you are) and will be stored electronically as password-protected files on a password-protected computer. Access to the data will be limited to the primary and secondary investigators and to the Michigan State University Institutional Review Board (in the event of an audit).

4. Risks and Benefits: This study has been designed to minimize risks to the participants. You will NOT be asked any questions that directly address your experiences with self-injury. It is possible that some questions may be upsetting to some participants, and that some participants may experience a loss of privacy as a result of the interview.

Though there is no direct benefit to you, it is hoped that participation in this study will help to provide a better understanding of why people do or do not disclose their self-injury. It is also hoped that this information may help to reduce the stigma of self-injury and encourage others to speak out and seek help. 5. Contact Information for Questions and Concerns: If you would like to report a research-related injury or have questions or concerns about your rights and role as a research participant you may contact (anonymously if you wish) Michigan State University's Human Research Protection Program at 517-355-2180, fax 517- 432-4503, email irb@msu.edu or postal mail at 207 Olds Hall, MSU, East Lansing, MI 48824. You may also contact Meagan Hubbard at hubbar92@msu.edu or Marsha Carolan at carolan@msu.edu to obtain information about or offer input on this study.

6. Your Rights to Participate, Say No, or Withdraw: Your participation in this study is completely voluntary. You have the right to refuse to participate. You may at any time change your mind about participating and withdraw from this study. You may decline to answer any question or questions in the survey, other than the first six questions (which comprise the screening questionnaire).

7. Costs and Compensation for Being in the Study: There will be no financial cost to you as a result of participating in this study. Your participation in this study will consist of one online survey, which will take approximately 30-45 minutes. You will be provided with a list of resources at the conclusion of the survey.

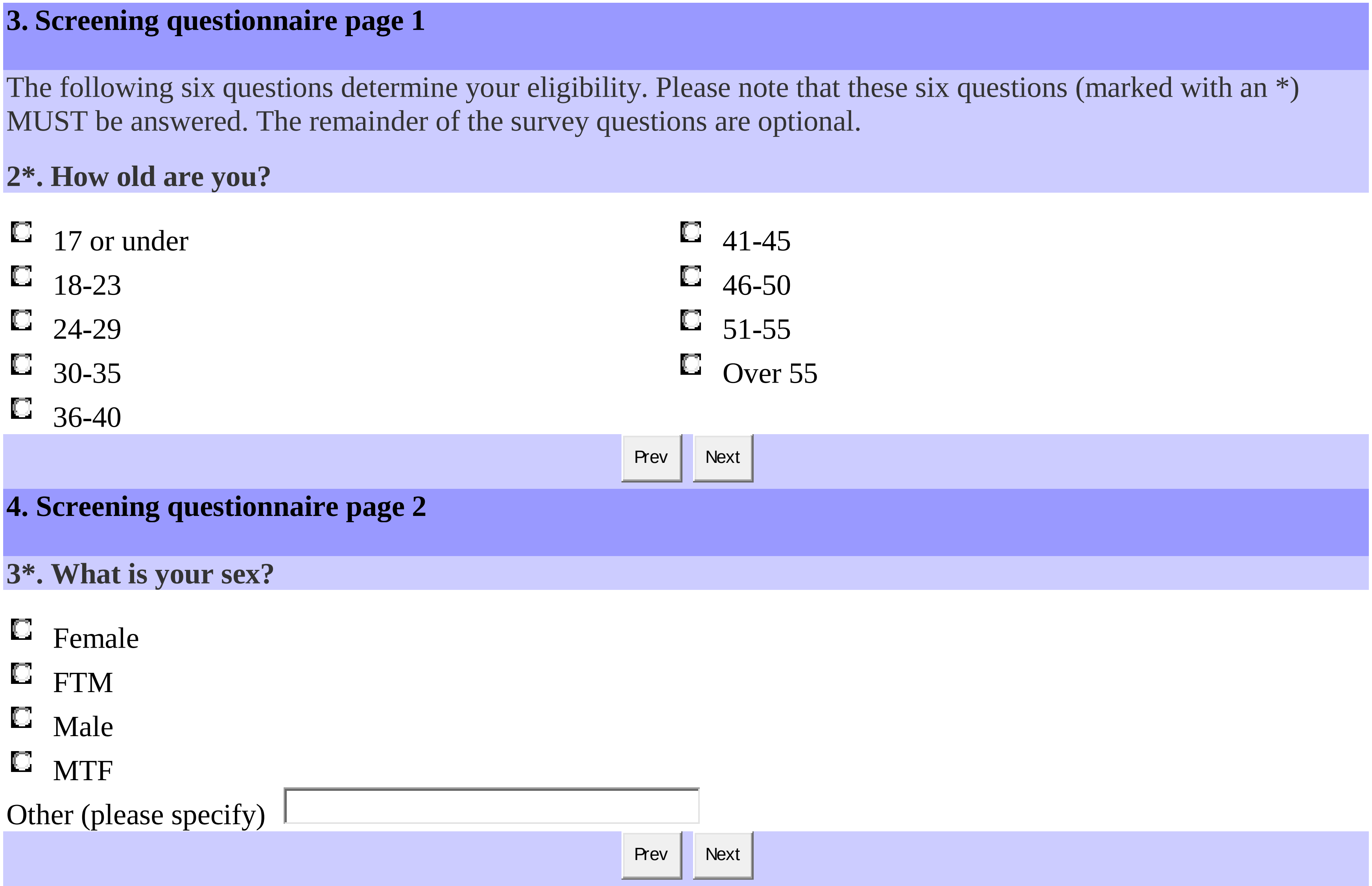
8. Documentation of Informed Consent: By clicking the "YES" box below, you indicate that you voluntarily agree to participate in this research study. If you would like a copy of this consent statement for your records, please email hubbar92@msu.edu to request one.

1*. Do you voluntarily consent to participate in this research study?

☐ YES, I have read and understood the consent statement and voluntarily agree to participate in this study.

☐ NO, I do not wish to participate in the study.

Prev Next



3. Screening questionnaire page 1

The following six questions determine your eligibility. Please note that these six questions (marked with an *) MUST be answered. The remainder of the survey questions are optional.

2*. How old are you?

○ 17 or under
○ 18-23
○ 24-29
○ 30-35
○ 36-40
○ 41-45
○ 46-50
○ 51-55
○ Over 55

Prev Next

4. Screening questionnaire page 2

3*. What is your sex?

○ Female
○ FTM
○ Male
○ MTF
Other (please specify) ☐

Prev Next

4*. Several conditions have been found to affect self-injurious behaviors. Have you ever been diagnosed with any of the following conditions? Please check all that apply.

☐ Autism
☐ Developmental Delay
☐ Schizophrenia
☐ Tourette's Syndrome
☐ I have never been diagnosed with any of these conditions.

Prev Next

6. Screening questionnaire page 4

5*. Are you currently in therapy (for any reason)?

☐ No
☐ Yes, outpatient
☐ Yes,intensive outpatient (i.e. day program)
☐ Yes, inpatient

Prev Next

7. Screening questionnaire page 5

6*. It is not uncommon for people, especially adolescents, to learn about self-injury somehow and try it once out of curiosity. However, this study is focused on women who consciously choose to engage in self-injury as a way to help them cope with negative, confusing or overwhelming emotions. Have you intentionally physically injured yourself on at least two occasions?

☐ Yes
☐ No

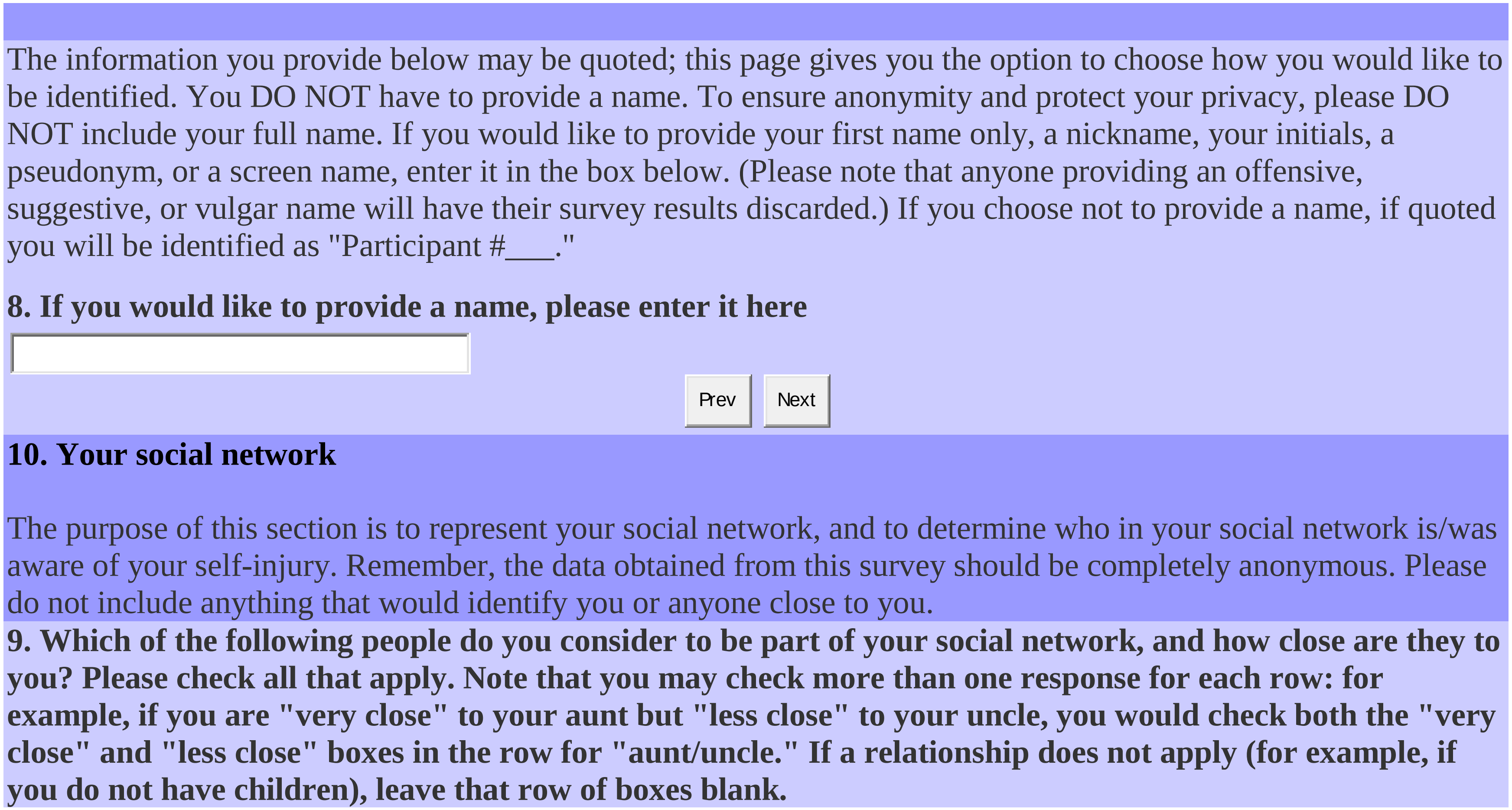
Prev Next

8. Screening questionnaire page 6

7*. Though every effort has been made to minimize the potential risks of this survey, there is a possibility that some questions may be triggering. How recently did you last self-injure?

☐ Within the last 2 months
☐ 3-5 months ago
☐ 6-8 months ago
☐ 9-11 months ago
☐ One year or more

Prev Next



The information you provide below may be quoted; this page gives you the option to choose how you would like to be identified. You DO NOT have to provide a name. To ensure anonymity and protect your privacy, please DO NOT include your full name. If you would like to provide your first name only, a nickname, your initials, a pseudonym, or a screen name, enter it in the box below. (Please note that anyone providing an offensive, suggestive, or vulgar name will have their survey results discarded.) If you choose not to provide a name, if quoted you will be identified as "Participant #___."

8. If you would like to provide a name, please enter it here

10. Your social network

The purpose of this section is to represent your social network, and to determine who in your social network is/was aware of your self-injury. Remember, the data obtained from this survey should be completely anonymous. Please do not include anything that would identify you or anyone close to you.

9. Which of the following people do you consider to be part of your social network, and how close are they to you? Please check all that apply. Note that you may check more than one response for each row: for example, if you are "very close" to your aunt but "less close" to your uncle, you would check both the "very close" and "less close" boxes in the row for "aunt/uncle." If a relationship does not apply (for example, if you do not have children), leave that row of boxes blank.

	Very Close	Close	Less Close
Acquaintance	☐	☐	☐
Aunt/Uncle	☐	☐	☐
Boyfriend/girlfriend	☐	☐	☐
Child (biological, foster, adopted, or step)	☐	☐	☐
Classmate	☐	☐	☐
Close/best friend	☐	☐	☐
Coach	☐	☐	☐
Colleague/co-worker	☐	☐	☐
Cousin	☐	☐	☐
Friend	☐	☐	☐
Friend of the family	☐	☐	☐

Grandparent	☐	☐	☐
Mentor	☐	☐	☐
Neighbor	☐	☐	☐
Niece/Nephew	☐	☐	☐
Parent	☐	☐	☐
Professor/teacher	☐	☐	☐
Religious leader	☐	☐	☐
Roommate/housemate	☐	☐	☐
Sibling	☐	☐	☐
Spouse/partner	☐	☐	☐
Supervisor/boss	☐	☐	☐
Teammate	☐	☐	☑
Therapist/counselor	☐	☐	☐

Other (please specify their relationship to you but DO NOT provide their name)

10. How long have you known the people in your social network? Please check all that apply. Note that you may check more than one response for each row: for example, if you have known one friend for 2 years and one friend for 3 months, check both the "less than 1 year" and "1-2 years" boxes in the "friend" row. If a relationship does not apply (for example, if you do not have children), leave that row of boxes blank.

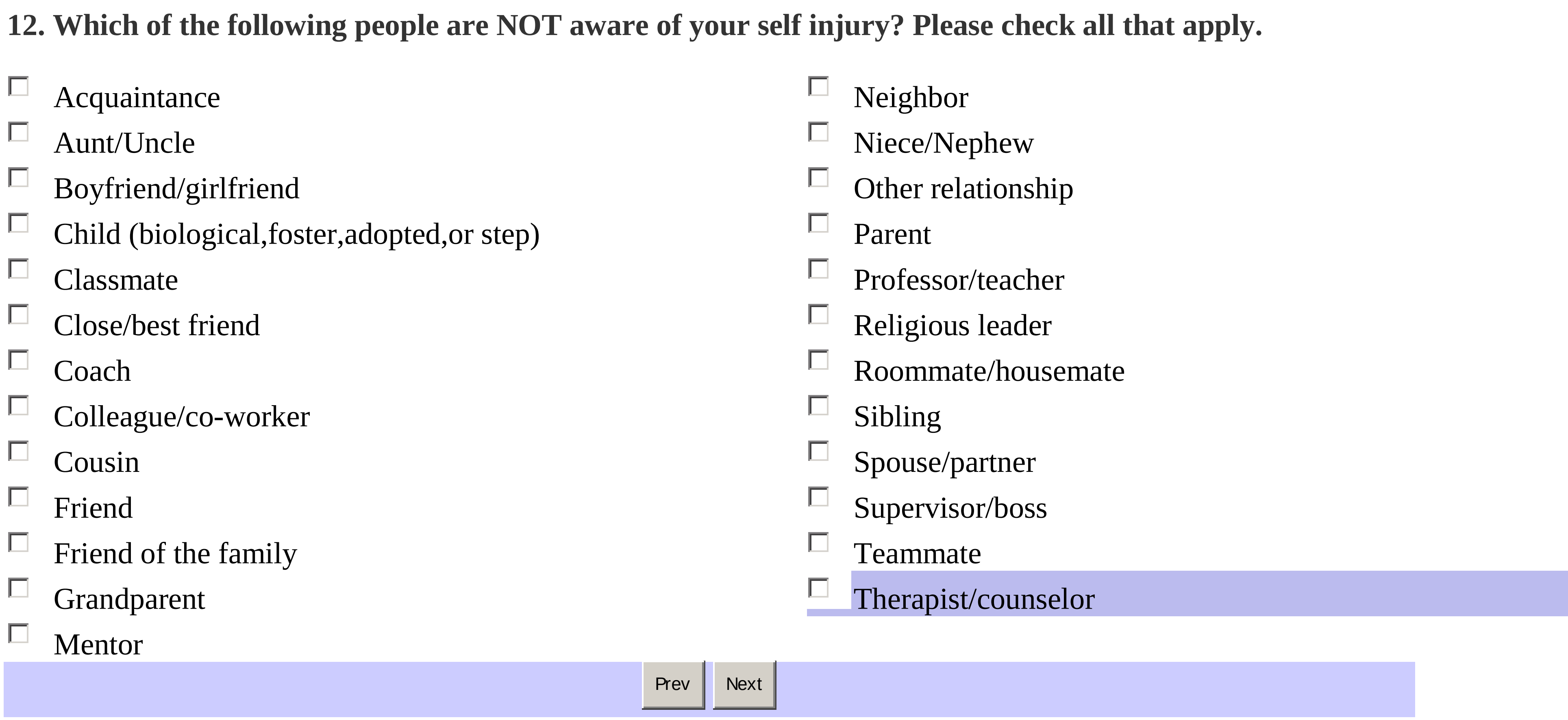
	Less than 1 year	**1-2 years**	**3-5 years**	**6-10 years**	**More than 10 years**
Acquaintance	☐	☐	☑	☐	☐
Aunt/Uncle	☐	☐	☐	☐	☐
Boyfriend/girlfriend	☐	☐	☐	☐	☐
Child (biological, foster, adopted, or step)	☐	☐	☐	☐	☐
Classmate	☐	☐	☐	☐	☐
Close/best friend	☐	☐	☐	☐	☐
Coach	☐	☐	☐	☐	☐

Colleague/co-worker	☐	☐	☐	☐	☐
Cousin	☐	☐	☐	☐	☐
Friend	☐	☐	☐	☐	☐
Friend of the family	☐	☐	☐	☐	☐
Grandparent	☐	☐	☐	☐	☐
Mentor	☐	☐	☐	☐	☐
Neighbor	☐	☐	☐	☐	☐
Niece/Nephew	☐	☐	☐	☐	☐
Other relationship	☐	☐	☐	☐	☐
Parent	☐	☐	☐	☐	☐
Professor/teacher	☐	☐	☐	☐	☐
Religious leader	☐	☐	☐	☐	☐
Roommate/housemate	☐	☐	☐	☐	☐

Sibling	☐	☐	☐	☐	☐
Spouse/partner	☐	☐	☐	☐	☐
Supervisor/boss	☐	☐	☐	☐	☐
Teammate	☐	☐	☐	☐	☐
Therapist/counselor	☐	☐	☐	☐	☐

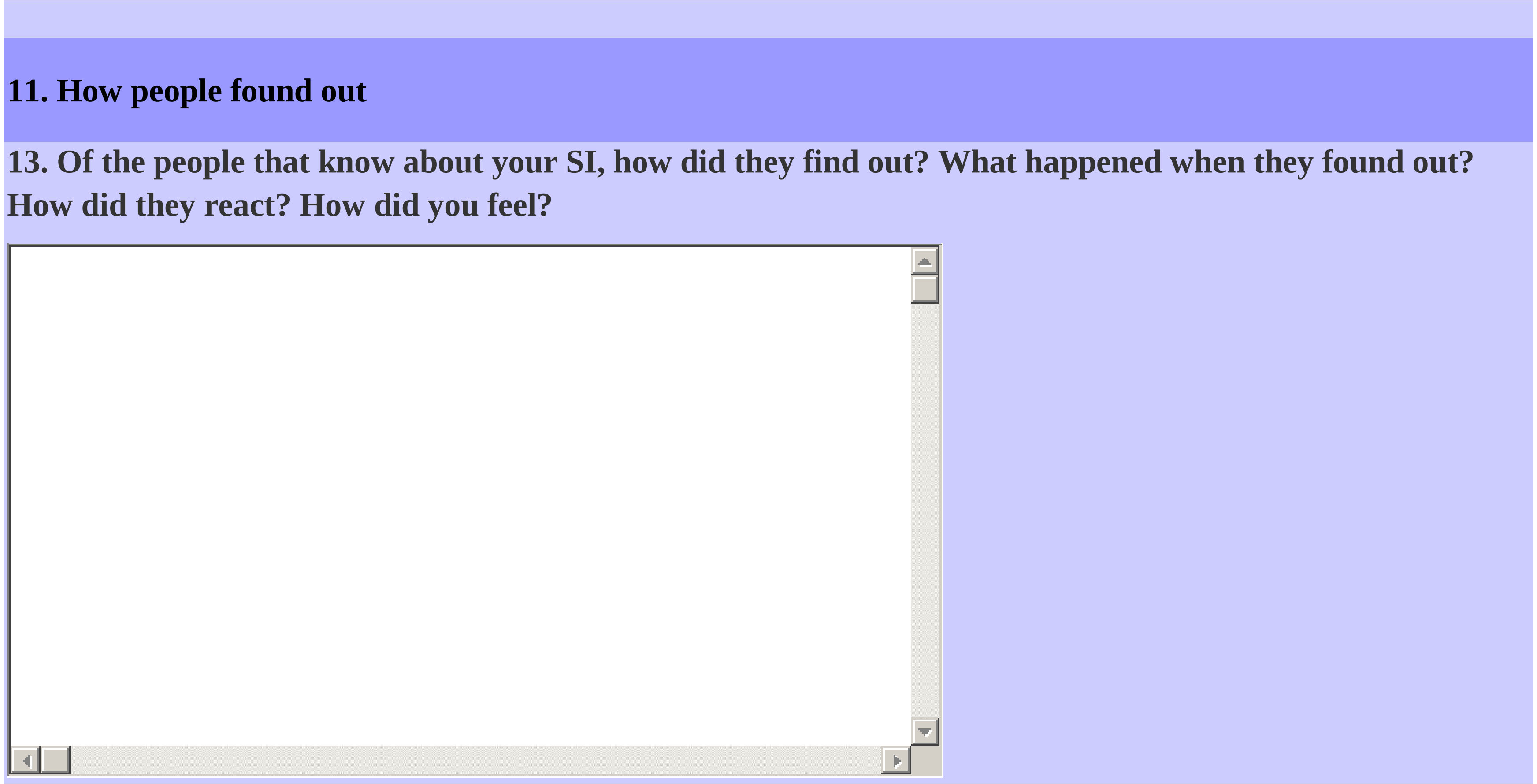
11. Which of the following people are aware of your self-injury? Please check all that apply.

☐ Acquaintance
☐ Aunt/Uncle
☐ Boyfriend/girlfriend
☐ Child (biological, foster, adopted, or step)
☐ Classmate
☐ Close/best friend
☐ Coach
☐ Colleague/co-worker
☐ Cousin
☐ Friend
☐ Friend of the family
☐ Grandparent
☐ Mentor
☐ Neighbor
☐ Niece/Nephew
☐ Other relationship
☐ Parent
☐ Professor/teacher
☐ Religious leader
☐ Roommate/housemate
☐ Sibling
☐ Spouse/partner
☐ Supervisor/boss
☐ Teammate
☐ Therapist/counselor



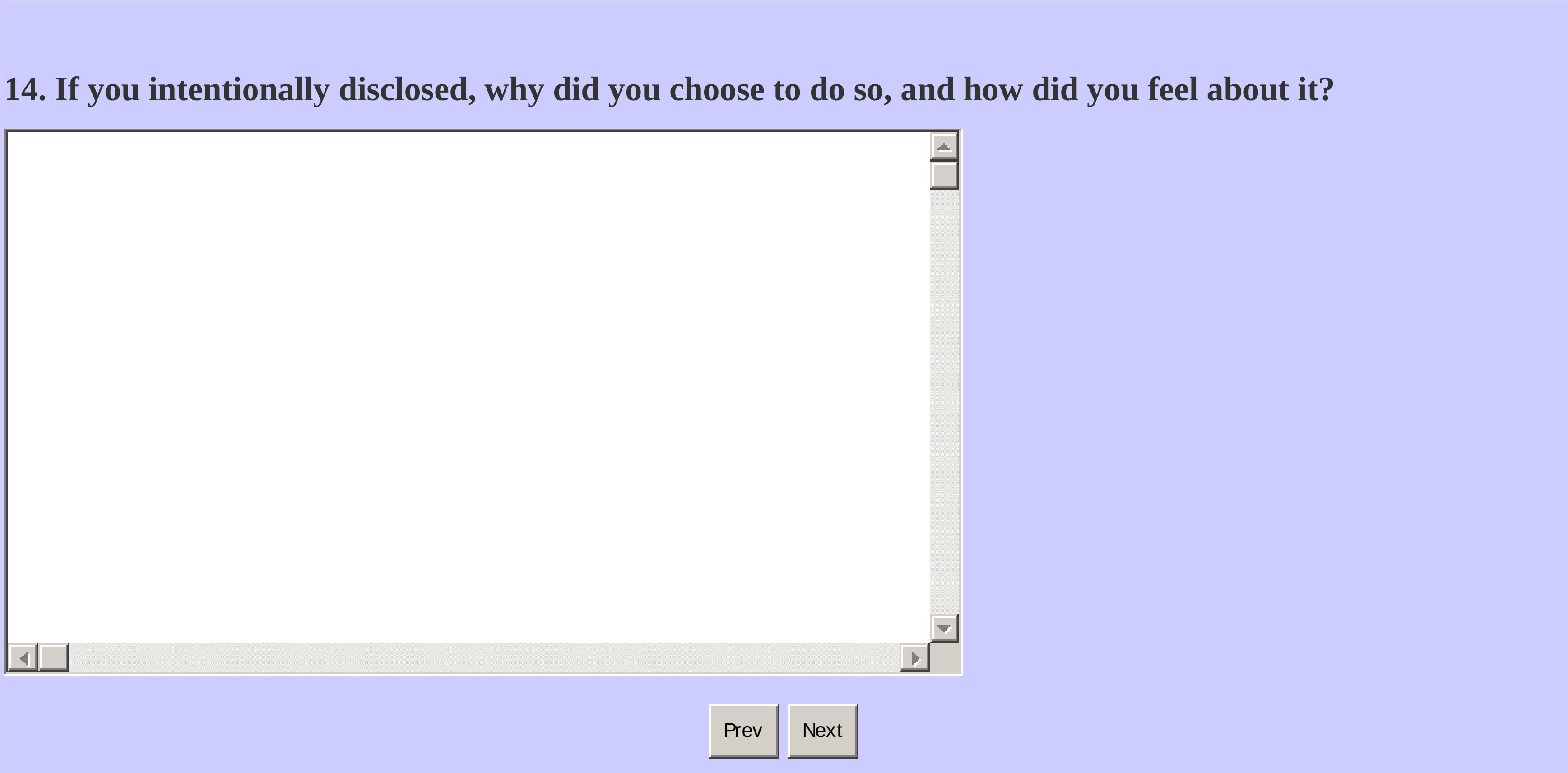
12. Which of the following people are NOT aware of your self injury? Please check all that apply.

☐ Acquaintance
☐ Aunt/Uncle
☐ Boyfriend/girlfriend
☐ Child (biological,foster,adopted,or step)
☐ Classmate
☐ Close/best friend
☐ Coach
☐ Colleague/co-worker
☐ Cousin
☐ Friend
☐ Friend of the family
☐ Grandparent
☐ Mentor
☐ Neighbor
☐ Niece/Nephew
☐ Other relationship
☐ Parent
☐ Professor/teacher
☐ Religious leader
☐ Roommate/housemate
☐ Sibling
☐ Spouse/partner
☐ Supervisor/boss
☐ Teammate
☐ Therapist/counselor

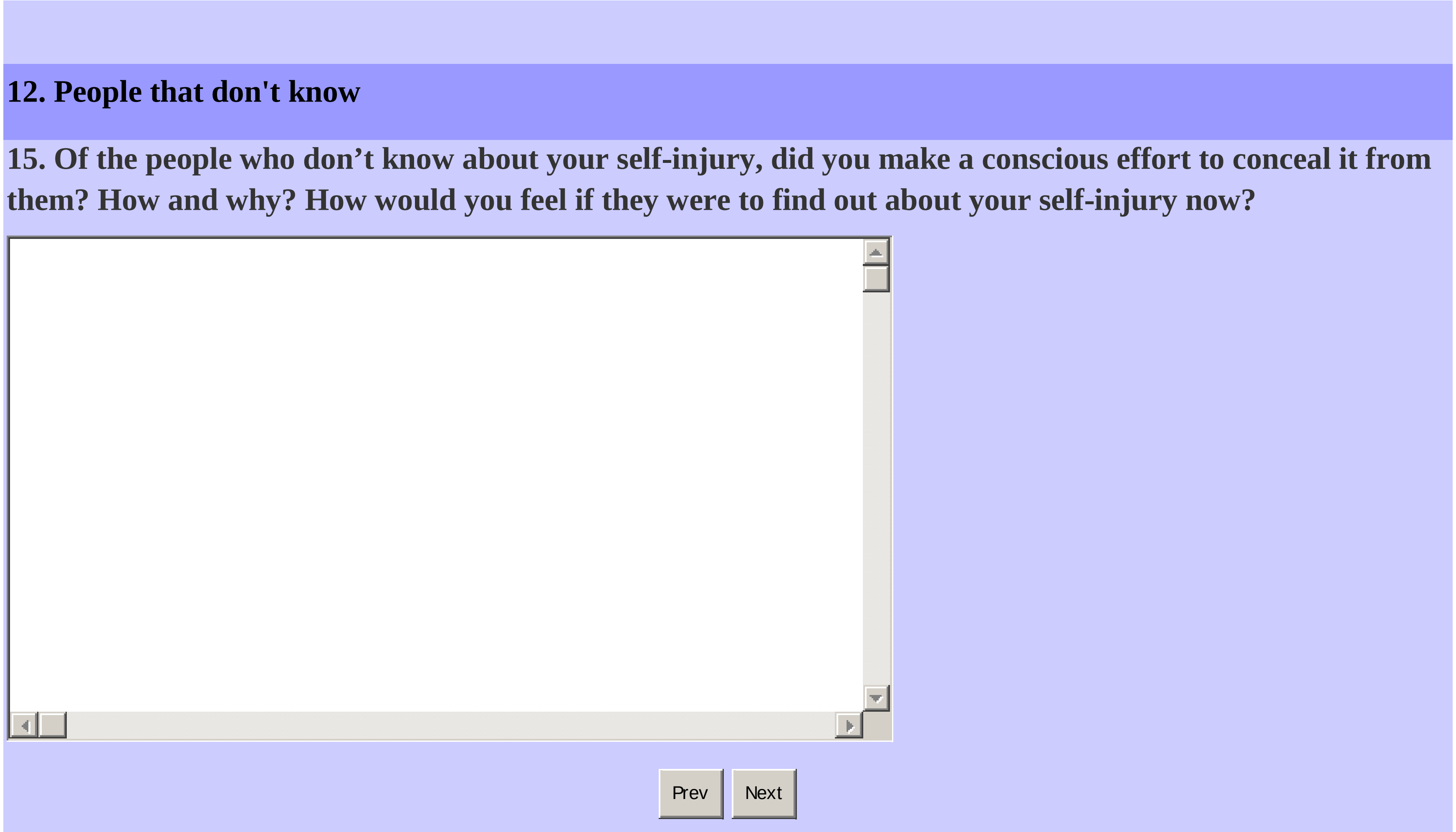


11. How people found out

13. Of the people that know about your SI, how did they find out? What happened when they found out? How did they react? How did you feel?

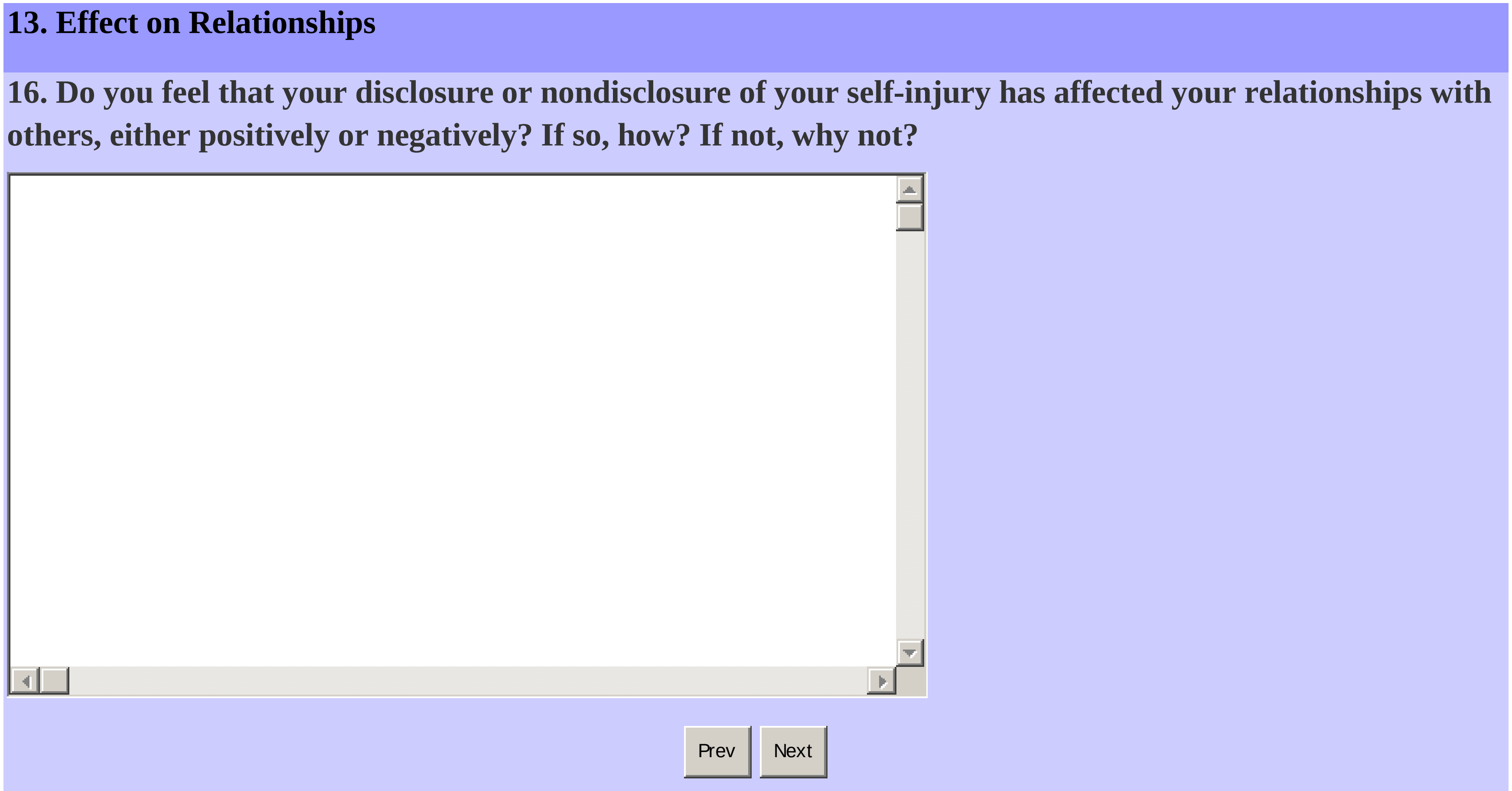


14. If you intentionally disclosed, why did you choose to do so, and how did you feel about it?



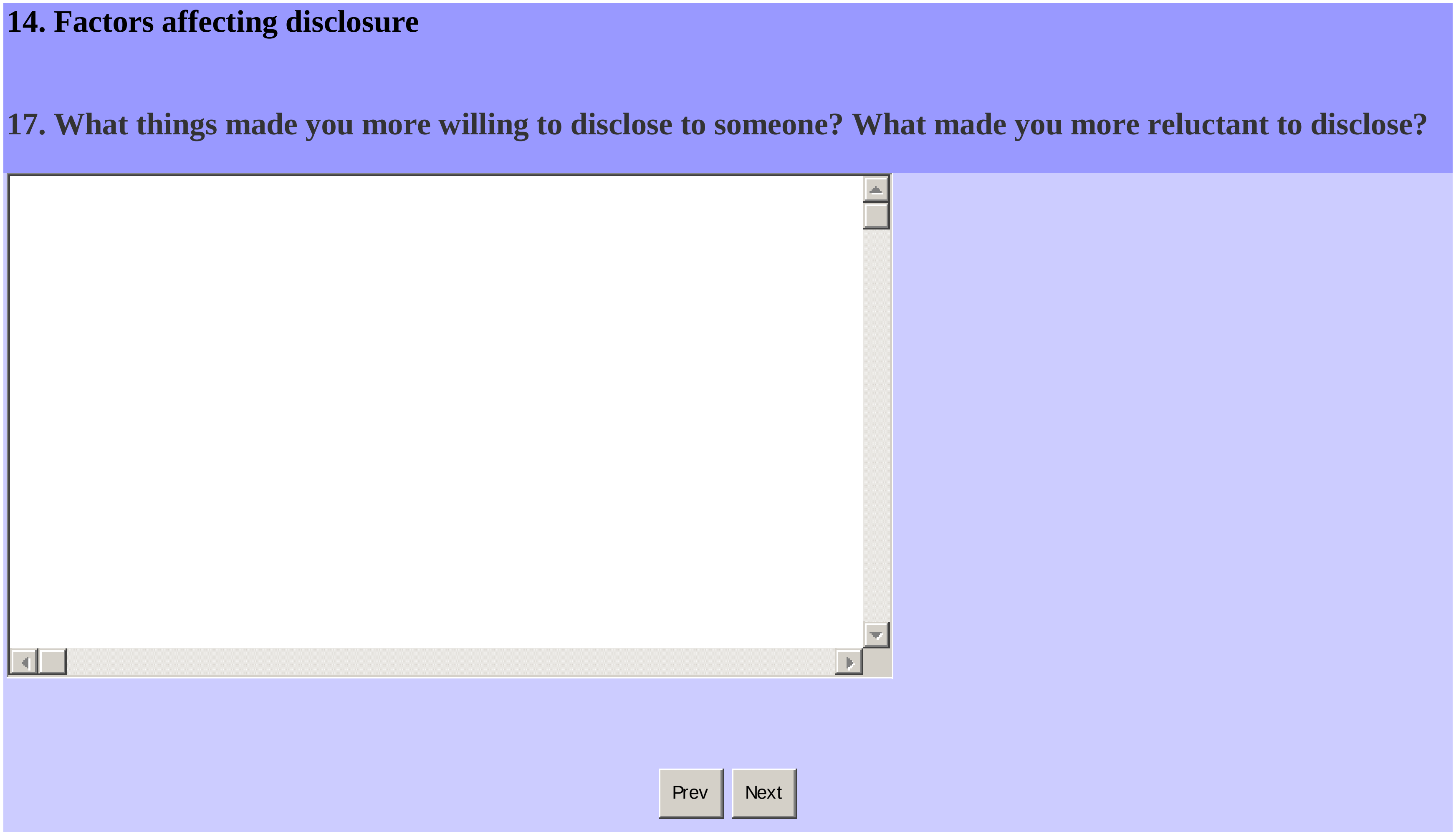
12. People that don't know

15. Of the people who don’t know about your self-injury, did you make a conscious effort to conceal it from them? How and why? How would you feel if they were to find out about your self-injury now?



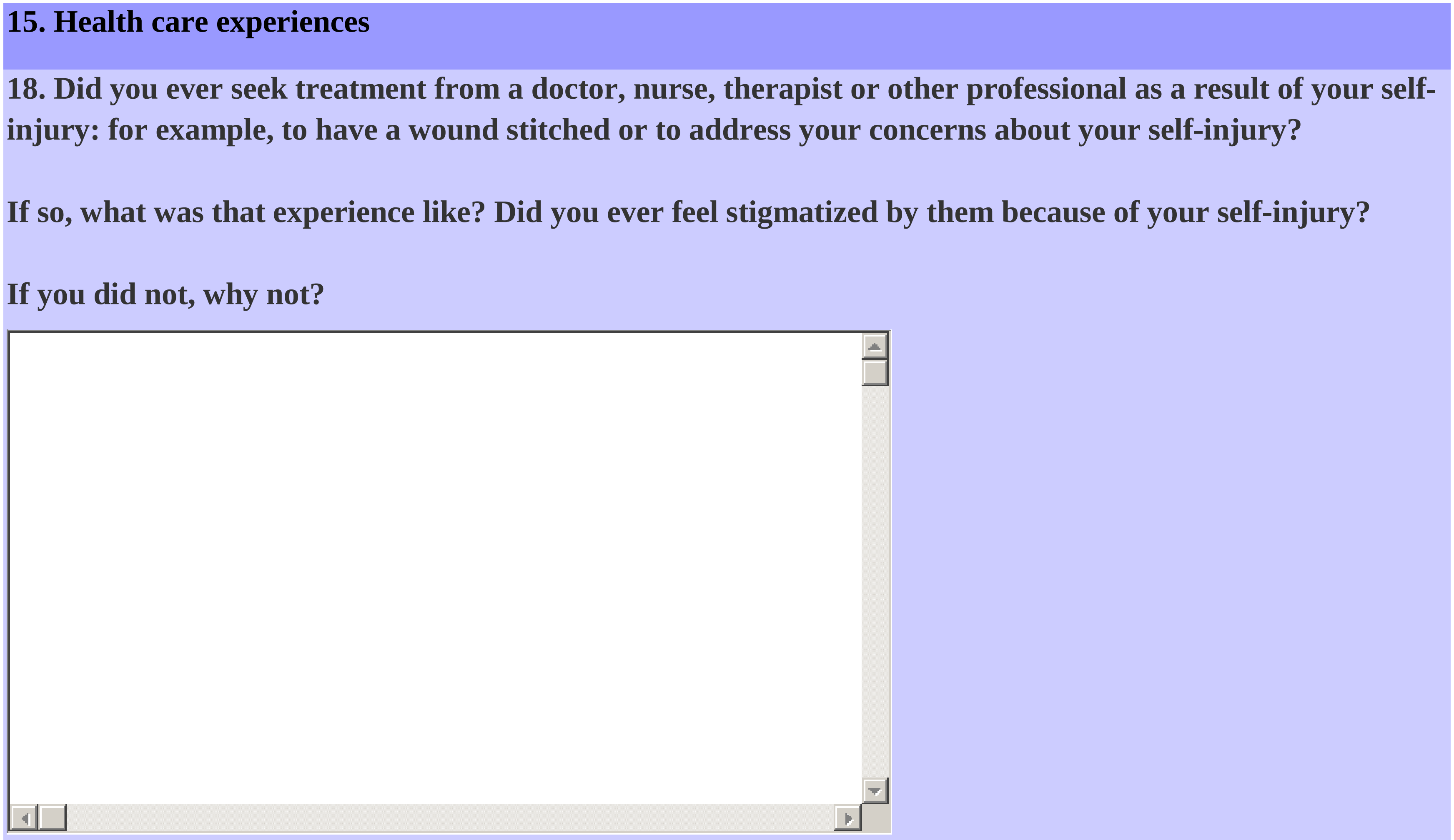
13. Effect on Relationships

16. Do you feel that your disclosure or nondisclosure of your self-injury has affected your relationships with others, either positively or negatively? If so, how? If not, why not?



14. Factors affecting disclosure

17. What things made you more willing to disclose to someone? What made you more reluctant to disclose?

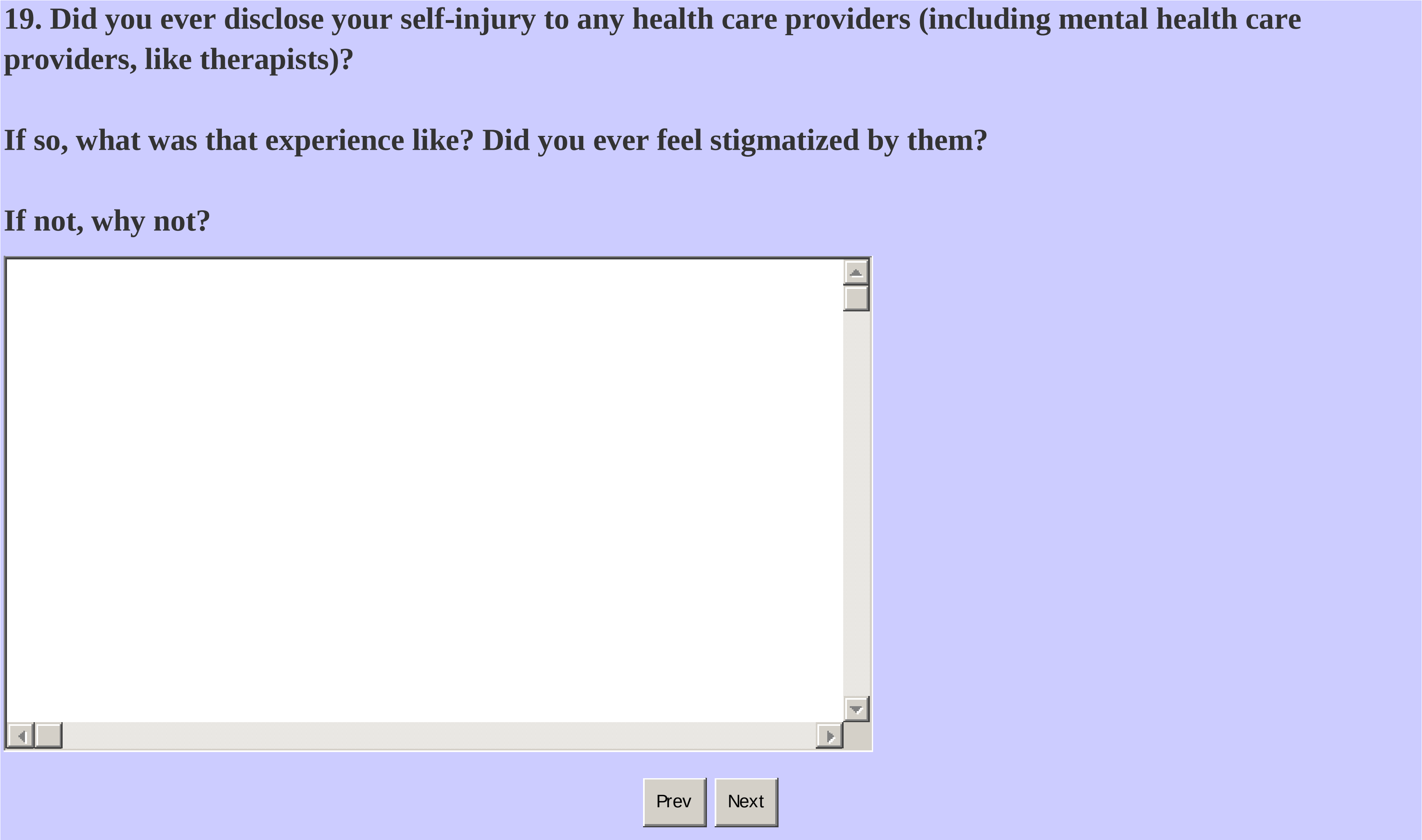


15. Health care experiences

18. Did you ever seek treatment from a doctor, nurse, therapist or other professional as a result of your self-injury: for example, to have a wound stitched or to address your concerns about your self-injury?

If so, what was that experience like? Did you ever feel stigmatized by them because of your self-injury?

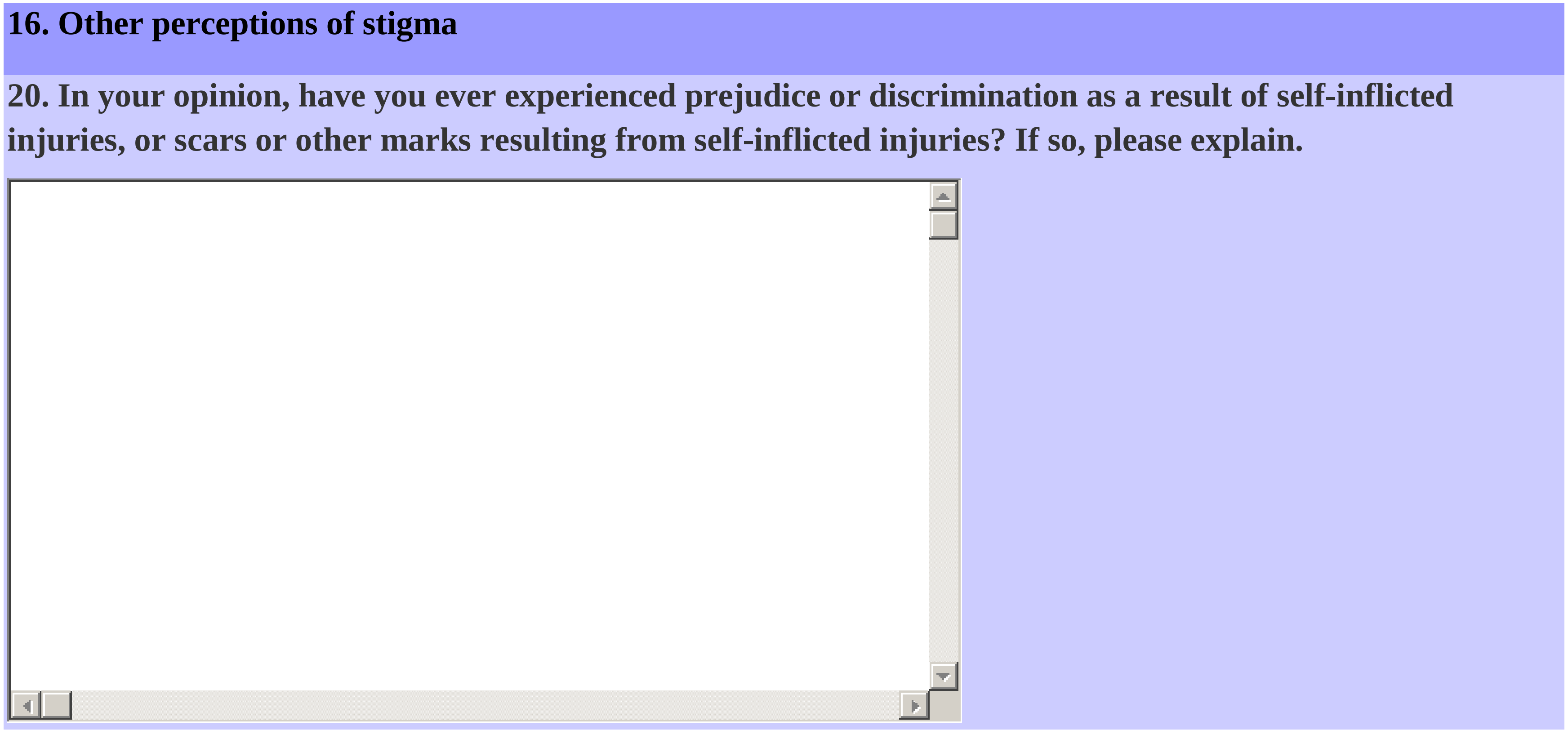
If you did not, why not?



19. Did you ever disclose your self-injury to any health care providers (including mental health care providers, like therapists)?

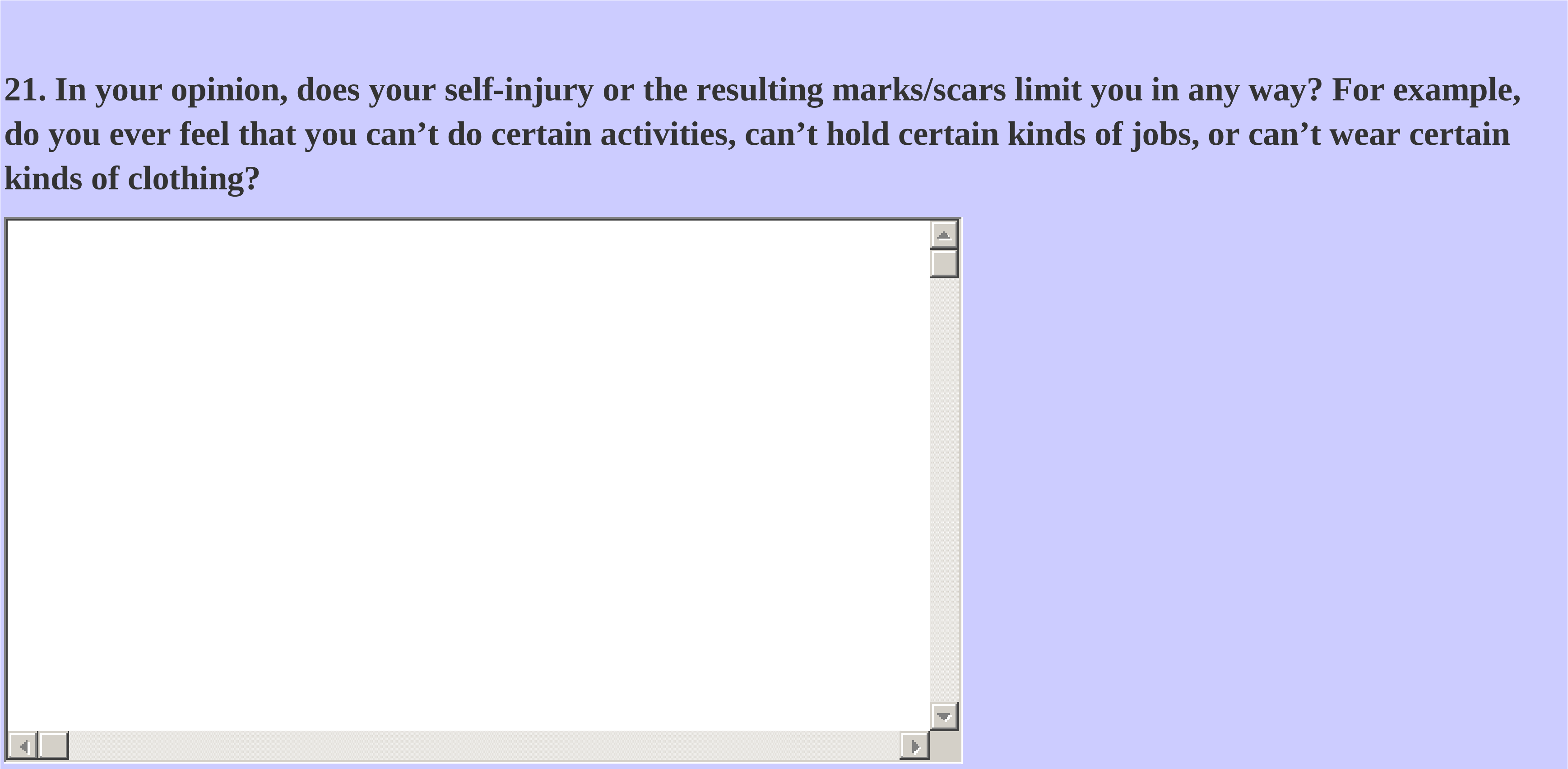
If so, what was that experience like? Did you ever feel stigmatized by them?

If not, why not?

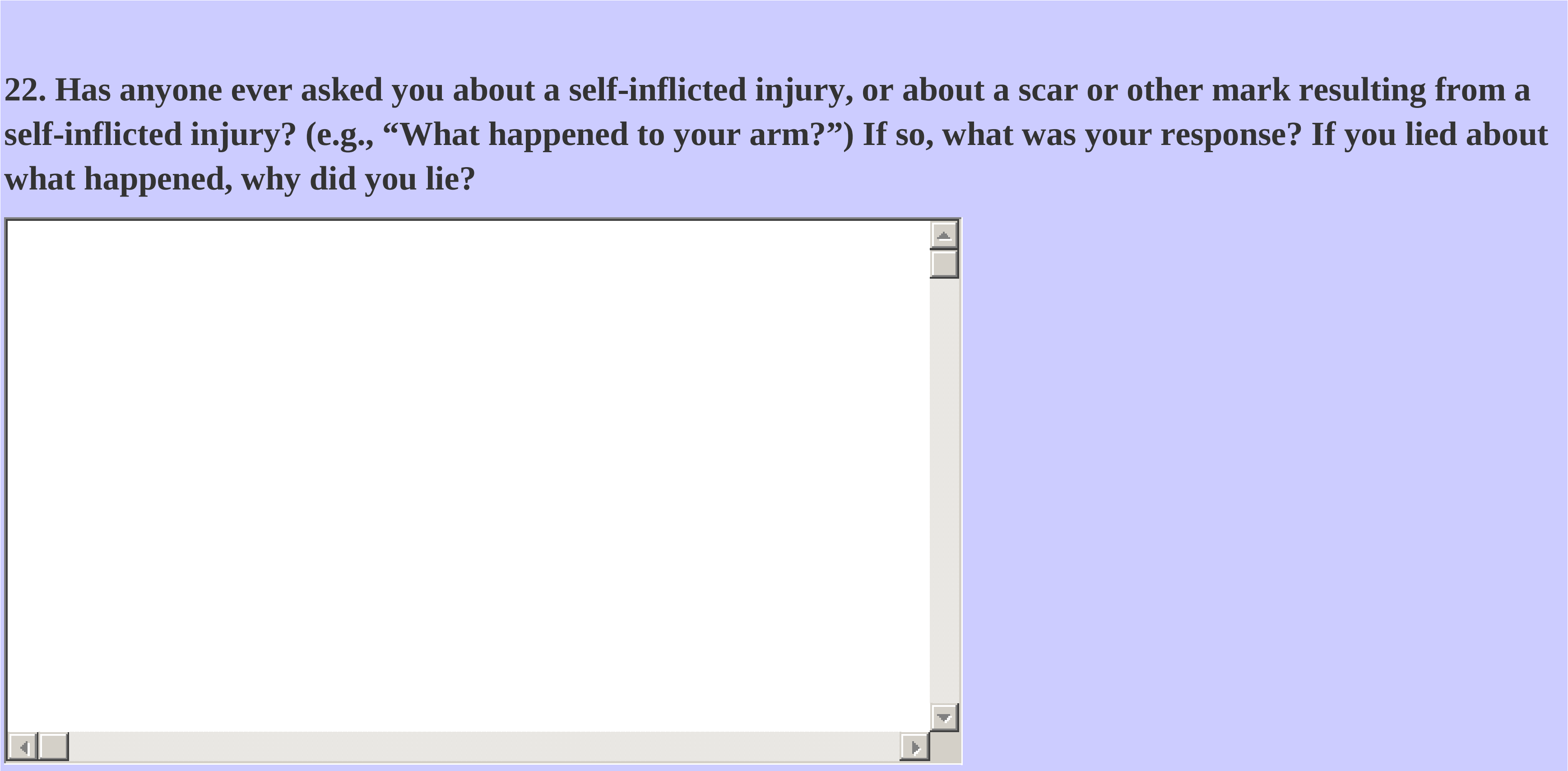


16. Other perceptions of stigma

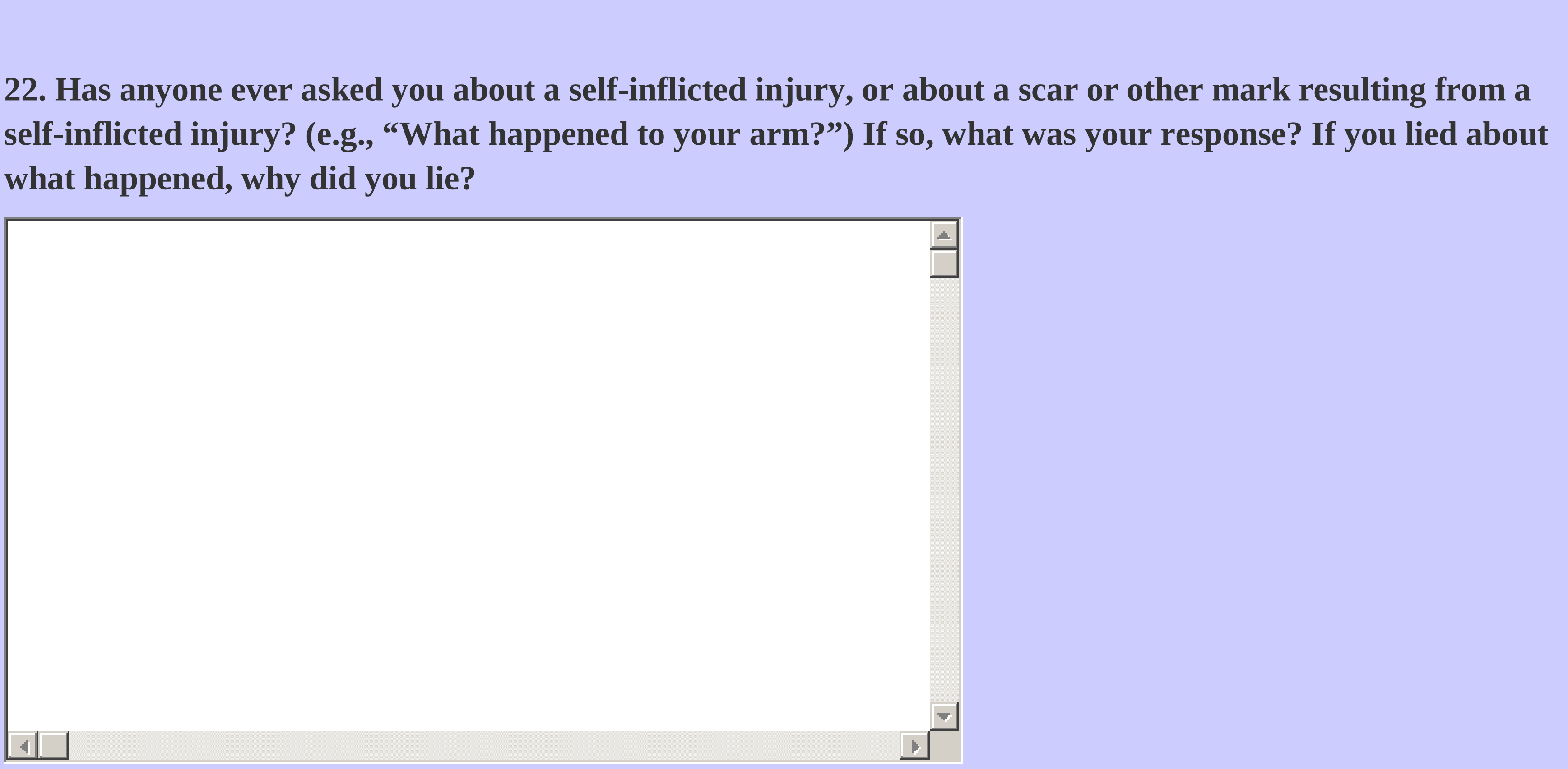
20. In your opinion, have you ever experienced prejudice or discrimination as a result of self-inflicted injuries, or scars or other marks resulting from self-inflicted injuries? If so, please explain.



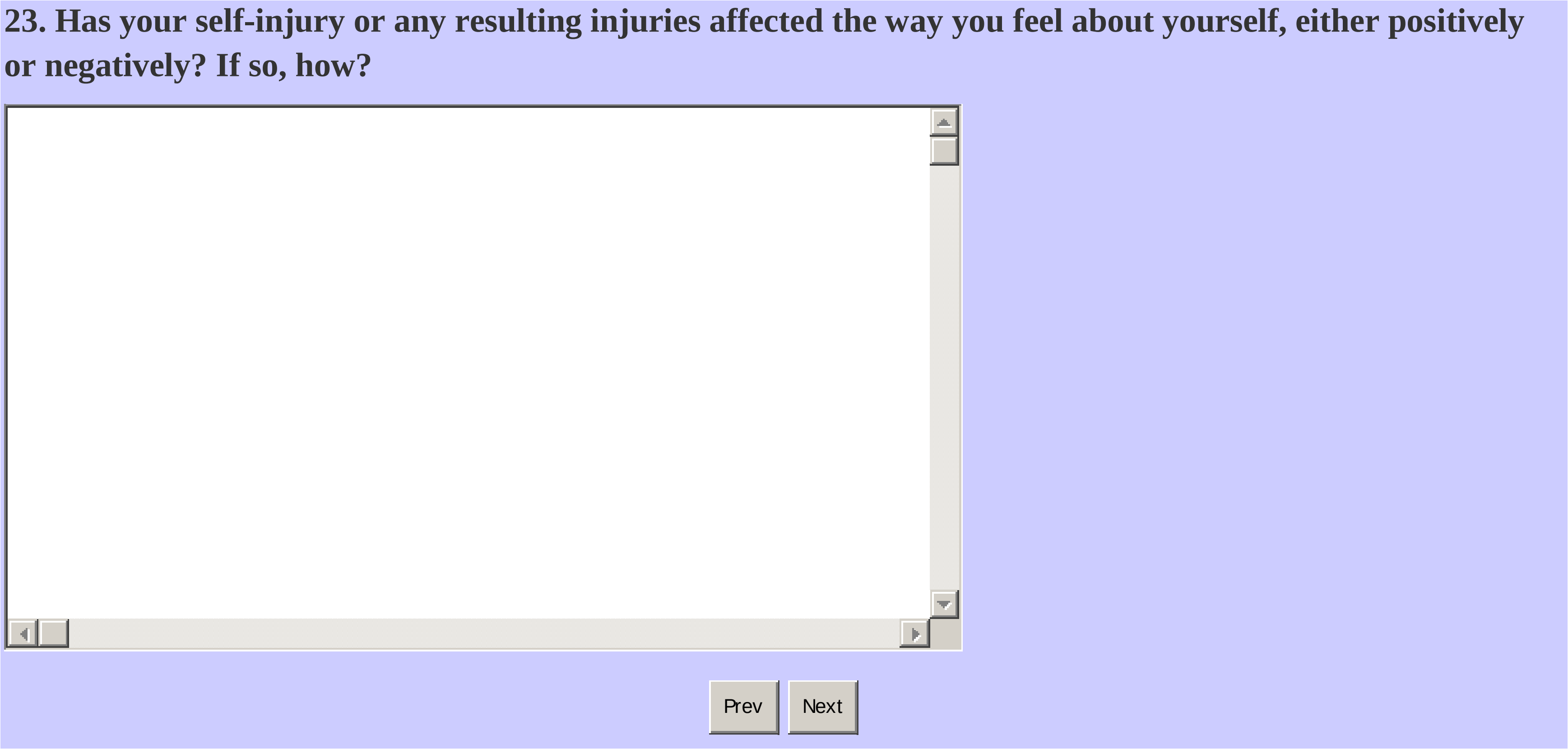
21. In your opinion, does your self-injury or the resulting marks/scars limit you in any way? For example, do you ever feel that you can’t do certain activities, can’t hold certain kinds of jobs, or can’t wear certain kinds of clothing?



22. Has anyone ever asked you about a self-inflicted injury, or about a scar or other mark resulting from a self-inflicted injury? (e.g., “What happened to your arm?”) If so, what was your response? If you lied about what happened, why did you lie?



22. Has anyone ever asked you about a self-inflicted injury, or about a scar or other mark resulting from a self-inflicted injury? (e.g., “What happened to your arm?”) If so, what was your response? If you lied about what happened, why did you lie?



23. Has your self-injury or any resulting injuries affected the way you feel about yourself, either positively or negatively? If so, how?

17. Other comments

24. Is there anything else you would like to tell me?

18. Thank you

Thank you for your participation in this study! If you have any questions or comments about this study, please feel free to contact Meagan Hubbard at hubbar92@msu.edu. Please continue to the next page for a list of resources.

19. Self-Injury Resources

This list is provided for your convenience and is not exhaustive. Though the Internet can be a wonderful resource for information about self-injury, some of the content may be upsetting or “triggering” (e.g., cause urges to self-injure). Please use caution and take steps to keep yourself safe, especially if you are feeling the urge to injure yourself.

Disclaimer: The inclusion of a resource on this page is not an endorsement. The research team (Meagan Hubbard and Marsha Carolan) have no connection to or affiliation with any of the resources listed below and cannot be held responsible for any content therein. Due to the nature of the Internet, some of the web sites listed below may be temporarily or permanently unavailable.

Inpatient/Outpatient Treatment:

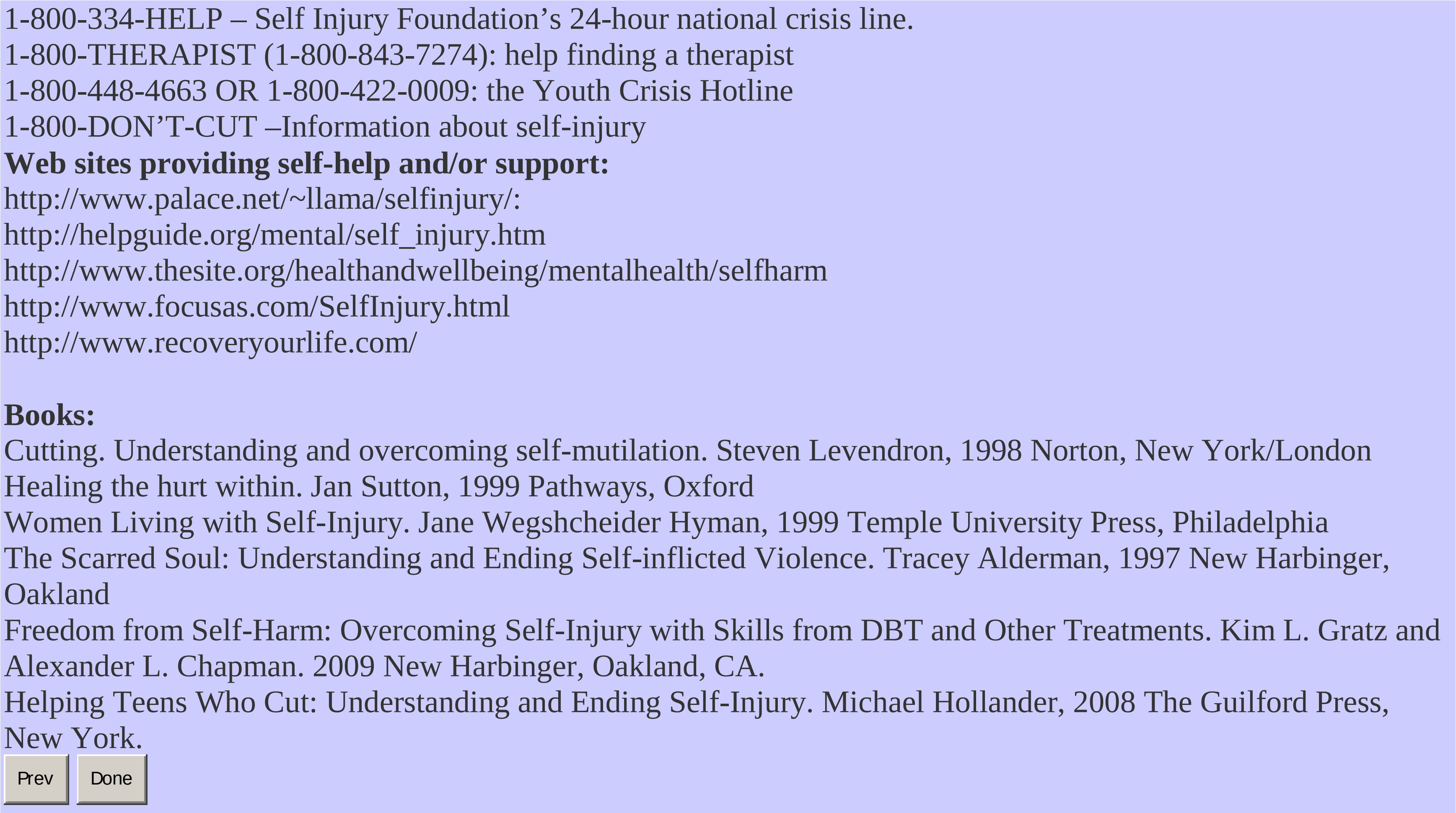
http://www.selfinjury.com/: S.A.F.E. (Self-Abuse Finally Ends) Alternatives: Nationally recognized outpatient treatment program: for locations, see http://www.selfinjury.com/admissions/locations/

http://www.alexianbrothershealth.org/services/abbhh/ourservices/self-injury/index.aspx: Web site for the Center for Self-Injury Recovery Services at the Alexian Brothers Behavioral Health Hospital: locations throughout Illinois

http://self-injury.net/information-recovery/recovery/therapy: Offers suggestions on what to look for in a therapist

http://www.goodtherapy.org/advanced-search.html: Has search function to look up therapists by location and/or specialty. *Tip: for help with self-injury specifically, try searching under “concerns: suicidal ideation and behavior.”

Hotlines:
1-800-273-TALK –24-hour crisis hotline



1-800-334-HELP – Self Injury Foundation’s 24-hour national crisis line.
1-800-THERAPIST (1-800-843-7274): help finding a therapist
1-800-448-4663 OR 1-800-422-0009: the Youth Crisis Hotline
1-800-DON’T-CUT –Information about self-injury

Web sites providing self-help and/or support:

http://www.palace.net/~llama/selfinjury/:
http://helpguide.org/mental/self_injury.htm
http://www.thesite.org/healthandwellbeing/mentalhealth/selfharm
http://www.focusas.com/SelfInjury.html
http://www.recoveryourlife.com/

Books:

Cutting. Understanding and overcoming self-mutilation. Steven Levendron, 1998 Norton, New York/London
Healing the hurt within. Jan Sutton, 1999 Pathways, Oxford
Women Living with Self-Injury. Jane Wegshcheider Hyman, 1999 Temple University Press, Philadelphia
The Scarred Soul: Understanding and Ending Self-inflicted Violence. Tracey Alderman, 1997 New Harbinger, Oakland
Freedom from Self-Harm: Overcoming Self-Injury with Skills from DBT and Other Treatments. Kim L. Gratz and Alexander L. Chapman. 2009 New Harbinger, Oakland, CA.
Helping Teens Who Cut: Understanding and Ending Self-Injury. Michael Hollander, 2008 The Guilford Press, New York.

Appendix H. Compiled responses to a single question

The following are responses participants gave to the question, "Of the people that know about your SI, how did they find out? What happened when they found out? How did they react? How did you feel?" In-person interview responses are take from transcripts of the interviews: *I:* indicates the interviewer is speaking, *P:* indicates the participant's response. Responses from the online survey are copied verbatim.

Sol: *P:*Well, I told them about it, but it was because of, like, them noticing that, um, that I wasn't like, probably like…like I was just-like something was wrong, or kind of thing, like they're like, 'Hey, are you okay?' or like 'What's going on? Do you want to talk about anything?' or kind of thing. And then, like, usually when that happens it's really hard for me not to, like, disclose, or something, where there's like, an issue, just because, this is also sort of during a time when I was kind of growing, as a person, sort of…And so, even though I was, like, still dealing with things, I was kind of like, 'Okay, well, um, clearly you know, like, certain things…certain steps you can take to be a little more healthy in your life, and maybe you opening up about this with this person right now could like, be, a way for you, like, really get a hold on it on whatever it is that's making you feel like you're not, you know, holdin' anything. *I:* And, um, when you told them, how did they react to it? Were they… *P:* They weren't judgmental at all of anything. l think most of them were just, like, trying to understand what I meant, and trying to understand the severity of how I was feeling, and so I guess, um, another thing might be, like, sometimes the way I speak or try to get my thoughts across, maybe I'm not experiencing the emotion like what you would normally expect somebody to be experiencing with that. [*I:* Mm-hmm] So, it kind of confused them in the sense of like, okay, well when you're sad you cry and when you're happy you smile, but right now you're doing things that are giving me mixed signals so I don't know if this is like, a serious issue or maybe you're like, you know, like if you do need help or if you're just, like, whatever… So, once they understood that I was serious or that it was like, something they'd be like, 'Okay, well, how does that … why does that happen? Like, what makes you…'whatever ,kind of thing, you know,[*I:*Mm-hmm] like- and just seeing if I even wanted to talk about it, 'cuz sometimes where I was just like….Like I remember with one of them, I was kind of like, not really wanting to talk about it. It was more just like important for me to say, 'okay, this is kind of what's going on' *[I:* Mm-hmm] …thing and I just, like, may disagree with somebody in general, so… I…..but yeah, they're pretty supportive, they're like, trying to help me understand. *I:*That's good….So, when you decided to tell them kind of what was going on with you, um, like what made you decide to just tell them and how did you feel about telling them-like, were you anxious, were you worried at all, like, how'd you feel about it? *P:* Well, I remember with um, one of them in particular-that's the person T.P. [points to initials in smallest circle on ecomap]- [*I:*Mm-hmm] I actually, kind of, ran to her for it, because , uh, I was at my house-she's actually my neighbor-so, um, I was just, like, feeling really-like, just every….I was just, like, wrecked emotionally and then, um, there was a sort of incident and I then was just like, 'Okay, well, I really can't be myself right now and I don't know who else to talk to about this. Okay, well, actually I do know who I can talk to about this' and I like, ran upstairs to her basically and was just like, 'Can you please help me for a minute?' just like-I just, like, I just did this, and if anything she actually was able to, uh-'cuz she's older so she was able to kinda put it in her own words kind of thing. Like she was like, Yeah, I mean, like I totally, you know, and it's okay, like, you know, she just wanted to make sure I was okay and then she's like, 'Well, I understand. Like, I get it. Like, you just needed to do this to be like, okay, well, everything else is going crazy but I have power over this one thing, and I'm going to take advantage of it' you know, kind of thing [*I:*Mm-hmm] and, um, so I was like, 'Yeah, like really….' And it wasn't like she was encouraging it, it was just more like, I get what happened, like, and I'm glad you're talking to me about it and, you know….And, like, her empathizing that strongly with it really, like, helped me to like, calm down immensely, like -[*I:*Right]... it wasn't like I had to explain the whole thing, kind of thing, you know? She just knew, and was kind of like, running with me with it, so….

Rose: *P*: Um…let's see-Well, M--- knew-she's my best friend- because, I told her. And M--- had also done it. [Noise on recording] *I*: (sheepishly) My pen just died. *P:* [chuckles, hands *I* another pen] *I:* Okay, so your best friend M--- knew- *P:* Mm-hmm. She was my best friend-and she still is- and of course with your best friend you tell each other everything. So, that was her. Um...my mom and dad I don't really know to the extent of how much they knew about it. I wouldn't say it was, like, a really, like, intense cut-I wasn't cutting, like, different areas of my body, it was mainly my left-my left wrist. Um, my mom…is just very, um, she doesn't, she's just a really "don't ask, don't tell" kind of person. She doesn't want, you know, her life to be more complicated than it needs to be. Um, she's one of the reasons I did do it, actually. Um, so I-she knew, but it was just kind of-she didn't want to ask questions, it was just she turned a blind eye. Um, my dad saw it , but..I told him it was, like, the creases of my bed sheets, 'cuz I had just woken up. So he-I don't really know if he knew or not. Um, and of course my other good friends from high school-'cuz that was during the time in which I did it-were, um, R---, M---, L---, and they knew 'cuz they saw. And I think R--- had done it once before. It was actually a lot more common than I would have ever thought. Um- [P's cell phone goes off] Sorry. *I:* It's all right. Do you need to take that? *P:* Oh no, no. Um, [clicks tongue] and then of course, my current boyfriend knows from, you know, I've told him. [*I:* Mm-hmm] And then –but people like grandparents and uncles, they didn't know… I'm pretty sure I've listed all the people.

Alison: *P*: They noticed- I tried to lie… sometimes… try to cover it up. Or when I OD'D, they noticed-I got caught. There's been friends in the past that demonized later on…My daughter caught me with a knife…..blood everywhere. There's been times when it's been more severe than other times. And whether you had a long sleeve shirt, it's easier to cover up, or you got busted, or…*I:* So you never intentionally told someone, they just noticed? *P:* Yeah … it's not something you're proud of.

Courtney: Of the people who know--they've either seen me self injure or they saw the scars or cuts on my arms. Most of the time their first reactions are of confusion--they don't understand why someone would cut. This makes me feel nervous/anxious that they are judging me or think I'm "crazy." Of those who know I SI and have seen me do it numerous times, they always seem upset and don't understand why I lash out the way I do. They don't understand the feelings I have or how sometimes it feels good to cut. I usually feel guilty and extremely embarrassed by my cuts and try to hide them, but I also love them too. I've taken pictures of them and think they are like art. Crazy, I know.

Casey: The first person I told was my best friend at the time. I was in high school. I already knew she cut too. After she told me about it, I also told her. It made us grow closer, but apart from other people. We isolated ourselves, would share our injuries with one another, and talk about how we felt. Neither wanted other people to know because we didn't want to have to go to therapy and were ashamed. We didn't know that others did it too and worried that other people in school would judge us or think we were freaks. We lived in our own little world and didn't let other people in. At the time, I felt like only my friend knew how I felt. Being able to tell her made me feel less alone, but I thnk it made us both more destructive. Toward the end of high school, I told my aunt. I thought I could trust her and she was worried about me. She was worried b/c I also drunk a lot at the time. She didn't respond well. SHe didn't understand. She asked me 'what is wrong with you?' and wondered how someone so beautiful could make themselves ugly. She cried. I yelled at her. She told my mother, though I asked her repeatedly not to. She wanted me to get help, which I now appreciate. At the time, I felt betrayed, angry, embarassed, and ugly. My mom tried to understand. She read up on self injury online and bought a book to read. I didn't want to talk to her about it though b/c all she really wanted to know was why I did it. She blamed herself. I felt bad making her feel guilty. She was really worried I had been molested or something b/c the book said a lot of people who cut have been assaulted. I told her over and over that I wasn't. She insisted I go to therapy, but wouldn't come with me. I wanted to go to family therapy, but she said she didn't have time or think it would be beneficial to go. I felt alone. Like she wouldn't put in the effort I needed her to. I thought she just wanted to know why I did it so that she could feel better about herself. My mom told the therapist I was there b/c I cut myself and 'needed help.' She found me a therapist who was supposedly really good with working with adolscent women. I didn't get a say in it and didn't like the therapist one bit. None of th ebooks on her walls were about self-injury. She insisted at our first meeting that if I cut myself, I must do other things to hut myself or other things I shouldn't be doing. She wanted me to get it all on the table upfront to 'know what were dealing with.' I didn't trust her. I kept going, but mostly sat on the couch with my arms crossed silently. I went for like a year before I told my mother I wasn't going to waste me time or her money anymore. About a year and a half ago, I met someone who used to cut. She was older, like my moms age, but I met her in a college class. She talked about it in class and I thought she was so brave. I wanted to talk to her but was nervous. I ended up telling her toward the end of the class and we had some good talks. I think of her lke a mentor. She has helpe dme more than the therapist ever did. She gave me some books and website support group information. We mat like once a week for lunch and she has helped me open up a lot. She listens, doens't judge and is the only person I knew at the time who stopped doing it. She was like a sponser like you hear about in AA. When I cut, could call and talk to her and not be judged. When I wanted to, I could call her and we would do something else to take my mind off it. She taught me things to do to occupy my mind. It is b/c of her that I haven't cut in so long. She was a blessing. A co-worker found out recently, but not b/c I told her. She overheard a conversation I was having. I know she knows, but we never talk about it. She never brought it up, so I am not going to.

KLH: -I would either tell them or they would find evidence of it -It was mostly shown by fear/worry for my safety, and some watched my behavior closer. -Depending on who it was, I was either ashamed (parents) or felt like I could show someone (boyfriend for example) a bit of my "darker side.”

Ann: When I was younger, I tried not to tell people about it. While I still self-injured, really only my therapist knew. I told my therapist after I had been seeing her almost a year. Even when I told her, I was nervous. I debated telling her for months before I decided to. She wasn't surprised though and I shouldn't have worried about telling her because she was very understanding. I didn't feel judged, which was what I was worried about. I could hide it because I was smart about it. I self-injured in an atypical way, in part to hide it. I would hurt myself in lots of different ways that I could explain away as accidents. I didn't have just one way. That way, I could do it without people suspecting something was wrong with me. I could also do it in public rather than be secretive about it. So, I'd spill hot tea or coffee on myself. I'd bump into sharp objects on purpose. I slammed my fingers in doors quite often and once hit my thumb with a hammer. I got a reputation for being a klutz. I did it this way because I knew I could continue to hide it that way. No one ever suspected anything other than that I was a klutz. So many people know about it now because I make a point to tell them. I havn't purposefully hurt myself in over 6 years, so I have some distance from it now. As a nurse, I also think it is part of my professional responsibility to inform people about illnesses they may not be aware of or may misundertand. I make it a point to talk openly about it because I think it is really misunderstood. It is a shame people don't speak up about it more. I believe lots of people were like I was when I was younger -not willing to speak about it. They don't want to give it up, sure. But, they also know people don't understand it and may think less of them. They don't want to be labeled. They don't want to be thought of as suicidal. Years ago as part of my recovery process, I began to tell people. My husband, my best friend, my daughter. Some just hugged me and told me that they loved me. My husband cried, said he didn't understand it, took it personally, and was just glad that I had stopped doing it. We never really talked any more about it. I told my niece a few years ago when I suspected she was doing it. I was right in my suspicion and we talked about it a lot. She told me she was glad that I told her because she felt really alone and that no one understood. Helping her reaffirmed my committment to speak up about it. She's since gone to therapy and stopped as well. We've talked often about why it is people are so turned off by it and why it is so harshly judged. Because of our shared bond with self-injury, she's become one of my closest friends. I took a class on mental illness and I told a story during class about it. We were talking about borderline personality disorder and someone made a comment about how they can't understand how people would intentionally hurt themselves. I explained why I had done it. Some of the students talked with me about it more after class. The professor said he appreciated my frankness and candor and was glad that I had received the help I needed. After the class ended, one of the students in that class also approached me and confessed to self-injuring. I was one of the few people she had told.

P.N.: My parents and siblings saw it (many years ago). I told my husband. Each responded differently - my family reacting with anger and not understanding. My husband with compassion and understanding. I always feel ashamed.

Greylin: (No response-never disclosed)

K.M.: I self injured as an adolecent (pre-teen) because I was having difficulty dealing with a very difficult home life (though I didn't understand that was the reason at the time, I simply felt compelled to do it). My mother discovered it by seeing it on my body. She told my father about it. She was very angry. I felt shame, confusion, and hurt. I felt frustration that I couldn't make her understand that I wasn't trying to commit suicide. As an adult I have disclosed it to a few close friends and family (spouse) because I no longer feel shame about it. I understand it as a mal-adaptive coping mechism of a young child trying to deal with overwhelming difficulty at home. I don't tend to broadcast my difficult childhood, so not many people know about it. Thus, they wouldn't know about my SI. However, if I have confided my difficult childhood to someone, I have no problem confiding my SI to them if an appropriate conversation arises. I have also briefly admitted to it on 2 online forums where I feel comfortable. The readers of these forums are known to me, but I have never met most of them other than online. I discuss certain aspects of my life honestly on there (though not indepth) and have touched on the fact that I did SI in the past. The reactions to these adult admissions have generally been sympathy and understanding, often with surprise. I don't have strong feelings about those reactions one way or the other. I have come to terms with my SI and put it in it's proper context in my life, so I am not swayed one way or the other by how others feel about it.

Losingmyself: Had a friend tell me of their self injury and I told them of mine to comfort them. They were shocked and we cried together. I felt better after the fact knowing I wasn't alone.

P.T.: We found our that our teenage son had self injured from a classmate at school. In the process of addressing that issue I told my husband then my son that I had self injured myself at around the same age (15 years)and that to this day when I feel overwhelmed I too still feel the impulse to self injure although since my teen years I have never acted it out. It's strange too as it's an impulse not a desire or a need or a want. I think at some point In time researchers will determine that the pathway for this is similar to the pathway for an itch. My older child knows but my younger child does not. My husband of 25 years was surprised as he had no idea and did not know that I still experience this feeling. In addition I found out something about myself in that when my son started to do this I began to research the behavior to understand it more and I was suddenly able to put a name on this feeling/issue that I had for so long. My son was able to talk a bit more about and since that time as he has grown older we are able to converse somewhat about his continuing self injury upfront

Seppie: Most of the time people see my scars. In the beginning I didn't know what to say... and felt uncomfortable. But the further away from SI I get the more matter of fact ecome about it. However, my parents, when they first learned of my SI Golda lotof there friends so they could "pray for me" this was disclosure I'd did not want and in a way made me feel ashamed of my SI inaway I never did when I self disclose.

Jenny: My Mom found out that I SI when she saw the cuts on my legs. My Dad found out when she told him. They were very upset. They didn't understand why I was doing that to myself. I felt guilty when they found out. I don't remember how my brothers found out but they managed to berate me about it and it made me feel terrible. My friend found out when I told her. She was very supportive. It made me feel like I could talk to her. I willingly told my therapist about my SI and she responded in a supportive way, but not too supportive. It was like she didn't want to make a big deal out of it so that I wouldn't do it just for the attention.

Bella: Compassionate

P.S. : my parents found out throught finding razor blades i had kept in my room. they were very upset and immediately insisted i see a counselor and start theray and meds. i felt very ashamed and guilty that i was upsetting them so much. my closet friend found when i confided in her. she was very calm about it and tried to help my not by constantly pestering/ forcing my into treatment but by trying to by there to talk if i needed to and she supplied my with any medical bandages and things i needed but couldn't get openly. i intense relief that there was someone i did not have to hide around anymore. after i had stopped i got a job later and because i was working next to ovens all day long sleeves weren't an option. my co workers found out that way and obviously noticed but never adressed it directly or brought it up even though the scars looked pretty horendous at that point. my boss at one point directly asked me about but not so much as worry for me but as a couriosity for why i participated in such an extreme behavior. my co workers never made me feel uncomftorble but when my boss 'interogated' me about i was very nervous and uncomftorble about the conversation because i had already taken measure during the interview and whenever she was around me to hide any scars becuase i was worried she would fire me.

P.E.: I told them- my boyfriend cried and said that he had lost respect for me, which hurt me a lot. My friends didn't have a particular reaction, and I was apathetic towards that.

REFERENCES

REFERENCES

Abrams, A. S. & Gordon, A. L. (2003). Self-harm narratives of urban and suburban young women. *Affilia, 18*(4), 429-444. doi: 10.1177/0886109903257668

Angermeyer, M. C., Beck, M., Dietrich, S., & Holzinger, A. (2004). The stigma of mental illness: Patients' anticipations and experiences. *International Journal of Social Psychiatry, 50*(2), 153-162. doi: 10.1177/0020764004043115

Antaki, C., Barnes, R., & Leudar, I. (2005). Self-disclosure as a situated interactional practice. *British Journal of Social Psychology, 44*(2), 181–199. doi: 10.1016/j.jpsychores.2005.07.007

Berman, J., & Wallace, P. H. (2007). *Cutting and the Pedagogy of Self-Disclosure*. Amherst: University of Massachusetts Press.

Bronfenbrenner, U. (1981). *The ecology of human development: Experiments by nature and design*. Cambridge, MA: Harvard University Press.

Brown, B. (2007). I thought it was just me (but it isn't). New York, NY: Gotham Books.

Bubolz, M. M., & Sontag, M. S. (1993). Human ecology theory. In P. G. Boss, W. J. Doherty, R. LaRossa, W. R. Schumm, & S. K. Steinmetz (Eds.), *Sourcebook of Family Theories and Methods: A contextual approach* (pp. 419-448). New York, NY: Springer Science and Business Media.

Chandra, A., & Minkovitz, C. S. (2007). Factors that influence mental health stigma among 8th grade adolescents. *Journal of Youth and Adolescence, 36*; 763–774. doi:10.1007/s10964-006-9091-0

Chapman, A. L., Gratz, K. L., & Brown, M. Z. (2006). Solving the puzzle of deliberate self-harm: The experiential avoidance model. *Behaviour Research and Therapy, 44*(3), 371–394. doi:10.1016/j.brat.2005.03.005

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. Los Angeles, CA: Sage.

Connors, R. (1996). Self-Injury in trauma survivors: Functions and meanings. *American Journal of Orthopsychiatry, 66*(2), 197-206. doi:10.1037/h0080171

Corbin, J., & Strauss, A. (2008). *Basics of qualitative research* (3rd Edition). Los Angeles, CA: Sage.

Corrigan, P. W., Lurie, B. D., Goldman, H. H., Slopen, N., Medasini, K., & Phelan, S. (2005). How adolescents perceive the stigma of mental illness and alcohol abuse. *Psychiatric Services*, *56*(5), 544-550. doi:10.1176/appi.ps.56.5.544

Corrigan, P. W., Watson, A. C., & Ottati, V. (2003). From whence comes mental illness stigma? *International Journal of Social Psychiatry*, *49*(2), 142-157. doi: 10.1177/0020764003049002007

Creswell, J. W. (2007). *Qualitative Inquiry and Research Design*. Thousand Oaks, CA: Sage.

Dovidio, J. F., Major, B., & Crocker, J. (2003). Stigma: Introduction and Overview. In T. F. Heatherton, R. E. Kleck, M. R. Hebl, & J. G. Hull (Eds.), *The Social Psychology of Stigma* (pp.1-30). New York, NY: Guilford Press.

Edwards, T. M. (1998, November 9). What the cutters feel. *Time*, *152,* 93-94.

Farber, B. A., Khurgin-Bott, R., & Feldman, S. (2009). The benefits and risks of patient self-disclosure in the psychotherapy of women with a history of childhood sexual abuse. *Psychotherapy Theory, Research, Practice, Training, 46*(1), 52-67. doi:10.1037/a0015136

Favazza, A. R. (1998). The coming of age of self-mutilation. *Journal of Nervous & Mental Disease*, *186*(5), 259-268.

Fine, M. (1992). *Disruptive voices: The possibilities of feminist research.* Ann Arbor: The University of Michigan.

Finkenauer, C., & Hazam, H. (2000). Disclosure and secrecy in marriage: Do both contribute to marital satisfaction? *Journal of Social and Personal Relationships, 17*(2), 245–263. doi: 10.1177/0265407500172005

Finkenauer, C., Engels, R. C. M. E., & Meeus, W. (2002). Keeping secrets from parents: Advantages and disadvantages of secrecy in adolescence. *Journal of Youth and Adolescence, 31*(2), 123–136. doi: 10.1023/A:1014069926507

Friedman, T., Newton, C., Coggan, C., Hooley, S., Patel, R., Pickard, M., & Mitchell, A. J. (2006). Predictors of A & E staff attitudes to self-harm patients who use self-laceration: Influence of previous training and experience. *Journal of Psychosomatic Research, 60*(3), 273-277. doi:10.1016/j.jpsychores.2005.07.007

Garbarino, J. (1992). *Children and Families in the Social Environment*. Edison, NJ: Aldine Transaction.

Gibb, S. J., Beautrais, A. L., & Surgenor, L. J. (2010). Health-care staff attitudes toward self-harm patients. *Australian & New Zealand Journal of Psychiatry, 44*(8), 713-720. doi: 10.3109/00048671003671015

Gibson, R. C., Abel, W .D., White, S., & Hickling, F. W. (2008). Internalizing stigma associated with mental illness: Findings from a general population survey in Jamaica. *Pan American Journal of Public Health, 23*(1), 26-33. doi: 10.1590/S1020-49892008000100004

Goffman, E. (1963*). Stigma: Notes on the management of spoiled identity*. New York, NY: Simon & Schuster.

Greene, K., Derlega, V. J., & Mathews, A. (2006). Self-disclosure in personal relationships. In A. L. Vangelisti & D. Perlman (Eds.), *Cambridge Handbook of Personal Relationships* (pp. 409-427). New York, NY: Cambridge University Press.

Haw, C. (2000). Psychological perspectives on women's vulnerability to mental illness. In D. Kohen (Ed.), *Women and mental health* (pp.65-105). Philadelphia, PA: Routledge.

Heath, N. L., Toste, J. R., & Beettam, E. L. (2006). "I am not well-equipped": High school teachers' perceptions of self-injury. *Canadian Journal of School Psychology, 21*(1/2). doi: 10.1177/0829573506298471

Heijnders, M., & Van Der Meij, S. (2006). The fight against stigma: An overview of stigma-reduction strategies and intervention. *Psychology, Health & Medicine, 11*(3), 353-63. doi: 10.1080/13548500600595327

Heller, P. (2009). Challenges Facing LGBT Asylum-Seekers: The Role of Social Work in Correcting Oppressive Immigration Processes. *Journal of Gay & Lesbian Social Services, 21*(2-3), 294-308. doi: 10.1080/10538720902772246

Herek, G. M. (1999). AIDS and stigma. *American Behavioral Scientist, 42*(7), 1102-1112. doi: 10.1177/0002764299042007004

Hinshaw, S. P. (2007). *The mark of shame: Stigma of mental illness and an agenda for change.* New York, NY: Oxford University Press.

Hodgson, S. (2004). Cutting Through the Silence: A Sociological Construction of Self-Injury. *Sociological Inquiry, 74*(2), 162–179. doi: 10.1111/j.1475-682X.2004.00085.x

Holmshaw, J. & Hillier, S. (2000). Gender and culture: A sociological perspective to mental health problems in women. In Dora Kohen (Ed.), *Women and mental health* (pp. 39-64). Philadelphia, PA: Routledge.

Jason, L. A., Taylor, R. R., Plioplys, S., Stepanek, Z., & Shlaes, J. (2002). Evaluating attributions for an illness based upon the name: Chronic Fatigue Syndrome, Myalgic Encephalopathy and Florence Nightingale Disease. *American Journal of Community Psychology*, *30*(1), 133-148. doi: 10.1023/A:1014328319297

Jayaratne, T. E., & Stewart, A. J. (1991). Quantitative and qualitative methods in the social sciences: Current feminist issues and practical strategies. In M. M. Fonow & J. A. Cook (Eds.), *Beyond Methodology: Feminist scholarship as lived research* (pp. 85-106). Bloomington/Indianapolis: Indiana University Press.

Kimmel, M. S. (2000). *The Gendered Society*. New York, NY: Oxford University Press.

Klonsky, E. D. & Olino, T. M. (2008). Identifying clinically distinct subgroups of self-injurers among young adults: A latent class analysis. *Journal of Counseling and Clinical Psychology*, *76*(1), 22-27. doi: 10.1037/0022-006X.76.1.22

Kirsch, G. E. (1999). *Ethical Dilemmas in Feminist Research: The politics of location, interpretation, and publication*. Albany, NY: State University of New York Press.

Leary, M. R., Koch, E. J., & Hechenbleikner, N. R. (2006). Emotional responses to interpersonal rejection. In Leary, M. R. (Ed.) *Interpersonal Rejection* (pp.145-162). New York, NY: Oxford University Press.

Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology*, *27*, 363 – 385. doi:10.1146/annurev.soc.27.1.363

Levesque-Lopman, L. (1988). *Claiming reality: Phenomenology and Women's Experience*. Totowa, NJ: Rowman & Littlefield.

Mann, C. E. & Himelein, M. J. (2004). Factors associated with stigmatization of persons with mental illness. *Psychiatric Services*, *55*(2), 185-187. doi:10.1176/appi.ps.55.2.185

Markowitz, F. E. (1998). The effects of stigma on the psychological well-being and life satisfaction of persons with mental illness. *Journal of Health and Social Behavior*, *39*(4), 335-347. Retrieved from hsb.sagepub.com/

Martin, J. K., Pescosolido, B. A., & Tuch, S. A. (2000). Of fear and loathing: The role of 'disturbing behavior,' labels, and causal attributions in shaping public attitudes toward people with mental illness. *Journal of Health and Social Behavior*, *41*(2), 208-223. Retrieved from hsb.sagepub.com

Martinson, D. (2001). Self-injury: Beyond the Myths. In American Self-Harm Information Clearinghouse Fact Sheets and Documents. Retrieved from http://www.selfinjury.org/docs/factsht.html

McDonald, C. (2006). Self-Mutilation in adolescents. *The Journal of School Nursing*, *22*(4), 193-200. doi: 10.1177/10598405050220040201

McKillop, K. J. & Kelly, A. E. (1996). Consequences of revealing personal secrets. *Psychological Bulletin*, *120*(3), 450-465. Retrieved from http://www.apa.org/pubs/journals/bul/index.aspx

Miller, C. T. & Major, B. (2003). Coping with stigma and prejudice. In T. F. Heatherton, R. E. Kleck, M. R. Hebl & J. G. Hull (Eds.), *The Social Psychology of Stigma* (p. 243-272). New York, NY: The Guilford Press.

Omarzu, J. (2000). A disclosure decision model: Determining how and when individuals will self-disclose. *Personality and Social Psychology Review*, *4*(2), 174-185. doi: 10.1207/S15327957PSPR0402_05

Petronio, S., Reeder, H. M., Hecht, M. L. & Ros-Mendoza, T. M. (1996). Disclosure of sexual abuse by children and adolescents. *Journal of Applied Communication Research*, *24*(3), 181-99. doi: 10.1080/00909889609365450

Puhl, R. M., Moss-Racusin, C. A., Schwartz, M. B., & Brownell, K. D. (2008). Weight stigmatization and bias reduction: perspectives of overweight and obese adults. *Health Education Research*, *23*(2), 347-358. doi: 10.1093/her/cym052

Qian, H., & Scott, C. R. (2007). Anonymity and self-disclosure on weblogs. *Journal of computer-mediated communication*, *12*(4), 1428-1451. Retrieved from http://jcmc.indiana.edu/

Rosenfield, S. (1997). Labeling mental illness: The effects of received services and perceived stigma on life satisfaction. *American Sociological Review*, *62*(4), 660-672. Retrieved from http://www.asanet.org/journals/asr/

Sansone, R. A., Wiederman, M. W., & Jackson, J. (2008). Mothers' awareness of self-harm behaviors in their children. *Traumatology*, *14*(3), 22-27. doi: 10.1177/1534765608320336

Shapiro, S. (2008). Addressing self-injury in the school setting. *Journal of School Nursing*, *24*(3), 124-132. doi: 10.1177/1059840512344321

Smart, L., & Wegner, D. M. (1999). Covering up what can't be seen: Concealable stigma and mental control. *Journal of Personality and Social Psychology*, *77*(3), 474-486. doi: 10.1037/0022-3514.77.3.474

Smetana, J. G., Metzger, A., Gettman, D. C., & Campione-Barr, D. (2006). Disclosure and secrecy in adolescent–parent relationships. *Child Development*, *77*(1) 1, 201 – 217. doi: 10.1111/j.1467-8624.2006.00865.x

Smith, M. (2002). Stigma. *Advances in Psychiatric Treatment, 8*(5), 317 – 325. doi:10.1192/apt.8.5.317

Stewart, M., Keel, P. K., & Schiavo, R. S. (2006). Stigmatization of Anorexia Nervosa. *International Journal of Eating Disorders, 39*(4), 320-25. doi: 10.1002/eat

Storey, P., Hurry, J., Jowitt, S., Owens, D., & House, A. (2005). Supporting young people who repeatedly self-harm. *The Journal of the Royal Society for the Promotion of Health, 125*(2), 71-75. doi: 10.1177/146642400512500210.

Suddaby, R. (2006). What grounded theory is not. *Academy of Management Journal, 49*(4), 633-642. doi:10.5465/AMJ.2006.22083020

Suyemoto, K. (1998). The functions of self-mutilation. *Clinical Psychology Review, 18*(5), 531-554. Retrieved from http://www.journals.elsevier.com/clinical-psychology-review/#description

Tantam, D., & Huband, N. (2009). Understanding repeated self-injury: A multidisciplinary approach. New York, NY: Palgrave Macmillan.

Taylor, T. L., Hawton, K., Fortune, F., & Kapur, N. (2009). Attitudes toward clinical services among people who self-harm: A systematic review. *British Journal of Psychiatry, 194*, 104-110. doi: 10.1192/bjp.bp.107.046425

Walsh, B. (2007). Clinical assessment of self-injury: A practical guide. *Journal of Clinical Psychology: In Session, 63*(11), 1057-1068. doi: 10.1002/jclp.20413

Watson, A. C., Corrigan, P., Larson, J. E. & Sells, M. (2007). Self-stigma in people with mental illness. *Schizophrenia Bulletin, 33*(6), 1312-1318. doi:10.1093/schbul/sbl076

White, V., Trepal-Wollenzier, H., & Nolan, J. M. (2002). College students and self-injury: Intervention strategies for counselors. *Journal of College Counseling, 5(2);* 105-113. doi: 10.1002/j.2161-1882.2002.tb00212.x

Yanos, P. T., Rosenfield, S., & Horwitz, A V. (2001). Negative and supportive social interactions and quality of life among persons diagnosed with severe mental illness. *Community Mental Health Journal, 37*(5), 405-419. doi: 10.1023/A:1017528029127