

The ethics of self-report surveys assessing non-suicidal self-injury and other sensitive topics

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Introduction

Non-suicidal self-injury (NSSI) is a term that encompasses a variety of behaviors in which an individual intentionally inflicts harm to his or her body for reasons that are not socially sanctioned and are without suicidal intent (International Society for the Study of Self-Injury, 2007). As more researchers look to understand NSSI, questions about the behavior have become more common on mental health-related surveys. Researchers often raise concerns about the relative risks and liabilities of using self-report measures to collect sensitive data.

Several studies have examined respondents' levels of distress as a result of participating in a variety of sensitive survey research. One study assessing reactions to a telephone survey regarding violence and victimization found that the majority of respondents did not feel upset by survey questions, regardless of their victimization history. Of the small percentage of victimized participants who did report feeling upset, the majority believed that the survey contained questions that were beneficial to be asked (Black, Kresnow, Simon, Arias, & Shelley, 2006). Similar results were found in a study exploring adolescents' reactions to survey items assessing drug use, suicidal behavior, and physical and sexual abuse: only a small percentage of adolescents reported feeling distressed by the survey items (4.4%), with those who have experienced sensitive events more likely to feel upset (Langhinrichsen-Rohling, Arata, O'Brien, Bowers, & Klibert, 2006).

Little direct research, however, has focused on exploring distress related to answering survey items on NSSI and whether reports of feeling upset vary significantly by self-injury status. In addition, not much is known about the outcomes, both positive and negative, of reflecting upon difficult topics such as self-injury.

Objectives

The focus of this research project is to determine whether self-report survey items assessing sensitive topics, such as self-injury, suicidality, traumatic life events and eating disorders, cause distress for respondents as whether or not questions around these topics cause individuals to think more deeply about their lives. We are equally interested in assessing what kinds of positive feelings respondents might have as a result of participation. In particular, we seek to understand how sensitive survey items affect individuals with a history of self-injury.

Methods

Sample

Our quantitative data were taken from the two closing questions of an eight-college survey of student mental health and well-being. The survey was designed to assess various mental health issues in a college population, but was focused on self-injury in particular. The progression of questions in the survey differed based on early responses, with those participants indicating a history of NSSI given more questions on the topic than those who did not indicate such a history. All the surveys concluded with the same two questions: Question A, which asked participants to respond to the statement, "Answering some of the questions on this survey caused me to think more deeply about my life," and Question B, which asked them to respond to the statement, "Answering some of the questions on this survey caused me to feel upset." Respondents ranked their answers on a scale of 1-5, from "very untrue" to "very true." 13993 students responded to Question A and 13155 students responded to Question B. These responses were then grouped into 5 categories: 1) Not upset by survey, but thought more deeply, 2) Not upset by survey, did not think more deeply, 3) Upset by survey, but thought more deeply, 4) Upset by survey, did not think more deeply, 5) Ambivalent.

Respondents who answered each of the above questions were invited to expand upon their quantitative answer in an open-ended format. 2291 respondents expanded upon the question about thinking more deeply about their lives, and 1345 expanded upon the question about feeling upset. Of these responses, a random sample of 250 was chosen from each group for coding. Responses from individuals with a history of self-injury were read for further content analysis.

Coding

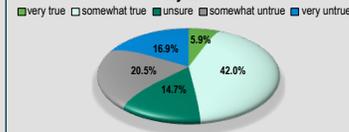
Responses that contained extraneous or irrelevant data were removed. After doing so, 232 unique responses to the open-ended qualitative question about thinking more deeply were coded as were 230 unique responses to the open-ended qualitative question about being upset by the survey.

Each response was studied separately by two research assistants and given a specific thematic code according to its key features. The responses were then organized into eight overarching codes for Question A and nine overarching codes for Question B. Any discrepancies in coding between the two research assistants were examined and a consensus was reached for each response based on what was deemed most suitable. Some responses received multiple thematic codes (up to three).

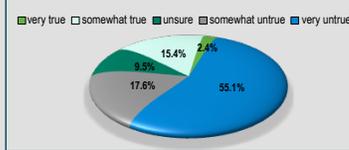
Results

Quantitative Findings

"Answering some of the questions on this survey caused me to think more deeply about my life"



"Answering some of the questions on this survey caused me to feel upset"



• Survey prompted about half (47.9%) of respondents to think more deeply about their lives.

• Almost three-quarters of respondents (72.7%) answered either "very untrue" or "somewhat untrue" when asked if they were upset by the survey.

• Differences in respondents with a history of self-injury, 62.4% of those currently engaging in self-injury still reported that the survey did not make them particularly upset, with approximately 1/3 saying that it made them somewhat upset and only 6.9% of those with a recent history of NSSI "very upset".

How did respondents react to the survey overall?

| Reaction | All respondents | History of NSSI or suicidality |
|---------------------------------|-----------------|--------------------------------|
| Not upset, thought deeply | 29.7% | 23.8% |
| Not upset, did not think deeply | 33.6% | 27.2% |
| Upset, thought deeply | 13.5% | 22.1% |
| Upset, did not think deeply | 2.7% | 5.4% |

All other respondents were ambivalent.

Individuals with a history of NSSI or suicidality reacted similarly to the survey and showed some differences from individuals without these histories. All of these relationships hold even when demographics and trauma history are taken into account. They were:

- 2.81 times more likely to say that the survey upset them and did not make them think, though both of these percentages were low overall.
- 2.26 times more likely to say that the survey was hard, but made them think.
- 1.46 times less likely to say that it did not upset them but did make them think.
- 1.46 times less likely to say that it had no effect.

Logistic regression on any suicide or non-suicidal self-injury, adjusted for race/ethnicity, sex, and sexual orientation (n=13,131)

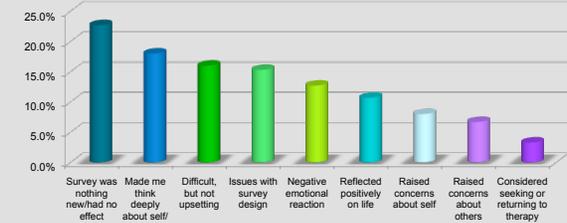
| Characteristic | Positive experience | | Difficult but inspired self-reflection | | Negative experience | |
|--|---------------------|-------------|--|----------------|---------------------|----------------|
| | N (%) | OR (95% CI) | N (%) | OR (95% CI) | N (%) | OR (95% CI) |
| History of suicide-related behavior | | | | | | |
| No | 4,044 (30.8) | 1.0 | 1,576 (12.0) | 1.0 | 302 (2.3) | 1.0 |
| Yes | 2,968 (22.6) | .7* (6-.7) | 3,033 (23.1) | 2.1* (1.8-2.4) | 709 (5.4) | 1.9* (1.5-2.5) |
| History of non-suicidal self-injury | | | | | | |
| No | 4,057 (30.9) | 1.0 | 1,562 (11.9) | 1.0 | 276 (2.1) | 1.0 |
| Yes | 3,033 (23.1) | .7* (6-.8) | 2,968 (22.6) | 2.1* (1.8-2.3) | 801 (6.1) | 2.7* (2.1-3.4) |

* p < .001

Results

Qualitative Findings

Content of open-ended qualitative question about survey experience (n=462)



Descriptions of survey experience from individuals with NSSI history

| Response category | Representative quotation from individual with NSSI history |
|----------------------------------|--|
| Nothing new/had no effect | "I was not asked anything I have not thought about on my own." |
| Thought deeply about self issues | "It caused me to remember old feelings, but also how you can overcome them." |
| Difficult, but not upsetting | "I have accepted my experiences as events that have made me who I am today. I cannot change what has happened in the past and talking about them while not always easy to do doesn't upset me today as it once would have." |
| Issues with survey design | "I wish the questions were more tailored to my experience at [school name] than my cutting habit from years ago." |
| Negative emotional reaction | "I did something I only do a few times a year - I cried. I'm going to have to meditate on this subject for some time today. I kind of feel upset now." |
| Reflected positively on life | "Glad I'm not the same way I used to be - determined to keep it up." |
| Raised concerns about self | "I feel concerned about my health that I use [drugs] too, but not upset." |
| Seeking or returning to therapy | "All in all, it makes me want to begin therapy again over the summer with my counselor from this past year, and perhaps bring up that I hurt myself. I'm sure she'd have something to say, and it would be nice to be rid of it, mainly because I know now what it's like to be healthier and stronger. Also, then no one else would ever have to worry about me. Thanks very much!" |

Discussion

In general, few individuals reported experiencing distress as a result of participating in the survey. Of all respondents, 72.7% reported no negative effect of the survey and 47.9% reported that it caused them to think more deeply about their lives.

Responses did vary between groups, with those reporting a history of NSSI or suicidality more likely 2.81 more likely to be upset, but not think deeply. The frequency of this report was low overall, and respondents were far more likely to report that while they found the survey upsetting, it also made them think more deeply about their lives. Those with a history of NSSI or suicidality were over twice as likely to endorse this response than those without such experience.

These findings suggest that while online surveys about NSSI may have the potential to cause stress in individuals with NSSI history, this stress could, in some instances, be beneficial and cause positive change. In their qualitative responses, respondents mentioned reflecting positively on their lives, thinking more deeply about their issues, raising concerns about themselves or others, and considering returning to therapy. More research is still needed to understand the particularized and/or lasting effects of survey participation.

References

- Black, M.C., Kresnow, M., Simon, T.R., Arias, I., & Shelley, G. (2006). Telephone survey respondents' reactions to questions regarding interpersonal violence. *Violence and Victims, 21*(4), 445-459.
- International Society for the Study of Self-Injury. (2007). *Definitional issues surrounding our understanding of self-injury*. Conference proceedings from the annual meeting.
- Langhinrichsen-Rohling, J., Arata, C., O'Brien, N., Bowers, D., & Klibert, J. (2006). Sensitive research with adolescents: Just how upsetting are self-report surveys anyway? *Violence and Victims, 21*(4), 425-444.