The Ethics and Practice of Digital Storytelling as a Methodology for Community-Based Participatory Research in Public Health

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*University of Massachusetts Amherst*

*Et al.*

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The Ethics and Practice of Digital Storytelling as a Methodology for Community-Based Participatory Research in Public Health

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Louis Graham, MPH, DrPH & Sarah Lowe, MPW
Mary Paterno, CNM, PhD
Alice Fiddian-Green, MPH
Aline Gubrium

An Ethics Framework for Digital Storytelling as a Multi-Purposed Public Health Method
Orientation

Prompts

Script writing

Story circle

Voiceover

Workshop airing

Final edit

Rough edit

Public screening

View Story

Review of Digital Storytelling Methods
A Situated Practice of Ethics: Addressing Challenges

An Ethics Framework for Digital Storytelling as a Multi-Purposed Public Health Method
Ethical Issue 1: Fuzzy Boundaries

• Confusion between where priorities lie (research vs. intervention/practice vs. advocacy) can lead to very different implementation approaches.
Ethical Issue 2: Recruitment and Consent to Participate

• There is a fine balance between protecting individuals who are in the midst of trauma from further harm and patronizing potential participants through exclusion. Those featured in the digital story may be unaware or upset about their inclusion.
Ethical Issue 3: Power of Shaping

• Facilitators may help “shape” the narrative to produce stories that will resonate with audiences, inadvertently imposing their own agendas. Sharing power often means losing control over messaging.
Ethical Issue 4: Representation and Harm

- Digital stories can misrepresent communities and/or reify stereotypes. Exposing illegal or illicit activity might endanger storytellers or subjects.
Ethical Issue 5: Confidentiality

• Stories are sometimes so distinct that it is impossible to guarantee confidentiality. Often participants want to be credited by name for their contributions. The visual and sharable nature of digital stories must also be considered.
Ethical Issue 6: Release of Materials

• Needs to be negotiated on an ongoing basis. Some stories reveal very personal issues that can make participants vulnerable to stigma and discrimination. Storytellers might want to change their stories or to change their minds later on.
Ethical engagement in public health research and practice is an ongoing, iterative, and complex process. Rather than positioning ethics as an introductory component to a project—a one-off occasion of gaining consent—ethics must be understood as a process that involves ongoing dialogue among all stakeholders about how best to design and implement an ethically responsible project” (Gubrium, Hill & Flicker, 2014).

“Mastering this form of respect—proper consent forms, arranging informed consent, filling forms and completing ethics applications—is only the first step. Putting our words into action, this is the real content of respect” (Menzies, 2012).
<table>
<thead>
<tr>
<th>Ethical Practice</th>
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<tbody>
<tr>
<td>Partners need agreement about specific goals, objectives, policies and procedures</td>
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<tr>
<td>Transparency with participants about benefits and risks of participation.</td>
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<tr>
<td>Provide safety and supports.</td>
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<td>Reflexive attention—cultural humility is key.</td>
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<td>Storyteller wellbeing should be at the center of a project.</td>
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<th>Power of Shaping</th>
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<tr>
<td>Personal stories are encouraged: Tension between process and products</td>
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<tr>
<td>“Shaping” of stories to resonate with audiences.</td>
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<td>Shared power = less control over messaging.</td>
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<tr>
<td>Shaping of presentations and materials according to venue (community vs. academic)</td>
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<tr>
<td>Sponsors want to recruit diverse or targeted participants to share their stories.</td>
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<td>Consent to participate is sometimes indirect.</td>
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<tr>
<td>Balance between protecting individuals in trauma and patronizing them through exclusion</td>
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<td>Those featured in story may be unaware or upset.</td>
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<td>Working within CBO constraints for recruitment and participation.</td>
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<td>Paris’s inclusion in the project and her story.</td>
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<td>Ongoing participation of storytellers.</td>
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<td>Nexus of public health intervention/practice, research and advocacy</td>
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<tr>
<td>Confusion between where priorities lie, affects implementation</td>
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<td>Research, training, strategic communications components, multiple partners involved.</td>
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Digital Storytelling for Healing, Transformation, and Justice

Digital Storyteller’s Bill of Rights

The Workshop

- The right to know from the outset why a workshop is being carried out.
- The right to assistant in deciding whether you are ready to produce a digital story.
- The right to understand what is involved in the process of producing a digital story.
- The right to know who might view your finished story, after the digital storytelling workshop.
- The right to decide for yourself whether or not to participate in a workshop.
- The right to ask questions at any stage of the workshop, before, during, or after.
- The right to ask for teaching instructions to be repeated or made clearer.
- The right to skilled emotional support, if your experience of making a story is emotionally challenging.
- The right to tell your story in the way you want, within the limits of the workshop.
- The right to decide whether or not to reveal private or personal information to fellow participants and instructors, at the workshop.
- The right to advice about whether revealing your identity or other personal details about your life, in your story, may place you at risk of harm.
- The right to leave information and/or photographs that identify you or others, out of your final story.
- The right to reject story feedback (about words and images) if it is not useful or offered in a spirit of respect/support.
- The right to decide what language to use in telling/creating your story.
- The right to be respected and supported by capable workshop facilitators.
- The right to a written consent form, if your story will be shared publicly, including a signed copy for your records.
- The right to know what contact and support you can expect after the workshop.

Sharing Your Digital Story After The Workshop

- The right to decide with project partners how your story will be shared after the workshop.
- The right to view and retain a copy of your story before it is shared publicly in any way.
- The right to know who is likely to screen your story and for what purposes.
- The right to know who is likely to watch or read your story and when (e.g. rough timeframe).
- The right to advice about how the process of publically sharing your story may be difficult.
- The right to emotional support if you are present when your story is shown in public.
- The right to demand that no one should be able to sell your story for profit.
- The right to know if any money will be made from your story being shared (e.g. to support not-for-profit human rights work).
- The right to withdraw your consent for the use of your story at any time.
- The right to information about the limits of withdrawing consent for your story to be shared, if it has already been circulated online or on CD, DVD, etc.

An international project of the Center for Digital Storytelling
Jointly developed by Lucy Harding and Amy Hill
www.silencespeaks.org
Ethics Questions

• How Will You Protect and Enhance Storyteller Well-Being?
• How will You Handle Consent Issues?
• How Will You Support Storyteller Benefits / Ownership?
• How Will You Make Sure Your Project is Locally Relevant?
• How Will You Weave Ethics Discussions Throughout Your Work?
• How Will You Ensure Ethical Distribution of Stories?

Applying the Ethics Framework
Stakeholder Engagement and Ethical Planning for Digital Storytelling: The MOCHA Moving Forward Project

Louis F Graham, MPH, DrPH & Sarah E Lowe, MPW
UMass Amherst School of Public Health and Sciences
March 3, 2017

U01MD010618 – NIMHD; Graham and Buchanan (PIs)
Project Overview and Aims

- Using a community-based participatory research approach:
  - Examine the bio-psychosocial determinants of stress among older, African-American men in Springfield, MA.
  - Assess the effectiveness of the MOCHA program to decrease stress among older, African-American men in Springfield;
  - Assess the comparative effectiveness of a narrative-based version of the MOCHA program to decrease stress among OAAM.
Introduction and Background

• Older, AA men experience high levels of stress.
  – Structural inequalities
  – Social networks
  – Gender identity

• Men of Color Health Awareness (MOCHA) Program
  – 12-weeks, 3-days/week (2 gym/workout, 1 discussion-based group meeting)
  – 15-20 men per cohort, ages 35-65
  – Holistic approach to health: physical, mental, social, spiritual (e.g. black masculinities)

• Research Collaboration (2016-2021)
  – UMass-Amherst SPH, Department of Health Promotion and Policy Investigators
  – City of Springfield Department of Health and Human Services (MOCHA Steering Committee)
  – Study Sites: YMCA, UMass-Springfield Center
Why do African-Americans have flattened cortisol profiles, higher levels, and cortisol dysfunction?

• ¾ black adults reported experiencing racially based daily discrimination (e.g., disrespectful treatment, receiving poorer services)

• Higher rates of chronic stress observed in minority populations across all socioeconomic levels.

• Discrimination during adolescence continued to produce dysfunctional cortisol rhythms by age 32 (Northwestern University 20-year study)

• Positive racial identity can help

• Internalized racism intensified stress
Stress and Digital Storytelling

• Why Stress?
  – Identified as community priority
  – Allows for investigation of other community priorities and interests
  – Contributes to poor mental health and chronic disease outcomes
  – Experience, expertise, and interest among researchers

• Why Storytelling?
  – Storytelling akin to historical and daily practices of narrative and cultural production for many AA communities.
  – Nuanced, complex, and contextualized communication
  – Data and intervention
  – Counter-narratives: education and advocacy

• How DST is being used in the project?
  – Led by Gubrium (Co-I), Lowe (GRA), and Scott (MOCHA Outreach and Community-Building Coordinator)
  – 4 digital storytelling workshops of 10 men each (n=40)
  – December-May
Fuzzy Boundaries in the DST Process

• **OUR GOAL:** To gather data on factors related to stress and produce stories that could be used as part of an intervention to decrease stress.

• **OUR PROMISE:** Participants are free to share, discuss, and create the story that they most want to tell, prioritizing their control and autonomy over their stories.

• How do we square these two goals?
Writing Prompts

Write about a moment when…

• You learned what it meant to be a man
• You felt like you had to “man-up” or someone expected you to “be a man”
• A meaningful relationship changed the course of your life
• You should have been stressed but you weren’t
• You felt seen or included, or felt overlooked or invisible
• You kept quiet or you spoke up
• You felt the need to react or not react to an act of everyday racism
• You couldn’t control something or someone, or you felt in control
• You felt proud to be a man, a man of color, or proud to be yourself
Fuzzy Boundaries Around Consent

• DST is both data and intervention.

• Participants are screened for PTSD prior to taking the pre-test or attending the workshop. This is a precaution to protect potential participants from a group-based storytelling process that could trigger previous trauma.

• ETHICAL CONCERN: Denying participants the right to participate in an intervention aimed at reducing stress because their stress levels are too high.
Participant Recruitment
Sample Story
Questions

1. What was it like for you leading or participating in DST workshops?
2. What lessons have you learned from engaging stakeholders in DST projects?
3. What advice regarding ethical considerations do you have for others who will conduct DST as part of their research?
4. When or in what situations have you found ethical issues surrounding DST especially challenging?
5. What drawbacks or cautions do you have about DST?
6. What challenges, barriers, or concerns have you confronted related to stakeholder engagement for DST?
Digital Storytelling as Health Promotion and Data: Ethical considerations from a peer mentor-based project to address perinatal substance use disorder in a rural community

Mary T. Paterno, PhD, CNM
University of Massachusetts Amherst
College of Nursing
Ethical Considerations

- Population
- Setting
- Confidentiality
- Researcher
Thank you!