



## Dispatch

# Co-producing Narratives on Access to Care in Rural Communities: Using Digital Storytelling to Foster Social Inclusion of Young People Experiencing Psychosis

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Arts-based research is a powerful method through which to advance social inclusion and justice (Rice, Chandler, Harrison, Liddiard & Ferrari, 2015) by empowering and engaging vulnerable individuals in dialogue and shared storytelling directed to initiate social change (Boydell, Gladstone, Volpe, Allemang & Stasiulis, 2012). Within the health and more recently, the mental health field, digital story telling (DST) is emerging as an arts-based participatory research method to enhance understanding of “lived experience,” promote social connections and address power imbalances. In this paper, we draw on our study with young people living with psychosis in rural communities to describe how participating in a DST research project can attend to their sense of social inclusion, contributing to their agency and possibly also to a more socially just experience of the world. We highlight the

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potential of DST as an engaging social research process and describe participants' experience of being involved in DST.

### **Early Psychosis and Pathways to Care in Rural Communities**

Comprehensive, accessible and equitable mental health care is the gold standard; however, rural youth experiencing psychosis are often disadvantaged by virtue of their age and geographical context (Starfield, 2002; Minore, Hill, Pugliese & Gauld, 2008). Of particular concern are significant barriers to equitable and appropriate mental health care that young people with psychosis face, including the isolation they experience in their pathway to mental health care, which results both from their illness and the rural environment mediating their isolation and access to care (Boydell et al., 2006). This paper addresses issues of access to mental health care by generating new knowledge about help seeking by young people who have experienced a first episode of psychosis in a rural community.

### **Digital Storytelling**

We used DST, an innovative arts-based research methodology using multimedia consisting of images/segments of video with background music and voice over narrative (Gubrium, 2009), in a workshop-based process whereby participants created their own brief autobiographical videos. DST can be understood as a media form as well as an area of cultural practice, "a dynamic set of relations between textual arrangements and symbolic conventions, technologies for production and conventions for their use; and collaborative social interaction (i.e., the workshops) that takes place in local and specific contexts" (Burgess, 2006, p. 207). A common aim of DST is to highlight the ordinary voice; this form of storytelling is posited as enabling the "ethics of democratic access" (Burgess, 2006, p. 207).

Digital stories are two to five minutes in length, and pair audio recordings with visuals such as photographs, short videos, artwork, etc. (Rice et al., 2015). These stories are created during immersive workshops designed to help participants develop and share their stories with one another through story circles, where they are also encouraged to receive feedback. Talking about their personal stories in this way is integral to the DST process and a key consideration in its transformative potential (Cunsolo Willox, Harper & Edge, 2013). DST productions enable policy-makers to understand the experiences of young people with psychosis in a way that enables them to make more effective policy (DeVecchi, Kenny, Dickson-Swift & Kidd, 2016).

There are commonalities between the DST process and group-based research methods. Both methods are reported to redistribute power

differentials between adult researchers and younger participants, allowing for a level of safety and comfort amongst peers, and they provide a multifaceted description of participant beliefs, perspectives and experiences as they build on interactions with each other over time (Hennessy & Heary, 2005, in Gladstone, 2010, pp. 71-72; Rice et al., 2015).

### **Conceptual Framework**

Participatory inquiry involved young people sharing their experiences of seeking help (Langhout & Thomas, 2010). We were informed by the work of Heron and Reason (1997) who note that knowledge is built on meaningful partnerships between (often vulnerable) individuals and groups, practitioners and academic researchers. Our work builds on repeated calls to engage young people meaningfully in research (see, for example, Mendenhall, Gagner & Hunt, 2015) because they are recognised as socially competent and engaged actors who have much to contribute to the creation and dissemination of new knowledge (Gladstone, Boydell, Seeman & McKeever, 2006; MacDonald et al., 2011). Involving youth in research generates valuable knowledge for individuals and communities and provides opportunities for the empowerment of young research participants, leading to benefits at the micro, meso and macro level (Clarke, 2015; Powers & Tiffany, 2006). Our participatory design was intended to counteract the isolation and marginalization often associated with first episode psychosis, rurality and age.

Our understanding of participation as a theoretical and methodological construct has emerged via a political-cultural agenda that underlines the importance of listening to and celebrating the “voices” and perspectives of those most fundamentally affected by the circumstances in which they are placed (Gardner & Lewis, 1996). We intentionally work from an ontological perspective that claims the social world “does not consist of separate things but of relationships we co-author” (Reason & Bradbury, 2001, p. 10) and which views truth as “not a matter of static fact, but a quality of relationship” (Reason, 1998, p. 165).

### **Methods**

*Participants:* Young people diagnosed with psychosis and affiliated with an early intervention clinic serving a northern, rural region, attended a DST workshop session to produce individual digital stories describing how they manage psychosis in everyday life. Participants worked together over the course of the study, guided by experienced DST facilitators and research team members to clarify study objectives and research questions, produce help-seeking narratives using DST, analyse the digital stories together, and discuss potential audiences for the stories. Following the workshop session, the

completed digital stories were collectively viewed and celebrated by participants. Two weeks later, participants re-convened and participated over three consecutive days in the analysis of the stories through a series of guided analytic group discussions and exercises.

*Setting and Data Collection:* The research took place in a rural community in Northwestern Ontario, with only one early psychosis intervention program for the entire region. The area served approximates the size of France at 406,820 km<sup>2</sup>, or 45% of Ontario's landmass. Project activities were documented using participant observation and informal interviewing, formal group discussions, and detailed observational and reflexive field notes.

## **Results**

Our nine participants ranged in age from 16 to 23 years; five were female and four were male. In this section, we focus on participants' experience of being involved in the participatory DST research project.

### *Reflections on story creation*

Overall, young people found the story creation process both challenging and rewarding. For instance, although creating the story was emotionally difficult and "scary" for participants, they reported feeling better and a sense of relief when it was completed. The most challenging aspect was the time constraints imposed by the script directives that forced them to create "partial stories." Participants found it difficult to make decisions about what part of their story to tell. Luke expressed his desire for a longer script so that he could explain things better and noted that capturing "four years in four minutes" was a challenge. This concern was echoed by Taylor, who spoke about the difficulties associated with deciding what to fit in and what to leave out. Niece wanted to put "way more stuff in there" and Anna felt it hard to choose what her message was about. On the other hand, Michael and Brendan countered that it was not necessary to put everything in the digital story and that it was good that it was short as the powerful effect is lost if too much time is taken.

Young people also highlighted the many rewards they experienced as participants in the research process. They identified the positive impact creating their stories had on them and saw the potential effect it could have on others. Both Anna and Luke described the freedom of being allowed to "open up," a stark contrast to their previous experiences of feeling mistrustful of mental health professionals. Young people appreciated sharing their experiences with others who had similar stories that they could "vent to" and "who won't judge you." Taylor shared that she was now less afraid to open up about mental illness with others and that she would write more songs

about her experiences. Michael supported this with his commentary on the process, “I’m trying to think of the word but it was just like, just like opening up and everything, just made you feel good. I just learned that the videos can have a really big impact.” John agreed with Michael’s statement and added that it was “pretty cool making the story as I got to learn more about myself.”

In addition to being allowed to be expressive in ways they had not previously experienced, young people highlighted how the actual creation of the digital story was an accomplishment. Elyzia stated that creating a video enabled her to put her past behind her. She now felt that she could be productive with her ideas as she learned how to write and tell stories and realized that she is worthy. Feeling better about themselves after creating, showing and talking about their stories in front of a group was significant for participants as exemplified in Taylor’s comment, “It feels good knowing that like even though, like, I went through shit it’s going to help someone else, you know like even though I suffered it will help someone. That feels good.”

## **Conclusion**

Digital stories are a powerful medium for young people experiencing psychosis to tell stories about issues they identify as important. We concur with Consolo Willox, Harper and Edge (2013), who indicate that DST has the potential to become a narrative method that represents a participatory and potentially more democratic form of social research, with an attendant focus on highlighting and sharing individual lived experiences via a multimedia digital format. DST serves as a method for participants to generate something substantial out of their experiences, thus providing a forum for advocacy on issues of concern.

Arts-based participatory research can foster critical awareness and facilitate understanding for those who participate in studies (Conrad, 2006; Kontos & Poland, 2009). Lack of engagement and social isolation are central issues for youth seeking help for a first episode of psychosis. The arts-based methods we used in this study are seldom used in the mental health field and have the potential to counter these experiences by increasing youth involvement in research and by contributing more broadly to the evidence base that influences how they are cared for according to needs they identify as important.

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