

# Addressing Self-Injury Stigma: The Promise of Innovative Digital and Video Action- Research Methods

Stephen P. Lewis  
*University of Guelph*

Nancy L. Heath, and Rob Whitley  
*McGill University*

## ABSTRACT

Stigma associated with non-suicidal self-injury (NSSI), the deliberate damage of one's body tissue for non-lethal reasons, is highly complex, far-reaching, and can have profound effects (e.g., shame, low self-esteem, thwarted help-seeking) on individuals with lived experience of NSSI. In concert with calls for greater inclusion of people with lived experience in NSSI research and advocacy, there are several robust and potentially impactful visual and digital research methods that directly involve individuals with lived experience, and which carry potential to tackle stigma. These methods, namely digital storytelling, photovoice, and participatory video, are largely underrepresented in contemporary NSSI research. Hence, the present commentary presents a concise overview of these methods and highlights their potential to address NSSI stigma.

**Keywords:** self-injury, stigma, participatory action research, advocacy, lived experience

## RÉSUMÉ

La stigmatisation associée à l'automutilation non suicidaire (AMNS), la destruction auto-infligée des tissus corporels sans intention suicidaire, est très complexe, vaste, et peut avoir des conséquences importantes (p. ex. honte, faible estime de soi, difficulté à chercher de l'aide) pour les personnes aux prises avec l'AMNS. De concert avec les demandes pour une plus grande inclusion de ces personnes dans le processus de recherche sur l'AMNS et la défense de leurs intérêts, il existe plusieurs méthodes de recherche visuelle et

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Stephen P. Lewis, Department of Psychology, University of Guelph, Guelph, ON; Nancy L. Heath, Faculty of Education, McGill University, Montréal, QC; Rob Whitley, Department of Psychiatry, Douglas Research Centre, McGill University, Montréal, QC.

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Correspondence concerning this article should be addressed to Stephen P. Lewis, PhD, Department of Psychology, University of Guelph, Guelph, Ontario, Canada N1G 2W1. Email: [stephen.lewis@uoguelph.ca](mailto:stephen.lewis@uoguelph.ca)

numérique solides susceptibles d'avoir un impact important qui impliquent directement ces mêmes personnes vivant une expérience d'AMNS, et qui représentent un réel potentiel pour lutter contre la stigmatisation. Ces méthodes, c'est-à-dire la narration numérique, la photographie et la vidéo participative, sont largement sous-représentées dans la recherche contemporaine sur l'AMNS. Dès lors, cet article présente un aperçu de ces méthodes et met en évidence leur potentiel pour lutter contre la stigmatisation de l'AMNS.

**Mots clés** : automutilation ; stigmatisation ; recherche-action participative (RAP) ; campagnes de mobilisation ; expérience vécue

Over the past 15 years, there has been a steady increase in the number of research articles focusing on non-suicidal self-injury (NSSI), the purposeful damaging of one's body tissue for reasons that are non-suicidal in nature (International Society for the Study of Self-injury, 2018). Notwithstanding the significant increases in NSSI knowledge gained through these efforts, far less attention has been paid to addressing NSSI stigma. This is problematic in light of evidence that NSSI is widely misunderstood (e.g., Lewis et al., 2014; Lloyd et al., 2018) and evokes negative attitudes (e.g., Berger et al., 2014; Heath et al., 2011; Saunders et al., 2012) and responses in others (e.g., Long, 2018; Mitten et al., 2016). The impact of this is substantial, with individuals who self-injure experiencing shame and embarrassment (Chandler, 2014; Long, 2018), low self-esteem (Long, 2018), efforts to conceal NSSI (Chandler, 2014; Hodgson, 2004; Long, 2018), and reluctance to disclose and seek support for NSSI (Rosenrot & Lewis, 2018). With this in mind, the present commentary discusses three robust participatory research methods which may be effective in addressing NSSI stigma. These methods are becoming increasingly common in public health and social science research. However, they are conspicuously underrepresented in contemporary NSSI research. Hence, we provide readers with a succinct overview of these innovative methods to inform future research and advocacy efforts in the area of NSSI.

## NSSI & STIGMA

Worldwide, NSSI represents a widespread and serious mental health concern (e.g., Hooley & Franklin, 2018; Lewis & Heath, 2015; Washburn, 2019). Indeed, about 18% of adolescents and 13% of emerging adults report having self-injured; among university students, rates are approximately 20% (Swanell et al., 2014). Although most often engaged in by these age groups, NSSI occurs across the lifespan with rates of about 8% among pre-adolescents between the ages of 8 and 12 (Barrocas et al., 2012) and 5–6% of the general population of adults (Klonsky, 2011; Swanell et al., 2014).

Most often, NSSI is used in an effort to obtain relief from painful emotion (see Taylor et al., 2018). Accordingly, it should come as little surprise that individuals who self-injure also report mental health difficulties (e.g., distress, difficulty coping) and mental illness (e.g., depression, eating disorders, borderline personality disorder; Hooley & Franklin, 2018; Lewis & Heath, 2015; Washburn, 2019). Further, many individuals report scarring which may foment shame (Lewis, 2016; Lewis & Mehrabkhani, 2016) and adversely impact recovery (Lewis et al., 2019). Most worrisome is a growing line of inquiry indicating that self-injury confers unique and significant suicide risk (Franklin et al., 2017; Kiekens et al., 2018; Klonsky et al., 2013).

Compounding the plight of NSSI for many individuals is stigma (Burke et al., 2019; Lewis & Seko, 2016; Long, 2018; Piccirillo et al., 2020; Staniland et al., 2021). Stigma in the context of NSSI is highly complex and can present in many ways (Staniland et al., 2021). Akin to stigma associated with mental illness, this can include public stigma (Corrigan & Watson, 2002), which refers to the attitudes and belief sets held by the general public (e.g., people who self-injure are weak, people who self-injure are just attention-seeking and manipulative); enacted stigma (Scambler, 1998), or the outward discrimination and stereotyping experienced by individuals (e.g., individuals receiving poor care in a clinical setting, people not being hired due to visible NSSI scarring); self-stigma (Corrigan & Watson, 2002), the internalization of beliefs and attitudes stemming from public stigma (e.g., I am weak; I don't deserve to be treated with compassion); and, anticipated stigma (Quinn & Chaudoir, 2009), the expectation that one will be stigmatized by others irrespective of whether one has previously experienced stigma (e.g., if I disclose my NSSI experience, people will think I'm disgusting).

A voluminous literature documents the impact of stigma on many mental health difficulties, with considerable evidence pointing to stigma as a major barrier to service utilization, recovery, and empowerment (e.g., Angermeyer & Matschinger, 2003; Corrigan & Kleinlein, 2005; Corrigan & Watson, 2002; Whitley & Campbell, 2014). While research on NSSI and stigma is comparably nascent, several reports nevertheless point to both the prominence of such stigma and its impact (see Staniland et al., 2021). Indeed, there are enumerable reports of people in the general public (e.g., Burke et al., 2019), in healthcare settings (Karman et al., 2015; Saunders et al., 2012) and in schools (e.g., Berger et al., 2014; Heath et al., 2011), who hold negative attitudes toward NSSI. Individuals who self-injure have correspondingly reported negative reactions and interactions from others regarding NSSI (Mitten et al., 2016; Rosenrot & Lewis, 2018). These collective reports may help to explain why individuals with lived experience of NSSI experience feelings of shame (e.g., Mahtani et al., 2018; Rosenrot & Lewis, 2018), embarrassment, and invalidation (Mitten et al., 2016). As suggested by others, this may, in turn, thwart help-seeking efforts and reduce hope for recovery (e.g., Long, 2018). Considering the many risks associated with NSSI, this is concerning.

Following the above, the necessity for stigma-reduction initiatives to tackle NSSI stigma is evident. Commensurate with this, there is substantial reason that anti-stigma work in the area of mental illness must involve people with lived experience (e.g., Corrigan & Watson, 2002; Griffiths et al., 2014; Mehta et al., 2015; Thornicroft et al., 2016). Contact-based approaches are not only rated as essential components of anti-stigma efforts (Corrigan et al., 2014) but are also more effective than traditional, educational approaches (e.g., Corrigan et al., 2012; Thornicroft et al., 2016). Given some of the parallels between NSSI and mental illness stigma (Staniland et al., 2021), this is likely true for NSSI as well. Indeed, inclusion of lived experience voices has been highlighted as a priority in the NSSI field given its potential to directly address stigma (Lewis & Hasking, 2019). Interestingly, several innovative, robust, and promising new action-research methods have emerged in recent years that directly involve those with lived experience of mental health difficulties. These approaches have the potential to incorporate people's lived experience, and also impart psychosocial benefits to participants (e.g., greater empowerment) as described below.

## PARTICIPATORY ACTION RESEARCH

Participatory action research directly involves individuals with lived experience as active agents in the research process. Such involvement is related to the growing evidence suggesting that *contact-based sessions* may be especially effective in addressing stigma associated with mental illness (Corrigan & Watson, 2002; Griffiths et al., 2014; Mehta et al., 2015). In each of the participatory action research methods discussed below, people with lived experience deliver in-person presentations to audiences in which they discuss their personal stories, associated challenges, and recovery narratives. In this way, these sessions have potential for a double-benefit: the first-person contact may be especially effective in reducing public stigma, and by default, enacted stigma. At the same time, the meaningful involvement of people with lived experience of NSSI can potentially lessen self-stigma and potentially anticipated stigma. Participatory initiatives, such as those described below have also informed and emphasized the use of visual and digital methods to investigate and reduce stigma (e.g., Buchanan & Murray, 2012; Flanagan et al., 2016; Gubrium & Harper, 2016). Thus, below, we describe the three most common innovative visual and digital research methods that have considerable potential to examine and concurrently tackle NSSI stigma, empower those with lived experience, and cultivate needed social change (e.g., attitudinal, behavioural). These are digital storytelling, photovoice, and participatory video (Gubrium & Harper, 2016).

### Digital Storytelling

Digital storytelling (DS) involves the creation of brief first-person narrated videos, sometimes blended with imagery and music (Ferrari et al., 2015; Gubrium & Harper, 2016; Wexler et al., 2013). The resultant videos tell the story of the narrator's experience and/or focuses on a topic salient to them, for example, recovery from schizophrenia. In this manner, DS draws on the power of storytelling and audio-visual message conveyance (Gubrium & Harper, 2016; Wexler et al., 2013). Central to DS is telling stories that have traditionally gone untold or unheard (Gubrium & Harper, 2016), rendering the method relevant in the context of stigmatized mental health difficulties. Once the final stories have been developed, participants are subsequently involved in sharing the stories with targeted audiences in public screenings. These contact-based interactions work toward fostering a rich understanding of people's lived experience thereby challenging stigma and contributing to positive change. Moreover, the resultant products from DS can also represent a digital proxy for face-to-face contact and, in turn, can be disseminated widely for widespread impact.

For example, in one study researchers used DS to allow Alaskan Native youth to communicate and share reasons for living while inspiring hope in order to safeguard against suicide risk in other youth (i.e., those who viewed the developed videos); moreover, the resultant videos served as reminders for youth of their inner-resources and reasons for living (Wexler et al., 2013). In another investigation, individuals with a recent first episode of psychosis took part in a three-day DS workshop. By sharing their stories through this means, participants reported therapeutic benefits, including reclaiming their voice and connecting with others (Ferrari et al., 2015).

Given the manner by which stigma can impact individuals with lived experience of NSSI, including feelings of shame (e.g., Rosenrot & Lewis, 2018), invalidation (e.g., Mitten et al., 2016), and lower levels of support-seeking and less optimistic views regarding recovery (e.g., Long, 2018), DS may serve as a means

to give voice to people's experiences. In turn, individuals may be able to cultivate needed hope by virtue of identifying their own strengths and hearing those of others. Much like the methods discussed next, sharing these stories with individuals who do not self-injure may also work toward changing others' views for the better.

### **Photovoice**

Photovoice involves stigmatized individuals collaborating to document, share, and represent aspects of their life experience via photography with the goals of education, empowerment, and social action (Cabassa et al., 2013; Flanagan et al., 2016; Gubrium & Harper, 2016; Thomson et al., 2008). Specifically, participants work as a group to develop a montage of photos depicting key features of their experience, which are displayed at events and venues to educate, inform, and catalyze change. From here, the group directly engages with pre-identified audiences to share the resulting photographs and corresponding stories through photo-exhibits. In this way, when the resultant photos are shared with targeted audiences (e.g., healthcare providers, policymakers, families), greater dialogue about the expressed concerns can be facilitated, which has potential to change attitudes, reduce stigma, and contribute to social change (Cabassa et al., 2013; Flanagan et al., 2016; Gubrium & Harper, 2016; Thompson et al., 2008). And, similar to DS, the resulting products from photovoice projects can be shared beyond the initial contact-based sessions to wider audiences (e.g., via online platforms).

For instance, in a US study, researchers used photovoice to illuminate the healthcare and psychosocial experiences of people with severe mental illness to use in the education of healthcare professionals (Thompson et al., 2008). In doing so, participants who felt misunderstood and marginalized were able to communicate their experiences, which was both of value and meaningful to them; moreover, individuals who saw the resultant photos and heard the stories that accompanied them experienced greater empathy and were moved by the experience. In another study, photovoice was used with a sample of individuals with severe mental illness and histories of substance dependence and homelessness. Findings indicated that photovoice offered a powerful vehicle for participants to communicate meaning regarding their recovery experience and may serve as a means to reduce stigma (Cabassa et al., 2013).

Considering past research indicating that health professionals (e.g., Karman et al., 2005; Saunders et al., 2012) as well as other stakeholder groups (e.g., teachers, school staff; Berger et al., 2014; Heath et al., 2011) may hold negative attitudes toward NSSI, photovoice may hold promise to counter these views and cultivate fewer stigmatizing views toward NSSI. As this method has also been shown to impact individuals who otherwise feel marginalized due to stigma (Cabassa et al., 2013), photovoice can be beneficial in addressing multiple types of NSSI stigma in tandem.

### **Participatory Video**

Participatory video (PV) is a well-established research method whereby a group of people with lived experience create educational videos about shared issues and topics affecting them (Buchanan & Murray, 2012; Carmichael et al., 2019; Gubrium & Harper, 2015; Sitter, 2012). Beyond its methodological robustness, PV represents a pragmatic means to provide individuals, who might not otherwise have a platform, an

opportunity to communicate their experiences (Gubrium & Harper, 2016; Sitter, 2012). Indeed, a core aspect of PV (much like DS) is the screening of resultant videos to pre-determined targeted audiences. Specifically, this contact-based component of PV involves introducing the video, discussing and screening the video, and then responding to the audience's questions (e.g., Whitley et al., 2020a, b). Ultimately, this can have the dual effect of addressing negative attitudes and stigma (when presented to targeted audiences) while concurrently empowering those with lived experience. Further, much like both DS and photovoice, the final outputs (i.e., videos) can also be shared by online means (e.g., via YouTube) to maximize their reach and impact.

In one such study, researchers examined the utility of PV as a means to address stigma associated with mental illness (Buchanan & Murray, 2012). Specifically, individuals who previously used mental health services developed a short video to capture difficulties they had in social interaction as well as concerns about the portrayal of mental illness in the media. Findings indicated that taking part in the PV project positively impacted viewers, challenged their misconceptions about mental illness, potentially changed their negative attitudes, and directly benefited participants who developed the videos. In addition to this, evidence from a recent study indicated that videos developed via PV are much more positive and recovery-oriented than network TV clips about mental illness (Carmichael et al., 2019). Accordingly, PV holds potential to educate and inform target audiences (e.g., healthcare providers, other people with lived experience) in future anti-stigma efforts.

Stigma associated with NSSI is multi-faceted (Staniland et al., 2021). As noted above, PV can address stigma among individuals by empowering group participants while simultaneously addressing stigma among video viewers by way of enhancing knowledge and changing attitudes. Thus, in the context of NSSI, PV may serve as a viable means to address multiple types of stigma. Moreover, PV commonly involves presentation of recovery-based narratives (e.g., Buchanan & Murray, 2012; Whitley et al., 2020b) in the context of addressing self and public stigma. Considering such narratives are among those with lived NSSI experience, many wish to share (e.g., Lewis & Seko, 2016; SiOS, 2021) and research indicates people who self-injure may directly benefit from hearing hopeful stories about recovery (e.g., Lewis et al., 2018). PV efforts that centre on NSSI recovery may have particular salience.

### **PRACTICAL AND ETHICAL CONSIDERATIONS**

To date, no studies of which we are aware have applied any of these methods to address NSSI stigma. Accordingly, there may be concern about the use of these approaches in this regard. For instance, some may worry that participant discussions about NSSI (e.g., sharing personal experiences) will evoke distress or even NSSI urges. In these cases, fostering open and ongoing communication about the nature of possible reactions to these conversations would be prudent (Lewis & Hasking, 2019). In concert with this, ensuring that coping and community-based resources for additional support are shared throughout the entire research process is critical (Lewis & Hasking, 2019; Lloyd-Richardson et al., 2015). Research personnel involved in interactions with participants should also be equipped to effectively engage in discussions about NSSI; use of recent guidelines in such contexts are likely to be fruitful (Lewis & Hasking, in press). As the above participatory methods make use of visual content, there may also be some concern that the resulting products (e.g., photo exhibits, videos) will contain upsetting or graphic imagery (e.g., injuries), which have potential to upset individuals with lived NSSI experience (e.g., Baker & Lewis, 2013; Lewis & Seko, 2016). Although

many individuals who have lived experience will be aware of this potential and may naturally avoid such occurrences, having discussions about this early in the research process is advised as it can help circumvent these risks. For further information, we encourage readers to consult recommendations regarding the inclusion of people with lived NSSI experience in research (Lewis & Hasking, 2019) and ethical guidelines for conducting NSSI research (e.g., Lloyd-Richardson et al., 2015).

Beyond NSSI-specific concerns, DS, photovoice, and PV are methods typically conducted in groups with peers who share similar lived experiences. This allows for the organic development of peer support, with participants helping and supporting each other with practical issues (e.g., filming techniques) as well offering emotional support (e.g., comforting someone in distress when recounting an event during a group meeting). This is quite different from many one-time qualitative methods (e.g., interviews). Should there be concerns about the need for additional support when using DS, photovoice, or PV, peer support workers can be integrated into workgroups. Each of these participatory methods also involve developing content that is shared with audiences in contact-based presentation events as well as broader dissemination efforts (e.g., posting online). Because of this, it is incumbent on researchers to ensure that the concept of a digital footprint is fully understood by participants. Use of permission and release forms are thus recommended. In the event participants wish to be part of the project but prefer masking their identities, project coordinators can facilitate this by using voiceovers, pixilated images, silhouettes/shadows, among other strategies. These discussions should also address the possible outcomes of having one's created content viewed by the public (e.g., others' reactions, feelings of embarrassment). For these reasons, a staged and ongoing approach to consent is advised. Doing so ensures informed consent is sought actively and ongoingly throughout the project. By drawing on ethical guidelines when conducting participatory research (University of Sheffield, n.d.), researchers will be better positioned to address these and other concerns.

### CONCLUDING COMMENTS

The aforementioned methods are known for their research potency and seem well-situated to challenge NSSI stigma and its multiple manifestations. As these methods have also been shown to impact recovery and support-seeking, that is, areas noted as highly relevant to individuals with lived NSSI experience (e.g., Lewis & Hasking, 2019; Lewis et al., 2019; Rosenrot & Lewis, 2018), their application to NSSI may have far-reaching effects. Indeed, these are robust action-research methods in their own right, and their resultant grassroots-produced video and digital products can be shared online with substantial reach (Gubrium & Harper, 2015). These methods may therefore carry significant appeal and impact in today's digital age, especially among young people. As this demographic also represents the group reporting the highest rates of NSSI (Swanell et al., 2014), and research points to the salience of online communication among individuals who self-injure (see Lewis & Seko, 2016), the potential suitability of these approaches is notable.

Notwithstanding the above, these approaches remain underutilized in traditional NSSI research. It is our contention that the relative absence of these methodologies from mainstream NSSI research is largely due to lack of awareness of these recently emerging and innovative approaches. Moreover, the centrality of addressing NSSI stigma (Staniland et al., 2021) and involvement of people with lived NSSI experience in research and advocacy efforts has been cited as critical (Lewis & Hasking, 2019). With this in mind, participatory visual, digital methods hold tremendous promise. Given the complex nature of NSSI stigma and

its profound impact, consideration of such methods in the context of NSSI research focused on stigma may not just be germane but also a formidable and necessary mechanism of change.

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