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## A pilot study of participatory video in early psychosis: Qualitative findings.

Arlene G MacDougall

Elizabeth Price

Sarah Glen

Joshua C Wiener

*Western University*, [jwiener2@uwo.ca](mailto:jwiener2@uwo.ca)

Sahana Kukan

*See next page for additional authors*

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**Authors**

Arlene G MacDougall, Elizabeth Price, Sarah Glen, Joshua C Wiener, Sahana Kukan, Laura Powe, Richelle Bird, Paul H Lysaker, Kelly K Anderson, and Ross M G Norman

Correspondence: Arlene G. MacDougall, Parkwood Institute, Mental Health Care Building, St. Joseph's Health Care London, London, ON, N6A 4V2 PO BOX 5777, STN B, Canada.  
Tel.: 1-519-646-6100 ext. 47240.  
E-mail: arlene.macdougall@sjhc.london.on.ca

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## A pilot study of participatory video in early psychosis: Qualitative findings

Arlene G. MacDougall,<sup>1,2,3</sup> Elizabeth Price,<sup>3</sup> Sarah Glen,<sup>4</sup> Joshua C. Wiener,<sup>2</sup> Sahana Kukan,<sup>2</sup> Laura Powe,<sup>1</sup> Richelle Bird,<sup>3</sup> Paul H. Lysaker,<sup>5</sup> Kelly K. Anderson,<sup>1,2</sup> Ross M.G. Norman,<sup>1,2,3</sup>

<sup>1</sup>Department of Psychiatry, Schulich School of Medicine and Dentistry, Western University, London, Ontario; <sup>2</sup>Department of Epidemiology and Biostatistics, Schulich School of Medicine and Dentistry, Western University, London, Ontario; <sup>3</sup>Parkwood Institute Research, St. Joseph's Health Care London and Lawson Health Research Institute, London, Ontario; <sup>4</sup>Faculty of Health Sciences, McMaster University, Hamilton, Ontario, Canada; <sup>5</sup>Department of Psychiatry, Indiana University School of Medicine, Indiana University, Indianapolis, Indiana, United States

### ABSTRACT

For people with psychotic disorders, developing a personal narrative about one's experiences with psychosis can help promote recovery. This pilot study examined participants' reactions to and experiences of participatory video as an intervention to help facilitate recovery-oriented narrative development in early psychosis. Outpatients of an early psychosis intervention program were recruited to participate in workshops producing short documentary-style videos of their collective and individual experiences. Six male participants completed the program and took part in a focus group upon completion and in an individual semi-structured interview three months later. Themes were identified from the focus group and interviews and then summarized for descriptive purposes. Prominent themes included impacts of the videos on the participants and perceived impacts on others, fulfillment from sharing experiences and expressing oneself, value of collaboration and cohesion in a group, acquiring interpersonal and technological skills, and recommendations for future implementation. Findings of this study suggest that participatory video is an engaging means of self-definition and self-expression among young people in recovery from early psychosis.

### Introduction

Psychotic disorders are a group of serious mental illnesses that are characterized by clusters of complex symptoms classified as positive (e.g., disorganized speech, erratic behaviour, delusions, hallucinations) or negative (e.g., lack of emotion, motivation, interest).<sup>1</sup> The first episode of psychosis typically occurs in the late teens and early twenties, a crucial period of personal development,<sup>2</sup> which can have a considerable impact on long-term health outcomes.<sup>3,4</sup> Recovery from psychosis is traditionally defined in terms of clinical outcomes, specif-

ically the remission of psychotic symptoms.<sup>5,6</sup> However, more recent conceptualizations of recovery encompass improvements in functional, cognitive, psychosocial, and personal outcomes, as well as the process of achieving these improvements.<sup>5,6</sup>

According to the narrative perspective of psychosis, the early stages of recovery involve developing a coherent understanding of psychotic experiences and integrating them into meaningful personal narratives.<sup>7,8</sup> People with psychotic disorders often have less elaborate and coherent personal narratives than others,<sup>9,10</sup> and thus, they may require active interventions for narrative development that encourage self-reflection, promote self-awareness, improve self-esteem, and challenge self-stigma.<sup>11,12</sup> Research evidence suggests that therapies for psychotic disorders focusing on narrative development can facilitate recovery, including reduced symptoms and improved functioning.<sup>13–17</sup> However, we are not aware of a narrative development therapy designed for young people experiencing early psychosis.

Participatory video is an intervention that has been used to foster identity formation and personal empowerment in a variety of marginalized populations.<sup>18</sup> The intervention is a dynamic process in which a group of participants create short videos about their shared and personal life stories with the guidance of trained facilitators.<sup>19,20</sup> Video is a particularly engaging and accessible tool for young people to develop and perform their personal narrative; through video narrative, people can view themselves as active agents in their reclaimed life stories.<sup>19,21</sup> The exercise of creating videos enables participants to explore and express their unique experiences and perspectives in a safe environment, while viewing the videos can inspire further reflection, awareness, and definition of oneself.<sup>20,21</sup> As such, participants can benefit from both the process and the outcome of participatory video.

Currently, there is limited research evaluating participatory video as an intervention in early psychosis. Prior studies have found that the videos created by participants with serious mental illness were successful in raising awareness of their needs and desires to healthcare workers<sup>22</sup> and in challenging stigma about mental illness among the general public.<sup>23</sup> However, these studies examined participatory video as a knowledge translation tool regarding mental illness rather than as an intervention for the benefit of the participants. In contrast, the purpose of this pilot study was to gain experience with participatory video as a clinical intervention for young people experiencing early psychosis and to describe participants' reactions to and experiences of the participatory video process.

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## Materials and Methods

### Design

This study reports on qualitative data from a mixed methods, pre-post interventional pilot study. A focus

group with all participants was completed two weeks after the intervention, and individual, semi-structured interviews with each participant were completed three months later. Quantitative indices of the acceptability, feasibility, and potential clinical utility of the intervention are reported elsewhere.<sup>24</sup> The study protocol was approved by the Western University Health Sciences Research Ethics Board (ID 106332).

### Setting

The pilot study was conducted at the Prevention and Early Intervention Program for Psychoses (PEPP) in London, Ontario, Canada. PEPP is an outpatient early psychosis intervention clinic located at Victoria Hospital, a public acute care hospital part of London Health Sciences Centre (LHSC). The LHSC hospital network is affiliated with local educational and research institutions and provides care to the City of London and its neighbouring counties. The standard treatment at PEPP involves assertive case management, psychotherapy, and pharmacotherapy, as well as supports for education, employment, and recreation. The care provided at PEPP has been previously described in detail.<sup>25</sup>

### Participants

Participants were eligible for inclusion in the study if they were within their first three years of treatment at PEPP for a diagnosis of psychotic disorder, not exhibiting severe positive symptoms of psychosis (i.e., hallucinations, delusions, bizarre behaviours, formal thought disorders), and not involved in other research projects with active interventions at PEPP. Patients were approached by a research assistant who explained the study in detail and provided an opportunity for questions. Upon successful recruitment, all participants provided written informed consent.

A total of ten participants were initially recruited into the study. Four participants withdrew prior to the end of the study for reasons unrelated to the intervention: i) after two sessions due to starting full-time employment; ii) after two sessions due to resuming full-time post-secondary education; iii) after two sessions due to moving to another city; and iv) after six sessions due to relapse of psychotic symptoms. Baseline clinical and demographic characteristics of the final sample of six male participants are summarized in Table 1.

### Intervention

The novel participatory video intervention consisted of 13 semi-structured, group-based workshops lasting approximately two hours each held every two weeks over the course of six months. The workshops were facilitated by a psychiatrist at PEPP and two media facilitators from ProjectVideo Inc., an organization that works with a team of media professionals across Canada to develop high-quality video for complex stories in a variety of settings.

An overview of the participatory video workshop sessions is outlined in Table 2.

The participatory video process was divided into three stages: pre-production, production, and post-production. Each stage consisted of four workshops, which were followed by a viewing session and celebration. During the workshops, participants worked collaboratively as a production team to create a group video as well as personal videos for each participant. Media facilitators trained par-

ticipants in basic audio-video production using iPad™ tablets and the iMovie™ application which were used to record and edit the videos. Final editing was completed by the media facilitators alongside the participants using the professional video editing application Final Cut Pro™.

## Outputs

For the group video, participants determined by con-

**Table 1. Clinical and demographic characteristics of participants.**

Variable		
Age (years)	Mean (Standard Deviation)	23.1 (2.1)
Gender	Male	6
Primary diagnosis	Schizophrenia	2
	Psychosis not otherwise specified	2
	Schizoaffective disorder	1
	Fetal alcohol spectrum disorder	1
Ethnicity	Caucasian	3
	Hispanic	1
	Aboriginal	1
	Other	1
Living arrangements	Alone	3
	With parents	3
Marital status	Single/Never married	5
	Married/Domestic partnership	1
Education level	Some high school	3
	High school	1
	Some college	1
	College	1

**Table 2. Overview of participatory video workshop sessions.**

### Pre-Production Workshop, Sessions 1-4:

- Group connectedness: Who are we as a group? Why did we come together? How will we work together throughout the project?
- Development of group expectations, norms, and roles.
- Explore the concept for the project, its goals, visual treatment, and sources.
- Develop a storyboard with the participants to map out their plan for videos.
- Organize, manage, and schedule the production shoots.
- Personal/group reflections: What role am I in the group? Why did I choose this role? What do I hope to learn through this experience?

### Production Workshop, Sessions 5-8:

- Group check-in: How are we functioning? What is working? What needs to change?
- Film appropriate secondary footage and conduct interviews (where necessary).
- Record appropriate voiceover narration and music (where necessary).
- Discuss how to share feedback to others.
- Personal/group reflections: What have I learned, am learning, hope to learn? How has my role changed in the group? Am I comfortable with changes in the group and project?

### Post-Production Workshop, Sessions 9 - 12:

- Group check-in: How are we functioning? What is working? What needs to change? Are we where we thought we would be now?
- Develop graphic and music treatment.
- Author master versions of the video for distribution by agreed-upon deadline.
- Plan for how to share the final video with the group and others.
- Personal/group reflections: Where do we go from here? How do want to support each other now that we are ending our time together as a group?

### Final Viewing and Celebration, Session 13:

- Group viewing of the final group video and individual videos.
- Celebrating group and personal accomplishments.
- Certificate of completion and flash drive with personal video for each participant.

sensus that it would be a documentary-style video about psychosis, which they wanted to be “authentic” and ultimately “help people.” The four-minute video opened with a brief segment in which participants listed stigmatizing labels for psychosis and then transitioned to segments about each of the participants. These segments explored participants’ lived experiences of mental illness and what they have taken away from these experiences, along with their unique skills, interests, ambitions. Moreover, participants demonstrated how they are much more than, and are not defined by, their mental illness.

Personal videos varied in length and content, reflecting a personal narrative of their choice. One participant, for example, simply filmed himself describing his past delusional beliefs and hallucinatory experiences. Notably, this participant’s recounting of his psychotic symptoms through this medium was much more extensive and detailed than what he had previously disclosed to his psychiatrist and mental health clinicians at PEPP.

Upon completion of the intervention, all participants consented to sharing the group video with a variety of local audiences including mental healthcare providers, university students and faculty, and family members of other patients at PEPP. Four participants came to at least one of the viewing events to share their personal videos and to engage in discussions with audience members. Two of the participants also joined the research team in presenting the group video and their personal videos, along with preliminary study findings at a large conference on early psychosis intervention within Ontario.

### Assessments

Two weeks after the intervention, all six participants met for a facilitated focus group discussion lasting approximately 70 minutes. The discussion covered their overall reactions to the entire participatory video process (e.g., working together, creating the videos, and viewing the finished videos), positive elements of the process, aspects of the process that could be improved, and suggestions for enhancing the process (see Appendix A for details). Three months after the intervention, each of the six participants was interviewed in person using a semi-structured format averaging about 13 minutes. Participants were asked about their personal experience with the participatory video process and any changes that it may have engendered in their lives (see Appendix B for details).

### Analysis

The focus group and follow-up interviews were audio-recorded and transcribed with all participants’ permission. Separate thematic analyses of the focus group and interview transcripts were performed using NVivo 11 software (QSR International Pty Ltd., 2016). Thematic analysis is an effective and foundational qualitative method to identify, analyze, and report patterns and themes within data.<sup>26</sup>

Transcripts were initially read independently by three research team members who recorded general themes that they judged to be related to the participatory video experience. The research team then worked together and decided on the final themes to be used in coding the transcripts. For each analysis, there was a high degree of similarity in the themes each researcher identified, and thus, consensus was easily achieved.

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## Results

A total of 249 participant responses (110 from the focus group and 139 from the interviews) were coded into 16 themes. For each analysis, a substantial portion of participant responses reflected components of several themes and were coded more than once. The themes identified from the focus group and follow-up interviews were very similar; themes that displayed overlap were combined to reduce redundancy. The final themes reported are comprised of responses from both the focus group and follow-up interviews, unless otherwise specified. Seven themes were identified: i) personal and perceived impacts, ii) mutual creation, iii) sharing stories, iv) learning skills, v) self-expression, vi) group environment, and vii) recommendations and challenges.

### Personal and perceived impacts

The impact of participatory video on participants and its potential impact on others was a notable theme from participant responses.

#### *Personal impacts of creating the videos*

Participants often described undergoing some form of personal change through the intervention. Participant 1, for example, said that he developed better insight into his own experiences; for him, participatory video was “a huge opportunity for self-reflection and learning about yourself, and growth and development.” He further elaborated:

It’s given me an opportunity to look at different ways you can tell a personal story. It also fits into the bigger picture of my journey, how I see the pattern of my personal journey, the path of my life.

Thus, through the process of developing their personal narrative, participants gained perspective on their past experiences and present circumstances within the context of their lives.

Participants also touched upon changes in how they interact with and relate to others. As Participant 3 noted in his follow-up interview, “I definitely deal with people better. My people skills [increased] to an extent.” He also gained confidence in speaking about his personal experiences with psychosis, as he explained, “My confidence in being able to tell my story has changed, be-

cause at the very beginning I was too shy – almost embarrassed – to tell my story. But I’ve definitely come out of the box.” For Participant 4, the participatory video process helped alleviate feelings of isolation: “I understand now I am not alone.”

### *Personal impacts of watching the videos*

In the follow-up interviews, all participants indicated that they had watched the group video and their own personal video at least once since they were completed. An important personal impact of watching the videos was how they elicited reflection on past experiences, whether positive or negative. For instance, Participant 2 said that upon watching his personal video, “I remember all the bad what’s happened in the past.” In contrast, Participant 3’s personal video elicited optimistic thoughts about his main passion: “Mostly about my music... it’s kind of my career.”

Another impact of watching the videos was managing expectations. In his follow-up interview, Participant 3 explained about his personal video: “I started out with a more ambitious project and ran out of time.... I feel I was never going to get it finished if it was as elaborate as I was planning it to be.” He also described reacting to various production aspects of the group video: “The video was not the right length... [the music] had to repeat and it was a weird ending, and there was an awkward silence bit in the middle.”

### *Perceived impact of watching the videos on others*

Five participants indicated they had shared with others observations about the participatory video process, and two of those five also shared their personal videos online. These participants discussed possible benefits of sharing the videos such as increasing awareness and reducing stigma around psychosis. When describing the group video, Participant 6 said, “It would benefit whoever watches it, even in the community... to clear up the stigma and show them that there’s people trying to do the same, to better [themselves] and show guidance to people.” It was also suggested that the videos had potential to increase empathy among healthcare professionals. As Participant 4 expressed: “people watch the video and understand everybody talking about their self and psychosis.... Maybe doctor[s] don’t have what their patients [are] talking [about], and doctor[s] watch this and [think] ‘Oh... Some person like [my patient has] something [that is] similar.’”

Participants suggested that the videos could also have a positive impact on other people with psychotic disorders. By sharing their own experiences of psychosis, participants have the opportunity to show their peers that they are not suffering alone and possibly empower viewers to share their own stories. This sentiment was exemplified by Participant 1:

Everyone has a story and everyone can tell that story.... I would really like for people to feel that

it’s completely within their power to do something to magnify their own voice, which is what I think part of what we did here.

However, Participant 5 did not share his involvement in the project with others due to persistent feelings of stigma toward mental illness: “I wanted [the video] to be private because anything you do is connected to that ‘mental illness’.... It could ruin a reputation.”

### **Mutual creation**

Participants appreciated the overall communal and collaborative nature of the participatory video process. Their responses highlighted the experience of being part of a collective enterprise that was larger than themselves. During the focus group, Participant 1 explained:

I believe what drove the group to stay together was the common purpose that we all shared. You could see it reflected in our hearts. It’s larger than anyone of us individually, and even as a collective, it’s larger than us. It’s the idea that we had something to take care of and to see to the end. It was our responsibility, but also our complete joy and satisfaction to see accomplished what we initially set out to do.

For all participants, the group aspect of participatory video was a driving force for them to commit to and ultimately complete the project.

Participants reported improvements in their ability to work effectively with others and as part of a group. According to Participant 3, “There was an amount of trying to learn how other people’s ideas would work. Towards the end, I was like, ‘You know what? Let’s just get it all in there – it’s everybody’s project.’” He also recalled a moment of clarity about collaboration during the project: “‘That’s going to look great in the final shot’.... I remember thinking, ‘Yeah, this is what makes it good to work in a group with each other.’” Moreover, participants recognized the strength derived from the diversity of the group members. This notion was described by Participant 6 who said, “It’s awesome because we all have different backgrounds, we all come from different stuff, and we all come here for this certain – what’s the word – commonality?”

### **Sharing stories**

Participants’ desire to share their stories with a wider audience, and with each other, motivated them to complete the project. All participants articulated how they hoped to be seen by the public as more than their illness, as explained by Participant 4: “We had our experiences but we’re still just people, and we’ve got ideas and things to offer the world, and it’s good to acknowledge that once in a while.” The practice of sharing stories also helped participants de-

velop a deeper understanding of each other. Participant 3, for example, articulated that “Learning not necessarily [about] their abilities, but their personal lives and their experiences from their own stories that they told” was an important part of the participatory video process.

The importance of sharing the videos was reflected in participants’ pride for the group and for themselves, along with their satisfaction from meeting objectives and completing the videos. For example, Participant 4 described working on his personal video outside of the group:

I was working on [the video] at home and was really interested to bring back what I [d] done and add to it .... Then I would go to the group... talk about some of the ideas I’d have... and they were all excited to see the progress, so it was good on a personal level to be able to share .... That’s what kept me coming back.

For this participant, the opportunity to share his story with the rest of the group was yet another motivator for him to complete his video.

These feelings of accomplishment were still apparent among participants during the follow-up interviews such as when Participant 2 remarked that, “I’m proud of my involvement in the videos, and I’m proud of everyone else who helped make them.” Similarly, Participant 1 said that, “Having something to focus on for extended periods of time... helped me prepare for the direction I started going in. It helped me get into the practice of doing something and trying to finish something on time.” These sentiments were echoed by Participant 3, who also explained that the temporal demands of group work enhanced his sense of accomplishment: “There were many times that I was worried that... we wouldn’t have finished the group video. But we did finish it, and I was happy about that.”

### Learning Skills

Participants discussed learning technical, creative, and organizational skills throughout the participatory video process. Their responses highlighted the ease with which they acquired skills – and even developed a sense of mastery – in audio-visual production, including storyboarding, directing, recording, and editing. As Participant 3 described, “I learned setting up a camera shot and setting up the frame,” while Participant 1 shared, “The video editing software. That was a very fresh experience.” Participants reported learning specific skills not only from media facilitators, but by watching other participants in action. During his follow-up interview, Participant 3 remembered: “Two of the group members... were trying to set up a single shot.... [It] wasn’t some special effects, high production thing.... It’s not as difficult as it necessarily seems – that was something I specifically learned from other group members.” Moreover, participants noted how their ability to participate in and contribute to the project

was not contingent upon their prior experience with audio-visual production. From the perspective of Participant 3, “A lot of valuable skills can be learned from this group.... It doesn’t require any background knowledge on how to make a video.”

### Self-expression

During the focus group, participants expressed how participatory video gave them a platform from which to express themselves while also learning new ways to do so. As Participant 2 described: “it gave me a chance to not only express myself, but show people my music side of things, so that was cool.” The experience of self-expression was also noted as being cathartic, as explained by Participant 6: “It’s a good outlet if you hold onto your emotions and bottle them up. You can express yourself that way and it could lead you onto a better pathway.”

### Group environment

The overall tone and atmosphere of the group contributed to participants’ satisfaction with the participatory video workshops. Positive relationships between participants and facilitators appeared to create a group environment where participants felt supported and engaged. From Participant 1’s perspective, “the facilitators were super friendly, super encouraging. My co-participants were awesome too. It made the whole process more enjoyable.” Participants also conveyed that they genuinely looked forward to attending the workshops, as noted by Participant 2: “everybody was happy to be there, and I think that’s what made me happy to be there.” Accordingly, all participants expressed that they enjoyed participating in the project, which Participant 3 summed up as being “a good experience.”

Participants expressed willingness to join a similar participatory video project in the future. They cited their desire to make more videos and the positive feelings of finishing a project as their primary motivators for returning. For two participants, however, their involvement would depend on certain factors such as the project’s topic and the group members’ skills. As Participant 3 explained, “It would depend on the group. If it was a different group of more people with different ability of using the technology, like a ‘Round Two’ type group of people who have learned from ‘Round One.’” For Participant 6, his involvement would depend on his interest and motivation upon reflection: “I’ll think about it. If I feel up to it, I might.”

### Recommendations and challenges

Several recommendations for future participatory video groups were made during the focus group and interviews. Participants recommended that the participatory video project be expanded, including developing a larger network of participants and organizations. As summarized



by Participant 5, “I think it’s a good start. They should do this a lot more often with other people.” Participants also suggested that facilitators develop more structured goals during workshops and allow communication among group members between workshops. According to Participant 5, “we didn’t communicate as good as I think we should have. If we had a forum where we could have kept talking.... There was two weeks between the actual classes...[and] it made me less productive.”

For future participatory video group members, participants emphasized the importance of fully committing to the group and finishing the project. This point was noted by Participant 1 who stated, “Once you start, do your best to stick it out, go to the very end. Just showing up goes a long way.” Participants also stressed the value of keeping the entire process flexible, as explained by Participant 3: “It might turn [out] differently than you would expect. There will be last minute juggling to get everything together. But if you have the motivation and you put in the effort, you’re going to get some good results.”

Challenges experienced by participants included differing levels of skill, experience, and involvement among group members. These issues were summarized by Participant 3, who said in his follow-up interview, “in the sense of being there to support the rest of the group, not everyone was there. Some people were there every week and they did contribute valuable ideas, and other people showed up right at the end.” From his perspective, these differences in contribution and commitment were not properly reflected when assigning credit for the group video: “[The credits were] an alphabetical list. [The] name [that] was alphabetically first on the list literally did the least amount of work.”

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## Discussion

People with psychotic disorders often experience poor insight into the symptoms and consequences of their illness which can be a considerable barrier to their recovery.<sup>27</sup> Research suggests that developing a personal narrative concerning the meanings of one’s experiences with psychosis can enhance self-understanding, thereby facilitating improvements in symptoms, functioning, quality of life, and other long-term outcomes.<sup>28–30</sup> However, people with psychotic disorders may lack effective means of personally processing and expressing their difficult and isolating experiences as well as sharing them with family, friends, mental health care providers, and the wider community.<sup>27</sup> Participatory video can help fill this gap by providing a means through which participants can express themselves, validate their personal realities, and communicate their life stories, while having control over the process and outcome.<sup>19–21</sup>

Participants described several elements that contributed to their continued engagement in the project, many of which are characteristic of the participatory video

process.<sup>18</sup> The group environment made participants eager to engage in the workshops, and being part of a collective with a common purpose motivated them to collaborate throughout the project. Participants noted that the involvement of media facilitators enabled an effective and efficient process, while the use of iPad™ tablets allowed them to complete the project without having prior experience in audio-video production. The opportunity to share experiences, challenge stigma, and reach the broader community was relevant and important to participants, contributing to the perceived worth of the project.

People who construct fuller personal narratives tend to experience higher levels of mental wellbeing.<sup>31</sup> As such, several personal benefits of the intervention were cited by participants, including increased self-esteem and self-confidence, sense of pride and accomplishment, improving interpersonal skills, and learning new technical skills. These benefits are consistent with those reported in prior studies of therapies for narrative development, such as narrative enhancement and cognitive therapy,<sup>13–17</sup> as well as with the quantitative findings of this pilot study.<sup>24</sup> Beyond any direct benefits to participants, participants’ videos have the potential to enhance clinicians’ awareness regarding the nuances of patients’ recovery processes and to increase their compassion in supporting such processes.<sup>32</sup> In this respect, the narrative material generated through participatory video could have a unique knowledge translation impact compared to more traditional presentations of information.<sup>32</sup>

The goals of this pilot study were to gain experience with participatory video as a clinical intervention for early psychosis and to gauge participants’ reactions to and experiences with the participatory video process. Responses from the focus group and follow-up interviews suggested that participants found participatory video to be a particularly engaging modality for self-expression. All participants found the project enjoyable, and, if given the opportunity, most were willing to participate in the future. Furthermore, participants who withdrew from the study did so for reasons unrelated to the experience of the intervention.

Despite the strengths of this pilot study, it had some notable limitations. First, a standardized participatory video curriculum was not fully developed prior to implementation. Each workshop was planned by the media facilitators, but participants noted that using more structured workshop goals and providing means of communicating between workshops would have improved the project. Second, the final study sample was small and comprised of only male participants. While the focus group discussion and follow-up interviews were productive, contributions from participants of different backgrounds would have provided additional perspectives.<sup>33</sup> Third, people who have experienced psychosis were not directly involved in either designing the intervention or conducting the study. Although the participatory video process was largely driven by the participants, it would have been particularly valuable to

have involved people with lived experience of psychosis throughout the entire research process.<sup>34</sup>

This pilot study demonstrated the potential value of participatory video in promoting narrative development in young people with psychotic disorders, which can help facilitate the recovery process. These findings justify future research on a larger scale to determine the full clinical utility of participatory video as a recovery-oriented intervention for early psychosis.

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