



Ethical practices in community-based research in non-suicidal self-injury: A systematic review



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ABSTRACT

Background: The growing interest in community-based research on non-suicidal self-injury (NSSI) reflects the high prevalence rates found among vulnerable adolescents and young adults. A significant concern in research with vulnerable populations, and on sensitive topics, is the development of an ethical framework that protects the needs and rights of the participants while responding to researchers' goals and limitations and the broader clinical and public health concerns.

Aim: The aim of the present study was to review the ethical practices followed in community-based research on NSSI.

Method: A systematic review of literature was conducted, based on PRISMA guidelines, on community-based surveys in NSSI, published between 1995 and 2016. A total of 93 studies were included in the review.

Results: The results examine a range of ethical issues; the procedures for consent and assent for study participation, protection of confidentiality and the limits of confidentiality, assessment of imminent risk of suicide and subsequent processes, and debriefing measures. The interaction between the study characteristics and the reported ethical procedures has been examined, with a focus on participant age, study design (cross-sectional or longitudinal), survey modality (paper-based survey or online survey) and primary variable/s of interest (only NSSI or NSSI and suicidal ideation/behavior) under study. The review describes the typical ethical practices in community-based research on NSSI, identifies the gaps in the existing literature, and has implications for the formulation of best-practice guidelines.

1. Introduction

Typically, in planning and conducting research, the translation of ethical principles into practice is fraught with a number of pragmatic challenges. This difficulty increases when conducting research with vulnerable populations and on sensitive topics. Navigating the ethical issues involved in studying Non-Suicidal Self Injury (NSSI), “the intentional destruction of one’s body tissue without suicidal intent” (Nock and Favazza, 2009), can be a complex and ambiguous exercise.

NSSI becomes a sensitive topic of research due to various reasons. The highest rates of self-injury are among youth, with the initiation of self-injuring behaviours typically in adolescence (Nock and Prinstein, 2004; Whitlock et al., 2006). Help-seeking rates are usually low, with self-injuring youth tending to conceal their behaviours or limit help-seeking from adults (Hasking et al., 2015). Research has also indicated that self-injuring youth may also have comorbid psychiatric conditions or psychological vulnerabilities (Welch et al., 2008; Wilkinson and Goodyer, 2011). However, many youth who self-injure are likely to be

functioning well enough to go undetected by the health care system (Whitlock et al., 2006). Consequently, research has expanded to explore rates of NSSI behavior among youth in the community, where needed mental health resources have been found to be lacking (Duggan et al., 2011). This growing interest introduces ethical issues concerning research involving minor participants, such as definition of “minor” and procedures relating to assent and consent.

The relationship between NSSI and suicide is a complex one. The empirical and phenomenological distinctions between NSSI and suicide have been highlighted (Baetens et al., 2011; Favazza, 1996; Wichstrøm, 2009), with research illuminating how NSSI could aid in stopping suicidal thoughts and preventing suicidal acts (Klonsky and Muehlenkamp, 2007). This culminated in the efforts to classify NSSI as an independent diagnostic entity in the DSM V (Muehlenkamp, 2005). The distinction between NSSI and suicide means that an extrapolation of the ethical frame works used in research on suicide might not always be appropriate.

On the other hand, while behaviours such as cutting, scratching or

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burning skin, hitting or biting self may be performed without suicidal intent, there is the potential for unanticipated severe harm in the process of self-injuring (Lloyd-Richardson et al., 2015). Non-suicidal self-injurious acts have also been conflated with suicidal behaviours (Muehlenkamp and Gutierrez, 2007; Nock et al., 2006), or seen as a “gateway to suicide” (Whitlock et al., 2012). Researchers have raised doubts (self-harmCrowe, 2014; Kapur et al., 2013) regarding the dichotomy between NSSI and suicide, given the strong empirical link between the two (Andover and Gibb, 2010; Claes et al., 2010), suggesting NSSI and suicide would be better conceptualized as falling on a continuum (Kapur et al., 2013).

The current knowledge about the links between NSSI and suicide and other psychiatric co-morbidities behooves the ethical obligation to identify those at risk for suicide and/or other psychiatric disorders, and to facilitate mental health care for them. This, however, also involves complex issues about protection of confidentiality. The high prevalence rates of NSSI in the community further impact the feasibility of conducting risk-assessment and facilitating referrals.

A significant concern in research with vulnerable populations, and on sensitive topics, is the development of an ethical framework that protects the needs and rights of the participants while addressing the goals and limitations of the researcher, and the broader clinical and public health concerns. The guidelines for the ethical framework to be followed in research with vulnerable populations have been proposed by Council of International Organizations of Medical Sciences (2002) in collaboration with the World Health Organisation. However, the translation of these guidelines into practice may be difficult for researchers in their particular area of work, which would come with its own set of ethical dilemmas and practical constraints. The International Society for the Study of Self-Injury (ISSS) provides a forum for researchers in the field of NSSI. It supported the work of Lloyd-Richardson et al. (2015), which provided researchers with several recommendations on planning and conducting research on NSSI among youth, keeping in mind the ethical concerns in such research. They pointed out areas of uncertainty in the current research practice, such as the range of breach of confidentiality protocols currently in practice by researchers, and the interaction of the study design with the ethical framework followed. Most importantly, they pointed out how ethical requirements could vary depending on the *study design*; e.g. cross-sectional/longitudinal, *sample*: e.g. clinical/community; minor participants; *study variables*, e.g. does it assess suicidal intent/behaviours, and *survey modality*, e.g. paper-based or web-based survey

In recent years, NSSI has become a burgeoning area of research, with studies being conducted in a variety of settings. Web-based surveys have gained popularity as a survey modality, due to ease in data capture, data output and enhanced anonymity features (Wright, 2005). Preliminary evidence of cross-cultural differences in the prevalence and functions of NSSI has led researchers to recommend that more cross-cultural researches be conducted (Martorana, 2015; Muehlenkamp et al., 2012; Polanco-Roman et al., 2014). The ongoing efforts to clarify the relationship between NSSI and suicide translates into an increase in number of researches assessing both NSSI and suicide, and an increase in number of longitudinal studies being planned and conducted.

Overall, this is an exciting time for research in NSSI in the community population; interest in the field is rapidly growing, preliminary findings have indicated new areas of research, technological advances have led to assessment of NSSI in different contexts and there is a call for multi-wave longitudinal studies and international collaboration. At a time like this, it would be beneficial to review the range of practices currently being reported to address the various ethical concerns associated with research on NSSI. Reviewing community based surveys on NSSI between January, 1995 and October, 2016, the present paper focuses on the procedures for consent and assent for participation in the study, protection of confidentiality and the limits of the same, assessment of imminent risk of suicide and addressing the risk, and debriefing procedures reported. It also aims to examine how the ethical framework

varies according to study design, sample, study variables and survey modality.

2. Method

Following the PRISMA guidelines (Moher et al., 2009), a systematic review of literature was carried out using PubMed and ProQuest. The search terms “Non-Suicidal Self-Injury”, “Non-Suicidal Self-Injurious Behaviour” and “NSSI” along with “community” and “survey” were used as query strings. Studies published in English, and between January, 1995 and October, 2016 were included. Only studies that defined “Non-Suicidal Self-Injury” as “direct, deliberate destruction or alteration of body tissue, devoid of any conscious suicidal intent”, conducted with a community population, with a cross-sectional or longitudinal design, following a survey method of data collection (paper-based, web-based or telephonic) were included. Studies which did not provide an operational definition of the variable under study, or had an over-inclusive definition of self harm (e.g. suicidal ideation, suicidal attempts) were excluded. However, studies which measured suicidal behavior as a separate variable, along with NSSI were included. In cases where multiple articles were published on the basis of one study, only one published article was included, as the ethical framework remained the same. Case studies, interview-based studies, intervention based studies, studies on clinical populations, and experimental studies were also excluded from the review. This led to an inclusion of a total of 93 studies. (See Fig. 1 for details) The data was coded using PSPP version 0.8.4 (GNU Project, 2015) in the form of categorical data. The frequencies and percentages of each of the categories were calculated.

3. Results

The review indicated a progressive increase in the number of community-based surveys of NSSI, with an increase from one study being published in 2005, to 29 studies published in 2015. Cross-sectional studies formed the majority of the studies on NSSI (81%), with 19% of the studies being longitudinal in design. The primary variable under study was mostly only NSSI (71%), while a few studies (27%) studied both NSSI and suicide. In terms of the population under study, studies were almost equally divided between those with minor participants (44%) and major participants (48%) and eight percent of the studies recruited both minors and majors as participants. For the purpose of the present paper, “major” was defined according to two criteria: if the sample participant were above 18 years of age, or if the authors of the paper mentioned that the particular age cutoff defines “major” under the law of that nation. Looking at survey modality, the majority of studies (68%) used a paper-based survey modality, while the remaining (31%) were web-based surveys. Only one study used telephonic survey modality.

Table 1 presents the ethical procedures described in community based surveys on NSSI reviewed in this paper. The most noticeable finding was that the ethical procedures followed were not explicitly mentioned in the majority of the articles. This was most prominent with respect to conducting assessment of imminent risk of suicide (86%), conducting debriefing (73%), providing referral information of local mental health resources to participants (63%), assuring confidentiality (59%) and assuring participant anonymity (53%).

Assurance of anonymity was mentioned in 47% of the studies. Assurance of confidentiality was mentioned in only 32% of the studies. In very few studies (9%), participants were encouraged to disclose engagement in NSSI and/or suicidal behavior to caregivers, with the assistance of the researcher. Assessment of imminent risk of suicide was mentioned in only fourteen percent of the studies. Conduction of debriefing was mentioned in only twenty-seven percent of the studies. Of these 27% studies, an almost equal distribution was seen between providing participants with written debriefing sheets (14 studies), conducting debriefing in person (11 studies). The majority of these

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