World ▮ Cultural ▮ Psychiatry ▮ Research ▮ Review
OFFICIAL JOURNAL OF
WORLD ASSOCIATION OF CULTURAL PSYCHIATRY

Research report

Just say know: Engaging young people to explore the link between cannabis and psychosis using creative methods

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Abstract. *We know substance use in adolescents experiencing psychosis increases negative outcomes, but we need youth-friendly ways to explore and share this knowledge. The purpose of this study was to understand young peoples' experiences with cannabis while living with psychosis. A participatory approach was adopted and young people living with psychosis from early psychosis intervention clinics across Canada were trained in qualitative research methodology. These peer research assistants recruited 50 of their peers and conducted interviews and focus groups that explored the link between cannabis and psychosis. Interviews were transcribed verbatim and analyzed using thematic analysis. The lived experiences of participants' cannabis use were characterized by their fluidity and continuum-like nature. Participants talked about their use as mercurial and context-dependent. Individual experiences with cannabis ranged from relaxing to stimulating, exciting to fear inducing, a social experience to an isolating experience, from creative and free thoughts to bizarre and disturbing paranoia. Participants discussed the role that cannabis may have played in their illness. Sharing results of this research in non-traditional ways including on social media platforms, via documentary film and with animation were identified as key to connecting with their peers. As part of a knowledge translation strategy, youth-led messages and products were generated from the findings and shared with relevant stakeholders. Using creative and participatory approaches provided insight into the experiences and perspectives of young people living with psychosis in a way that traditional research may not, especially with a sensitive topic like drug use. We suggest that there could be a more pronounced gap between the perceived range of "highs" and "lows" of their experiences versus in those in other young people. This could explain why they start and keep using, but why they often reflect that using is ultimately not helpful in their recovery process. Sharing these findings and evaluating the impact of these kinds of initiatives may help young people differentiate between symptoms of psychosis and cannabis use, and support early intervention in ways that are relatable and creative, rather than threatening or judgmental.*

Keywords: Youth engagement, psychosis, substance use, health promotion, participatory, creative arts, digital media.

WCPRR September/December 2015: 201-220. **© 2015 WACP**
ISSN: 1932-6270

INTRODUCTION Cannabis is the most commonly used substance among young people with first episode psychosis, with prevalence estimates of up to 80% (Hall & Degenhardt, 2000). This is troubling because substance use during psychosis increases negative outcomes including treatment non-adherence, relapse, hospitalization, poor social functioning and increased treatment costs (Marshall *et al*, 2005). Clear messaging about this issue can be particularly tricky in a Canadian context as smoking cannabis is not unusual among the general population, including young people. In 2007 the United Nations reported Canada as the No 1 country regarding cannabis use (17% vs. 3.4% world use) and more recently, a UNICEF survey found more Canadian young people, approximately 30%, reported smoking cannabis than elsewhere in the Western world. Some existing

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Received March 15, 2014. Accepted March 6, 2015

social and cultural norms and representations downplay the risks of smoking cannabis; however, for young people with psychosis or for those who may be genetically vulnerable to develop psychosis, research shows that the same understandings about the relatively benign nature of cannabis use are not valid.

Although direct causality is debated, growing evidence shows that cannabis, combined with genetic and other environmental factors, exerts a mediated causal influence for the onset of psychosis on individuals genetically vulnerable to develop serious mental illness (Caspi *et al*, 2005). Cannabis use, in particular, heavy use in early adolescence, can increase psychosis risk by up to 40% (van Os *et al*, 2002). Qualitative work suggests that prevalence is heightened among this population because cannabis may temporarily relieve some negative symptoms of psychosis (Lobbana *et al*, 2010). These negative symptoms may include social withdrawal and lack of affect and are usually persistent for individuals living with psychosis. Positive symptoms are often present only at the active or acute phases of the illness and can include hallucinations, delusions and other disturbed thinking and behaviour. Other literature demonstrates that heavy use ultimately exacerbates both kinds of symptoms and delays recovery (Zammit & Lewis, 2004). It can be difficult for young people with psychosis using cannabis to differentiate between illness symptoms and effects of using cannabis.

Given these risks, education in the early psychosis intervention context (including youth already in treatment at early intervention clinics, as well as youth at earlier stages who may be at risk for developing full-blown psychosis) is critically important (Edwards *et al*, 2005), however communicating and engaging young people to bridge the gap between knowledge and action can be challenging. Importantly little is known about cannabis use from the perspective of young people with psychosis and there is a lack of "youth-friendly" information available. Youth engagement, defined here as meaningful participation and sustained involvement of a young person in an activity with a focus outside of him/herself, is important in order for young people to take control over their own health (Viner & Barker, 2005). A traditional "Just Say No" approach to drug education is typically prescriptive and fails to position young people to learn from both scientific and experiential knowledge in order to contribute to informed decision-making in relation to their experience and illness. Social isolation can also be a barrier in help-seeking behavior for young people with severe mental health difficulties (Boydell *et al*, 2006; Stephen-Reicher *et al*, 2010), and young people may hide or deny their symptoms.

This study took a youth-friendly approach to mental health and substance use research, combining participatory qualitative research methods and arts/media-based techniques, which we have named the "Just Say Know" approach. The overall purpose of this study was to engage young people in exploring the link between cannabis use and psychosis as there is a need for this youth-friendly and experiential information in the early intervention clinic context and beyond. This process involved training young people across the country in qualitative methodology in order to explore this topic area with their peers and also to develop creative ways to share this information with other young people at risk. Based on findings detailed in this paper, a youth-driven and youth-generated content was produced to promote and spread knowledge in ways that would best reach this population. The following sections specifically focus on the findings generated using participatory methods, although the other components of the project (e.g. the knowledge translation process and products) will be briefly reviewed to contextualize the project and foreshadow future directions to explore the impact of the "Just Say Know" approach. In this paper, we argue that this innovative peer-based approach combining a participatory approach and arts/media-based mediums allowed us to elicit honest and useful data about cannabis use from the perspective of young people living with a serious mental illness.

METHODS

Participatory approach

This study was funded by Health Canada and led by the Schizophrenia Society of Canada, under the guidance of expert researchers and youth ambassadors and partnering with early intervention clinics in Vancouver, London and Halifax. A participatory inquiry approach was used, with youth

involved in the process throughout. Research has shown that participatory action research has particular resonance and relevance in the content of mental health and addiction. The aims of our participatory action research strategy were two-fold, both process and product oriented (Ochocka *et al*, 2002; Nelson, *et al*, 1998). Through the process of being trained for and conducting study activities, the goal was to increase the capacity of participating youth and more firmly establish their recovery pathway. An advisory committee comprising youth, family members, service providers and researchers from across Canada met to discuss the proposal and explore best ways to implement the study; they identified engagement strategies and important questions to ask young people regarding their experiences.

Peer research assistants

In addition to contributing to study design and aims, young people were also trained as research assistants in order to play a key role in data collection. The idea was to engage their peers in an unintimidating and engaging manner, because of the sensitive topic of the research. An experienced qualitative research scientist (KMB) and research assistant (NB) trained 28 young people across three Canadian sites in qualitative research methods.

Inclusion criteria for research assistants included youth (defined by our team as up to 30 years), currently living with treated psychosis (vs. acute psychosis), actively engaged with one of the clinic study sites and with wide experiences with cannabis, from heavy use to no use at all. It was important to our advisory group to have a wide range of experiences on our research assistant team so that all perspectives were considered in drafting the interview and focus group protocol.

The 28 young people participated in an ongoing process of consent that gave their permission to reveal their identities in this public research project. This was an important element of the peer research process, as identified by this population, as this group was in a more advanced/mature stage of their illness trajectory and wanted to be identified as advocates or a "public face" for their peers struggling with the stigma attached to severe mental illness like schizophrenia and bipolar disorder.

Figure 1 Peer Research Assistants
Young people were involved in every step of the research process as Peer Research Assistants, from study conception to the dissemination of findings.

They chose to reveal and share their identities/biographies, stories, and photographs and other personal information for the project. We obtained written consent for their online and media presence (e.g. website, YouTube) though most of the links are unlisted, i.e. you would have to be referred a YouTube link or access a video via the website in order to view it. The rationale behind this procedure is that although these young people consented, they were still relatively young and we did not know how they would feel about being affiliated with this project indefinitely. As of now, they are happy to be involved and continue to be part of the project via conference presentations and other knowledge translation activities.

Photographs were used to capture three knowledge translation workshops held throughout the project and included peer research assistants, researchers and artists. All groups provided their

consent to be involved in this process. No photographs or videos were taken during the actual research process, that is, the interview and focus group component led by the peer-research assistants. Research participants remained anonymous.

Participants and setting

The study sites were three early psychosis intervention clinics in Halifax, London, and Vancouver. Peer research assistants were supervised by their clinic workers or coordinator. Research Ethics Board approval was obtained in each study setting. Participants were recruited from study clinics using a purposive sampling technique and were offered participation in either an individual interview or focus group. The Advisory Group made the decision to protect the identity of participants and therefore detailed demographic information was not obtained from interviewees. It is known however that participants were both male and female, ranged from regular cannabis users to non-users and had an age range from 16-30 years. A total of 36 in-depth qualitative interviews and five focus group discussions were held. A total of 50 young people across the country participated. Gender neutral pseudonyms will be used throughout the research findings to protect the identities of our research participants.

Data collection

In-depth interviewing, using the long interview method described by Charmaz (1991) was used. Focus groups were also conducted to provide youth the opportunity to engage in a dialogue about cannabis use and psychosis among their peers. Interview and focus group protocols included questions about use, including factors influencing decisions to use or not, whether they perceived that marijuana played a role in their first episode of psychosis, whether they had strategies that helped them control paranoia and how to share information on this topic with other young people. The interview guide was drafted by members of the advisory group with contributions from peer research assistants. Data was digitally recorded and transcribed verbatim by an experienced transcriptionist. Interviews ranged from 20 minutes to 1 hour in length.

Data analysis

A thematic analysis was conducted as it offers an accessible and theoretically driven approach to analyzing qualitative data (Braun & Clarke, 2006). We followed the six phases of analysis outlined by Braun and Clarke. Themes or patterns emerged from the data (inductive) as well as from the original research aims and guided by the interview questions (deductive). A portion of the text from individual interviews and focus groups was double-coded to ensure research rigor. The analytic team, consisting of youth from the advisory board and experienced qualitative researchers, discussed their coding and interpretation of transcripts in detail in order to refine codes and identify key themes. Original transcripts were then re-read, coded and indexed. The team approach to analysis allowed inconsistencies between data and themes to be debated, refined, and reflected in the final presentation of the main themes.

Figure 2 Input of Young People
Peer research assistants helped refine the interview guides, guide analysis and prioritization of findings.

Knowledge translation process

Our study took an integrated approach to knowledge translation, viewing it as a two-way exchange throughout the entire research process from inception to dissemination.

Workshops using arts and media

An important aspect of this information exchange throughout the study trajectory was the youth-driven workshops. Since this study was national in scope, we wanted to bring the team together at various points in the study, in addition to our regular advisory board meetings. We held three multi-day workshops spread over the study period. The purpose of the first three-day workshop, held in Toronto, was to work with peer research assistants to tell their stories via digital media. We used a technique called "digital storytelling", which involved intensive "circle workshopping" with experts in storytelling and media techniques (Burgess, 2006; McWilliam, 2009). Young people were given the skills to first find their own story via principles of personal narratives and storytelling and then the skills to produce this story using Adobe premiere software. Although the Centre facilitated narrative creation for Digital Storytelling, the "plot" or topic area, script, music, and essentially the digital shorts in their entirety were products of the young people themselves. The short videos tell the stories of peer research assistants, their illness and the role that substance use and/or other environmental triggers may have played in their psychosis.

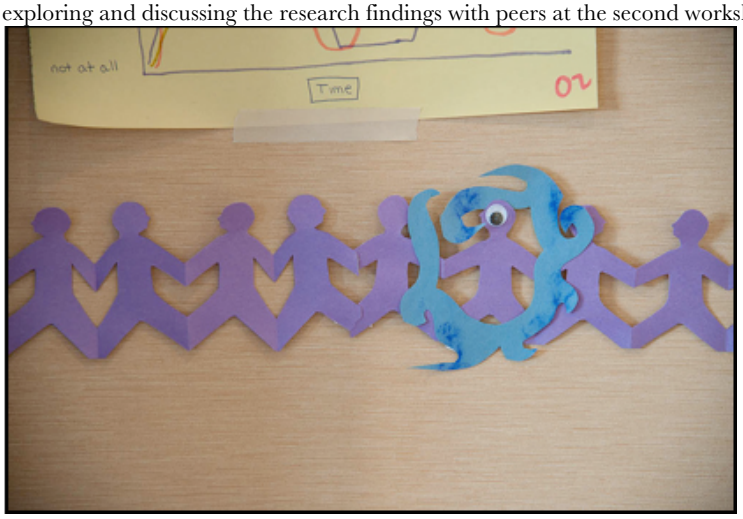
The second workshop was a two-day event also held in Toronto, aimed to bring peer research assistants together to work with findings of interviews and focus groups that they conducted over the previous year. At this time core team researchers drafted a formal report, but we felt it was most important to share results with youth research assistants to promote messages that came from their peers. Researchers, peer research assistants, communication specialists and artists explored findings together and used the workshop time to co-create arts and media-based products in order to more creatively translate and disseminate study findings. These products, along with digital stories and other information explored and created during the study, were showcased on a study website (cannabisandpsychosis.ca) and also shared via study team networks, including early intervention clinics and mental health centres, as well as with groups of clinicians and researchers at national and international conferences.

Figure 3 Brainstorming workshop
Workshops gave peer research assistants a chance to brainstorm ideas, work with study findings and share and collaborate with their peers, as well as researchers, and artists.

Figure 4 Spoken Word
A spoken word artist with lived experience worked with peer research assistants to create a poem based on youth perspectives from interviews and focus groups.

Figure 5 YouTube Poem
This poem was based on the findings from interviews and focus groups and created by youth research assistants in collaboration with a spoken work artist who has also experienced psychosis. View it on YouTube at: http://www.youtube.com/watch?v=eiCi2ZgtMLo#t=39

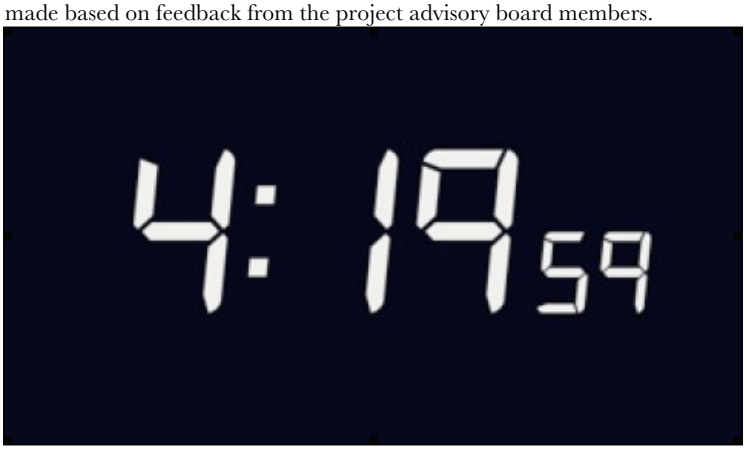
Figure 6 Artistic Products
Various artistic depictions and products were created by peer research assistants after exploring and discussing the research findings with peers at the second workshop.



The final workshop of the study was held in Ottawa. This two-day workshop brought together a range of stakeholders including young people from the general population, their families and staff affiliated with early intervention clinics across the country, youth engagement organizations, researchers, substance use organizations, policy makers, children's mental health agencies and educators. We shared study findings and key messages about the importance of finding alternative ways of engaging youth about this issue (and other related mental health and substance use problems) by using participatory research and arts and media-based approaches of creating and sharing knowledge within and beyond the study team. This workshop coincided with the Fifth Anniversary Awards ceremony of the Mental Health Commission of Canada. Our team received the Research Award during the ceremony, in recognition of our innovative approach to research and youth engagement.

Sharing the findings with others

Figure 7 YouTube
This explanatory video can be viewed at:
http://www.youtube.com/watch?v=n5y7n988r1Q
All of the images and words used in this video were based on findings from interviews and focus groups and professional animators created the final product. Multiple revisions were made based on feedback from the project advisory board members.



Peer research assistants and research participants identified online sources, such as a website, Tumblr and YouTube as the best methods to potentially disseminate results. Other young people experiencing mental health issues were reported to be important messengers of the results: sharing their experiences could help others and engage youth. Many participants stated that it would be a positive move to have role models (youth speakers) in schools, so that other young people could relate better, and have peers that think they "get me" and maybe for some "understand that they aren't the only ones having these kinds of thoughts".

> *I think it's a good thing to tell you the truth…more information about things. I guess psychosis is like, a lot of things to be learned and if it coincides with marijuana it should be found out.* (Jamie)
>
> *I think through music or through poetry and visiting high schools and telling them what the risks are. Having students talk about it not adults. Telling about their own experience.* (Rory)

In addition, creative methods such as visual strategies to share messages, as well as an interactive blog where people can write messages, were additional suggestions to further engage youth.

> *It's really fascinating, helpful and educative to bring people together who actually have this problem with psychosis from taking marijuana and sharing this with the youth I think that would help them to realize that drugs are not really good…they really need to say it can also happen to you.* (Harley)
>
> *Instead of just saying drugs are bad just say, "You know what? This is potentially what could happen. This is what specifically could happen to you, not just well, he started doing crack and now he doesn't have a house".* (Quinn)

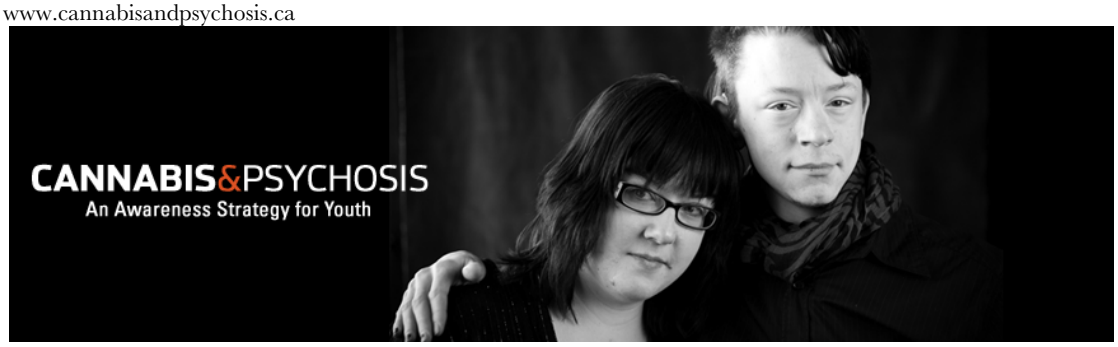
Based on these perspectives products were created based on study findings and shared with different audiences. Many products were based on recommendations that study findings should be communicated through media and the arts.

Figure 8 Art Project Collaboration
An artist and peer research assistants collaborate on a project.

Products were developed through youth-led process; often entirely youth-created and frequently involving collaboration between youth research assistants, participants, professional artists and media specialists. Products can be viewed on the study website (cannabisandpsychosis.ca) and were also shared with early intervention in psychosis and youth-oriented addiction facilities across the country, at various conferences and at workshops in Toronto and Ottawa (March 2010, March 2011 and October 2012 respectively) for young people and their families. Young people were given the opportunity to speak at conferences and were co-facilitators and participants at workshops. Products and findings were also shared on social media platforms.

Products include the website (cannabisandpsychosis.ca), interactive e-learning modules for young people, educators and parents (**Note 1**), a professionally produced explanatory video based on study findings and guided by the advisory team (**Note 2**), a youth-produced stop-motion video and illustrations (**Note 3**), a rap video (**Note 4**), a spoken word poem and video (**Note 5**), a co-created poem (see above **Figure 14**), youth research biographies (**Note 6**) and 23 youth-produced digital story videos (**Note 7**). A traditional report was also drafted by study team members, as well as a literature and resource scan, in order to have different types of information available.

Figure 9: Website
Information about the project, other resources, pertinent literature and all of the products can be found on www.cannabisandpsychosis.ca



Evaluation

The current initiative had certain elements of evaluation and feedback though there was not a formalized integrative evaluation strategy whereby participants were surveyed or interviewed at the start of the project on a variety of dimensions and then followed up on throughout the project at different checkpoints. This was not the focus of the current project. Instead, at each workshop there were open-ended "graffiti walls" where participants could share their thoughts about the workshop, the project or anything else they felt like sharing. There were also opportunities for participants to privately reflect on their experience in a qualitative manner (e.g. writing on a postcard and putting it into a sealed comment box).

> *The workshop was an amazing experience for me. For the first time in my life I felt as if I was heard. I could help other people, which I wasn't hiding from my life anymore… first time I was given the opportunity to make my story alive. Alive in the sense that other people could sense what I have gone through. In no way shape or form for just what I have been through but the seriousness of what so many people are going through in silence every day. Shining a light on the dark spots of life, spots that people don't understand nor in some cases try to.* (Tristan)

We received feedback that echoed the sentiment expressed above, transcribed from an interactive feedback mural where attendees could contribute their thoughts and feelings regarding the workshop and overall study approach. Many participants discussed the arts as a useful and engaging method of knowledge transfer, particularly regarding complex material that deal with emotion and interpersonal relationships. Participants also identified the arts' potential to educate and sensitize individuals about psychosis.

FINDINGS The lived experiences of participants' cannabis use were characterized by their fluidity and continuum or spectrum-like nature. Participants talked about their experiences using cannabis while living with psychosis as unpredictable and context-dependent, with the ability to vacillate between a more positively perceived end of the experience continuum to a more negatively perceived charged end. Their experiences also covered other points in between these two extremes and did not always move in a linear direction; rather they had, at times, an erratic back-and-forth manner.

Experiences can be conceptualized as affective states that ranged all the way, from relaxing to a catatonic state, from exciting to scary, from social to isolating, from use to abuse, from creative to bizarre thinking and from alleviating to exacerbating psychotic symptoms. Again, it is important to note that these findings should not be thought of as strict binaries or extremes, but instead as a range of experiences on a continuum.

Participants also discussed their attempts to manage these affective states and the role that their drug use may have played in their illness trajectory.

"The most insane rollercoaster": Unpredictable affective states

Figure 10 Cannabis as pleasant experience
This comic was co-created by peer research assistants and a communications specialist artist during the second workshop. It depicts some of these positive and relaxing perspectives with using cannabis.

Cannabis use often began as a pleasant experience for most participants. Words frequently used to describe feelings while smoking included "happy", "fun", "carefree" and "enjoyable". Different experiences were described, such that it resulted in laughter, provided energy, allowed focus (on one thing), spurred creativity or resulted in feeling more "in-tune" with the world. It also made some feel light-headed, or more talkative. Many participants described it as a way to relax and to "put their mind at ease"; while others said it expanded their mind. Participants also noted that it functioned to reduce stress and feelings of anxiety.

> *It's fun and disorienting like the most insane rollercoaster I've ever been on.* (Camryn)
>
> *It helps me relax a lot - it makes me carefree - like nothing matters except for the moment…I'm not used to living like that so it puts me in that state.* (Avery)
>
> *I think if I smoke marijuana it might help me relax but ultimately doing it would make me so nervous, that I wouldn't see a difference. I never felt a need to experience it.* (Sawyer)

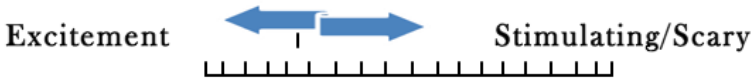


Figure 11 Cannabis as scary
Many participants' recounted stories of their substance use being new, different and intriguing at first but then becoming fear inducing as their psychosis became more entangled with their experiences**.**

Cannabis was considered by some participants to be a stimulant, enhancing mood or current state of mind. Reactions to the drug were dependent on the kind of day one was having, or the activities engaged in while smoking. As one focus group participant commented, "it changes…probably has to

do with how I felt before I did it", while another said, "depends what you're reading or see on T.V." Many mentioned feeling lazy, tired or sleepy after smoking marijuana; which can be considered as either positive or negative, depending on the person, situation or time of use.

> *At the same time I don't like how it makes me feel afterwards even if it cheers me up. I lose my motivation for the day, kinda similar to a hangover…I go through ups and downs, I feel pretty good, laughing, having a good time…then I start worrying about things and I get tired, too.* (Parker)

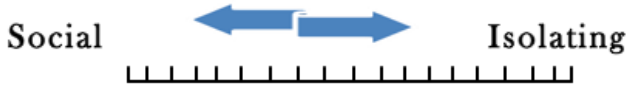
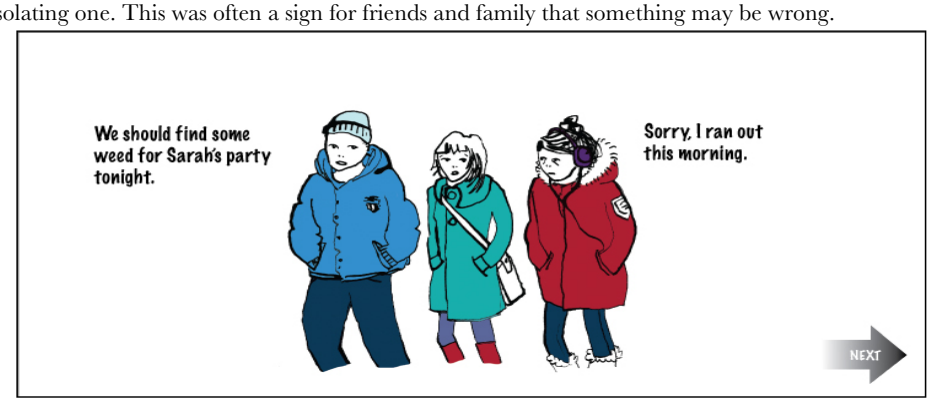


Figure 12 Cannabis as isolating
A panel depicting a common narrative for many participants. This tells the story of using marijuana as being an activity that transitions from being a fun and sociable activity to a more consuming and isolating one. This was often a sign for friends and family that something may be wrong.



Cannabis use can be both a social and isolating experience at the same time. What started with friends (at parties) frequently turned into at home (by oneself).

> *Sometimes I would have conversations and see things or understand things in the conversation that I would never have seen before. It would lead to psychotic sensations and I wouldn't talk to people. It would make me want to avoid discussion.* (005)

Although the majority indicated that their use was a social activity, many said that even when smoking with others, they experienced difficulty interacting normally, and often became preoccupied with their own thoughts. One participant mentioned their perspective that personality is a factor as to whether it is considered a social or isolating experience "I think depends on the person".

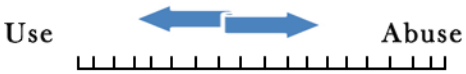


Figure 13 Continuum of use
A panel depicting the transition between using and abusing marijuana. This was described as a transitional period where priorities shift and certain roles and responsibilities in the young person's life are not being met.

When participants were asked to describe the difference between "using" versus "abusing" cannabis, there was a fine line between smoking socially now and then, to everyday reliance. Many described that "if you're smoking weed and disrupting your everyday life…then that's abuse".

> *Some people can use it as they can go to a party, but abuse is when you pretty much do as I was doing and the first half of my duration of using. I was just doing it all day everyday to deal with my problems instead of dealing with them in real life.* (Elliot)
>
> *It was constant, there were times being high all the time I don't remember being sober.* (Reese)
>
> *Use means something that you do recreationally and abuse is something that you're mostly dependent on.* (Taylor)

Factors identified to distinguish between use and abuse included: frequency, timing of use, issues of dependence/addiction and amount of money spent. If one smoked frequently and everyday, alone instead of socially and a lot of their financial resources went to purchasing cannabis, it was classified by most as abuse.

"Go to a calm, safe spot": Managing experiences with cannabis

Another overlapping idea that emerged in data about vacillating affective states is how participants attempted to manage these physical and emotional states, often with unanticipated results.

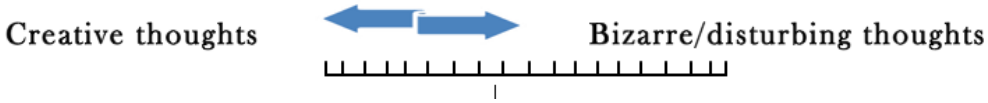


Figure 14 Cannabis as disturbing
Many participants described the mild hallucinatory effects of cannabis to be an interesting and mind-opening experience at first. However, after their psychosis started acting up these hallucinations became stronger, more bizarre and often extremely frightening for participants.

When asked to describe negative experiences associated with cannabis use, almost all participants found that the effects of use became negative after experiencing psychosis. They explained feeling paranoid, and experiencing weird, negative, exaggerated, disoriented, or intense thoughts. They also described worsening voices, feeling isolated or anxious, and experiencing hallucinations, confusion, depression and negative feelings. Other negative experiences included short-term memory loss, getting caught (by parents or police), kicked out or suspended from school and the financial burden of frequent use. Only a small percentage mentioned worrying about their physical health. Some participants mentioned a fear of losing control.

> *When I'm high it's kinda scattered, you are walking then you are 10 steps ahead, in between those 10 steps I don't remember. At first it's fun then it gets scary.* (Eden)
>
> *I feel like people are coming after me, really paranoid.* (Teagan)
>
> *It was chaotic, my thinking was scattered when I smoked and I had a lot of bizarre thoughts. Some of the stuff, like how to control other people through thoughts…got really paranoid I would go too in depth with it on my own away from my friend.* (Rylan)

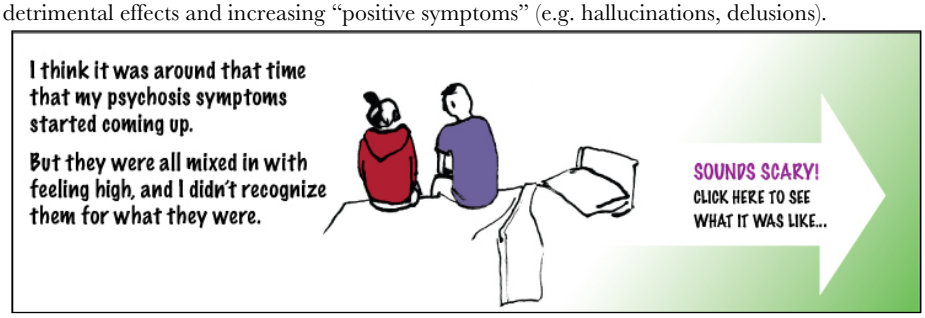
Many participants felt they had less control when smoking marijuana, but this depended on extent of use.

> *I feel in control until I smoke way too much…then it's not a good thing…I will go to sleep or I don't understand what people are talking about because I'm focused on something else.* (Jordan)

Many participants also actively incorporated strategies to control their paranoia and anxiety involving a focus on distractions such as: going for a walk, watching TV or movies, or playing videogames. A few participants tried to control their breathing instead "take deep breaths" or "close my eyes and calm myself down". Others described attempts to "ignore it" or "not think about it" when experiencing paranoid thoughts.

I try and talk myself down if I have the clarity to know that I'm overacting to something…being out in public and thinking someone's talking about me…tell myself that it's not real…or just remove myself from the situation altogether and go to a calm, safe spot. (0013)

Figure 15 Increasing delusions
At first using marijuana was helpful in reducing some of the "negative" symptoms of psychosis (e.g. flat affect, not being sociable) but as time passed, participants described the drug having detrimental effects and increasing "positive symptoms" (e.g. hallucinations, delusions).



…Taking away the pain and depression at times then it all just back tracked - it instantly started to cause pain and depressing feelings. (Marley)

The above quote highlights that cannabis use was not easy to depict; it was described as a complex activity characterized as both positive and negative, depending on the person, place and/or time. However, usage ranged and changed temporally. Different patterns of use were described; either 'off and on', steadily increasing, or from constant to not at all, then socially (or the reverse pattern).

In the beginning it was if friends had it…to buying…to once in awhile…to once to twice a week…to everyday then to several times a day. (Kendall)

For most participants, cannabis use dramatically decreased over time, or was terminated altogether. Many respondents stopped smoking after their psychosis and "getting ill". Reasons included: simply choosing to stop, feeling sick, and having a different way of thinking or point of view.

Psychotic symptoms starting happening and I heard radio messages and voices in my head and then I stopped and I haven't smoked since. (Carter)

I quit because it was making me worse with the illness… it's hard to get my life back even without it. (Shae)

Overall, cannabis reduced feelings of anxiety and stress, represented a way to have fun with friends or 'to escape' from the everyday. The age of first experiences with cannabis ranged from 12 to 17 years, with one participant starting in their twenties. Many participants indicated that, over time, symptoms ultimately worsened with cannabis use, and reported experiencing them immediately following use. Increased paranoia and intensifying auditory hallucinations were also common.

"Taking the weed just brought it out": Understanding cannabis use in relation to psychosis

Another common identified was talking about cannabis and the role that it may have played in their mental health difficulties. Participants talked about their views of cannabis as a contributing cause of psychosis, their attempts to use cannabis to self-medicate and finally, their perspectives on their perceived vulnerability to develop psychosis.

Cannabis as a contributing cause of psychosis

Figure 16 Initiation of illness
Some individuals felt that the drug played a significant role in illness initiation

The majority of respondents believed that cannabis use was an associated factor for earlier onset of psychotic symptoms; they were convinced of an existing link between cannabis and psychosis. However, they acknowledged that it was also hard to distinguish this exact connection because of similar symptoms that can occur when smoking cannabis and having a psychotic break. As one focus group respondent stated,
"*I couldn't tell whether it was the weed that did it, or was it my brain (psychosis) that was affected…the weed is a trigger*". *(Jackie)*

Many other participants indicated this same confusion.

It could possibly trigger more hallucinations and disorganized thinking but I don't know it necessarily causes psychosis. (Aubrey)

I think there definitely is a link between psychosis and any type of drug use including marijuana. Because it makes you hallucinate. So it creates self-perceptions. (India)

I had a lot of thoughts, it's hard to remember because of my psychosis. I don't know if the marijuana induced it or not. (Mischa)

Cannabis as a self-medication device

Figure 17: Reducing negative effects
Many people believed that they used cannabis in order to reduce some of the negative effects of psychosis and also being on medication (including being anxious, unsociable and uncreative or numb due to side effect from the anti-psychotic drugs).

Several participants discussed cannabis use as a way to self-medicate, reporting that it helped them to sleep, cleared their mind of unwanted and/or confusing thoughts, and generally was used to cope with psychotic symptoms.

> *Didn't realize I had the symptoms so for a few years I guess I was self-medicating.* (Reed)

Other individuals spoke of the negative side effects of psychosis medication and how cannabis temporarily eased some of these effects.

> *Helps now with my anxiety…I'm on clozapam for that but I find cannabis helps a lot better. I shattered and dislocated my wrist so when I'm not smoking it hurts.* (Uri)

Vulnerability to psychosis

Figure 18: Complexity of the Issue

The majority of youth recognized the complexity of the link between their illness and substance use and acknowledge that their genetics and environmental stressors are deeply entangled, making this a tricky matter to discuss when trying to figure out the issue of causation.

Many participants had family members with a history of mental illness, and several felt that this resulted in a predisposition to developing psychosis. They explained how cannabis use brought out symptoms earlier on in life.

> *I don't think drug use causes psychosis but I 100% support that brings it out in people who are predisposed. I don't think smoking pot makes you psychotic I believe that I was predisposed to have psychosis and then taking the weed just brought it out.* (Val)

Participants expressed uncertainty regarding the role of cannabis use in their psychosis. The terms 'don't know' and 'not sure' were used repeatedly. However, there was a general sense that there was a link and that cannabis played a role in some way.

When initially asked the question, a number of participants expressed some uncertainty regarding the link to their first episode of psychosis and whether marijuana played a significant role. However, when participants further discussed their experiences, many found that their use did in fact coincide with episodes. More often, it was seen as a contributing rather than causal factor in their illness. A few participants specifically stated that they did not realize the link at the time (of first episode), but discovered the connection later. Many individuals used before psychosis or were smoking heavily during their first episode.

> *The heavy pot use coincided with my episodes of psychosis. Then after I have my psychosis I really cut back on the weed. I was scared to go to that place again so I didn't want to mess around with that.* (Nicky)

DISCUSSION For young people, particularly those experiencing or at risk for psychosis, cannabis can trigger negative experiences, earlier onset of psychotic symptoms and worsened illness prognosis (Maslin, 2003). When funding for this study was announced, there was a proliferation of

news reports and articles (unrelated to our study) containing headlines that reduced the complexity of the link, leading readers to assume that the average person who smokes a joint will become psychotic. Somewhat understandably, some members of the general public expressed skepticism about the way that links between cannabis and psychosis were being depicted in the press, and the validity of SSC's proposed study. However, moving beyond the popular press and into the scientific literature, there is significant growing evidence to support claims that cannabis is not a harmless drug for all people and that this link, although complex, is persistent (Arseneault *et al*, 2004). As our findings suggest, for young people living with psychosis, smoking cannabis can be a risky undertaking. In the words of our participants, it can feel like a "rollercoaster ride inside the mind". Participants explained that the way experiences are perceived is dependent on many often-interacting factors, and that it can be difficult to differentiate between negative effects of being high and genuine psychotic symptoms.

We learned that young people living with psychosis may be using cannabis for many of the same reasons that any young person uses. They may wish to feel more sociable, creative, stimulated, relaxed; or they may use to self-medicate. They also discussed experiencing a lot of the negative physical and emotional affective states that any young person may feel when smoking cannabis, such as bizarre and disturbing thoughts, isolation, fear or overstimulation. We suggest that there could be a more pronounced gap between the perceived range of "highs" and "lows" of their experiences versus those in other young people. This may help to explain why they start and keep using, but also why they also recognize that using is ultimately not good in their recovery process. Given what we know at this point, curbing use early on in the illness trajectory should be an important goal for early intervention services.

One significant task is how to communicate this knowledge to young people in an honest and engaging manner in order to ultimately affect attitude and behaviour change to promote good mental health. A related challenge is that little is known about the link between cannabis and psychosis from young people's perspective, making this study significant. First, it directly involved youth in the research process to gain the perspectives of their peers and used the power of the arts and online media to explore study findings. At the time of study's conception, the limited resources available to young people tended to be replete with facts and figures, catering to traditional help-seeking audiences (e.g. parents, teachers). We created a new approach: "Just Say Know", which we define as a creative, "bottom-up" approach to youth engagement in mental health research which values both experiential and evidence-based knowledge and allows youth to think about issues in a way that is driven by their own motivation and interests, whether that be through film, photography or speaking with their peers as researchers.

Future incorporation of non-traditional, creative based initiatives in the design of youth mental health prevention and intervention strategies should consider participatory methods, specifically when targeting hard-to-reach populations who may not respond to speaking honestly about their experience with traditional "white coat" researchers. The peer research element was a crucial part of getting young people to share stories and experiences in a qualitative research setting. Many of these young people may feel socially isolated and reticent about reflecting on acute periods of their illness, but in speaking with others with whom they can relate, they opened up and revealed their personal thoughts and feelings.

With this approach, we found that getting young people deeply engaged with the topic matter via research, enabled them to think critically and creatively about their use and their illness in a way that had resonance for them, allowing them to elicit meaningful responses from their peers. Young people were encouraged to reflect on their experiences with peers and share this information in ways that they identified as important. Thus, young people were exposed to evidence-based knowledge from scientific experts on the study team and lived experiences from their peers in a visceral and embodied way, giving them a "voice" in this mostly data-driven conversation about the link between cannabis and psychosis. Our approach combines principles of participatory inquiry, as well as arts and media-based methods and builds on previous work demonstrating this approach is well-suited to studies that wish to describe and share the illness experience by eliciting subjective experience (Baker & Wang, 2006; Boydell, 2011) and empower and engage participants in the process (Cox *et al*, 2010).

Having young people involved in the entire research process as peer researchers may have helped support a sense of autonomy, community belonging, ownership and empowerment that we heard echoed in evaluation feedback sheets from study workshops and supported in prior literature (Berg *et al*, 2009). This process values lived experience, may have also encouraged skill-building, and may result in outcomes likely to be interesting and useful to other young people. Future work needs to focus on exploring the impact of these creative processes in research and the "transformative potential of the arts" in a more meaningful way, an area that has been identified as needing further attention (Boydell *et al*, 2012).

The study was fortunate to have adequate resourcing and supportive partnerships. Consequently, research assistants and participants had prolonged and significant engagement with the study, critical in building group trust and rapport. According to team members, youth participants, as well as the Mental Health Commission of Canada, this engagement was identified as a key ingredient of study success.

A factor that may have supported project engagement and another area for future study was the emphasis on the online experience. We know that young people often turn to peers when dealing with difficult situations, and rely heavily on their personal network of friends, including online support and digital communication (Cash *et al*, 2013). Online communication played a significant role in our research process as well as the knowledge translation component of the project. It represents a useful way to reach young people and has the added bonus that when study funding ends, the products and stories can continue to live online as resources and tools (Gray *et al*, 2005; Stinson *et al*, 2009; Burns *et al*, 2009; 2010). There are also many ethical challenges to consider concerning media and arts-based process and products in a research setting, peer-based or not, which should be explored in subsequent work in this area (Boydell, 2012).

Another challenge is sustainability, a concern echoed in other new programs and innovations (Schell *et al*, 2013). Although the study lives online and continues to be shared in educational and health settings, it remains to be seen whether study youth will continue to stay involved and how this will affect their illness pathway and any future substance use. In order to explore long-term impact on youth perceptions, attitudes and behaviours, future work in this area should incorporate longitudinal design in methods and again, it would relate to the impact and evaluation of creative youth engagement strategies and approaches.

ACKNOWLEDGEMENTS Funding for this research was provided to the Schizophrenia Society of Canada by the Drug Strategies Community Initiatives Fund of Health Canada.

The study team would like to thank everyone involved during the study duration, especially advisory board members and the incredible talented and brave young people who made this possible.

NOTES

1. Available on the Internet at: http://cannabisandpsychosis.ca/interactive/
2. Available on the Internet at: http://www.youtube.com/watch?v=n5y7n988r1Q
3. Available on the Internet at: http://www.youtube.com/watch?v=eiCi2ZgtMLo
4. Available on the Internet at: http://www.youtube.com/watch?v=AABHMhi--BY
5. Available on the Internet at: http://www.youtube.com/watch?v=yhrz8Za4-bk
6. Available on the Internet at: http://cannabisandpsychosis.ca/audio-bios/
7. Available on the Internet at: http://cannabisandpsychosis.ca/youth/

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