

Help-seeking experiences of youth with suicidal ideations

Erika K. Neilson,^{a,b} Marissa Y. Mar,^{a,b} Iris Torchalla,^a Gregory R. Werker,^{a,c} Allison Laing^a and Michael Krausz^{a,b}

Abstract

Approximately 28 percent of Canadians begin to experience a mental health issue during their youth. In this article, we explore patients' perceptions of their mental healthcare experiences within a sample of youth who reported anxiety or depressive symptoms and past suicidal ideations. The study data is taken from in-depth interviews with 23 youth in British Columbia. Interview topics included support systems, help-seeking behavior and healthcare experiences. Our findings indicate that participant experiences were most positive when experiences were neither dismissive nor stigmatizing. Important factors for participants were respect, acknowledgement, information and choice. Our results generated the concept that treatment perceptions for youth with suicidal behaviours can be placed on a theoretical spectrum, which may be a useful tool for self reflection for those who support individuals with mental health conditions professionally or personally.

- a Centre for Health Evaluation and Outcome Sciences, Addictions and Concurrent Disorders Research Group, Vancouver, British Columbia, Canada.
- b University of British Columbia (UBC), Institute of Mental Health.
- c School of Population and Public Health, University of British Columbia, Vancouver, British Columbia, Canada.

Corresponding author

Erika K. Neilson

Centre for Health Evaluation and Outcome Sciences,
Addictions and Concurrent Disorders Research Group.
430-5950 University Blvd
University of British Columbia
Vancouver BC V6T 1Z3
Email: erika.kirsten@hotmail.com

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Keywords

depression; relationships; suicide; healthcare; user experience; health seeking; lived experience; mental health and illness; adolescents; youth

Introduction

Depression and anxiety are among the most common mental disorders in young people.¹ Among Canadian youth, 10.2 percent met criteria for lifetime depressive disorder and 12.1 percent for anxiety disorders; 12-month prevalence rates were 6.4 percent and 6.5 percent, respectively.² Experiencing anxiety and depressive disorders during adolescence is also associated with a two- to three-fold increased risk of these disorders in adulthood.³ Furthermore, nearly a quarter of youth report suicidal ideation.⁴

Despite experiencing emotional distress, only 18 to 34 percent of youth reporting high levels of either depression or anxiety seek professional help.⁵ Adolescents with suicidal ideation and depression are even less likely to receive treatment from a mental health professional than those with depression without suicidal ideation.⁶ To understand why help-seeking behavior is infrequent and how we might address it, we explored patients' experiences. Specifically, we sought to understand the experiences of youth struggling with depression or anxiety as they were accessing support.

Methods

To be eligible to participate, individuals were classified as youth (ages 16 to 24), were residents of Canada, self-identified as having experienced anxiety or depression, and reported lifetime but no current suicidal ideations. Recruitment took place through flyers at counseling locations on and off of a university campus, advertisements on two webpages, passive referral by healthcare professionals and snowball sampling through peers.

Snowball sampling was necessary due to the hard-to-reach nature of our sample. Recruitment took place from September 2012 to May 2013.

Section C of the MINI International Neuropsychiatric Interview Plus (MINI-Plus), version 5.0.0, a structured clinical interview for assessing mental disorders, was used to screen current suicide risk.⁷ Those administering the MINI were trained and experienced with this tool. The suicidality scale consisted of 11 self-report items related to lifetime suicide attempts and current (i.e., past month) suicidal ideations, plans, attempts and self injury. Responses are summed for an overall score between 0 and 52. A low (0-8) or moderate score (9-16) indicated eligibility to continue participation.

Eligible individuals were informed about the study goals and procedures, their participation and rights, and confidentiality. A research assistant screened and conducted the qualitative interview for those who provided consent; interviews were topically guided around healthcare treatment experiences. Participants were asked open-ended questions on several topics: systems of support, healthcare experiences, Internet usage and expectations for online support. For this article, we focus on the interview questions related to systems of support and the participants' patient experience (See Appendix 1). Interviews lasted between 20 minutes and 1.5 hours, and could be discontinued by participants at any time. Variability in interview time was linked with number of interactions that the participant had with the healthcare system. One participant chose not finish the interview due to emotional discomfort, and one withdrew the interview afterward as they felt their responses were affected by their concurrent psychiatric condition, giving a final sample size of 23 participants. Participants received an honorarium of \$20 regardless of interview completion. The University of British Columbia Behavioural Research Ethics Board provided ethical approval. This research was funded by Bell Canada to develop an e-Mental Health strategy for youth as part of the "Let's Talk Mental Health Initiative."

Interviews were transcribed and entered into Nvivo version 9. Initial codes were developed using interpretative phenomenological analysis. Codes were added as they arose through the analysis. The codebook is available in Appendix 2. All transcripts were coded by two independent reviewers and tested for intercoder reliability. After initial review, 90 percent of codes achieved a kappa greater than .80. The authors reviewed and agreed upon codes for the remaining 10

percent. Interviews were linked to the MINI-Plus suicidality scale to confirm information consistency. No discrepancies in information were noted.

Results

Twenty-two out of a final 23 participants were female, and the average age was 20.7 years (range: 18-24, SD= 2.18). More than half of the sample was East Asian (61 percent), while 17 percent were White and 22 percent were other ethnicities (Hispanic, Black or mixed ethnicity). Most participants were single (83 percent) and university students (91 percent) at the time of interview. The mean score on the MINI-Plus suicidality scale was 2.4 points (range: 0-10; SD = 3.7). A high number of participants (n=13) scored zero for present suicide risk, accounting for the low mean.

The interviews generated clear themes surrounding what was desired in terms of personal and professional support system response and behaviors. All participants emphasized the importance of their support network's initial reaction and continued response to their condition for their recovery.

Participants struggling with suicidality often relied solely on personal supports such as friends, family, or online peer groups, and did not develop sustained relationships with any mental health professional (n=14). These participants described how their personal support system's response left something to be desired and felt their problem was ignored or minimized. "My dad, he, I don't think he knew I was on medication, um he doesn't believe in mental illness, so that was really tough." Others worried that their personal supports would stigmatize their diagnosis. "It's like coming out of the closet ... none of my friends know."

Stigma within personal circles affected an individual's decision to seek professional help. "I wasn't [yet] 16 at the time ... my family sort of stigmatizes mental illness so ... I couldn't get doctor confidentiality." Self-stigma also prevented an individual from seeking professional help. "I felt a little self-conscious that I would have to see a psychiatrist, like I'd get feelings like, I'm not normal ... " As characterized by Eisenberg and colleagues, stigma appeared in our sample both internally, but more commonly externally.⁸ Stigma is a significant barrier for young people seeking help for mental health.^{9,10}

Participants who sought support from healthcare professionals encountered positive and negative experiences (n=9). Negative experiences involved caregivers dismissing the patient's

condition so that the support given did not match the participant's level of distress.

... went to the GP ... and we were told, okay, so you are not feeling good? Ah, it'll be about a year to 18 months to get in to see someone ... so then I started cutting myself because I was like, I had so much pain that I needed to like unleash it, so that was my translation, was from emotional to physical through the cutting, so then I went back to the doctor and they were like, oh, okay, well in that case, we can expedite the process.

One participant who was not actively suicidal said they felt they needed to pass a validity test to access appropriate care.

It's like you are failing the test of being serious enough to actually be there. So it was just kind of like humiliating, and I feel like I had stubbed my toe and I was going to the emergency room or something.

Another participant expressed that there were no services available unless their problem was deemed severe.

You are kind of stuck in this like limbo of, okay, like things are bad enough that like me just seeing my doctor every two weeks and going to like a mental health support group and doing some CBT, like that stuff is not doing anything. It's not enough care, but ... my mental illness isn't severe enough to be in the psych ward so now I'm floating in between with nowhere to go.

Sometimes, these experiences prevented the patient from seeking alternate sources of professional care.

Interviewer (I): Did you ask him for a referral?

Participant (P): No I didn't. I guess he was thinking that what I was going through was not severe enough to benefit from seeing a psychiatrist. That's the assumption that I think he made, which I didn't like.

Instead, the optimal point of support was one that acknowledged and respected the patient's issue, offering a variety of treatment options and information (n = 3).

We were always on the same page. It was very open and very professional. ... Oh [laughs] I've had a lot of support and like a lot of therapy ... and a mental health team who I could see more often if I felt like I needed to ...

Among those with only negative experiences (n = 3), participants similarly expressed a desire for respect and acknowledgement of their condition, a variety of treatment options and information.

Choice was important when considering treatment options. Although 14 participants were in a position to consider prescription pharmaceuticals, only three wanted their prescribed medication. Eleven initially did not want medication for reasons varying from stigma to fear of side effects, to discomfort of relying on medication, to beliefs of ineffectiveness.

It was very bad, um, the day I got prescribed medication. ... I had the stigma ... I'm gonna be on meds ... I walked out of this doctor's office ... I couldn't deal with that and got into a car accident that day. Totalled my car ...

For five of the 11 who did not want medication, their healthcare professional accepted their wishes and did not prescribe medication. The other six who were prescribed medication mostly did not adhere to treatment. "I took the prescription, burnt it, moved on with my life." For one participant, opposition to prescription drugs prevented them from accessing any mental health professional. "I don't want to rely on medication, which is why I haven't actually seen, sought help from a psychiatrist or a psychologist yet."

Frequently, participants sought help multiple times before accessing the optimal point of support (n = 10).

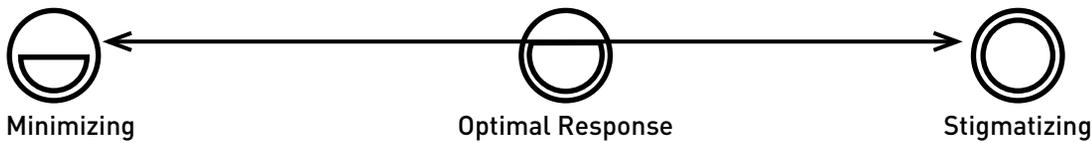
Yeah, the psychiatrist was actually really good. Like, I clicked very well with him. Um, like I went through a few therapists, and they were all like okay, but he, I don't know, I guess he really understood me.

Discussion

In agreement with these findings, Rickwood and colleagues reviewed studies exploring youth's mental health perceptions and found that experiences where individuals were not taken seriously led to attitudes that healthcare professionals were not useful.¹¹ Also, consistent with existing literature, our sample of young women strongly preferred psychotherapy over medication.¹²

Overall, positive support experiences were associated with individualized treatment and being offered multiple treatment options. Patients may be more likely to recover and adhere to treatment when receiving their treatment of choice.¹³ Participants

Figure 1 – Possible reactions to participants’ mental health concern from their support network



often reported their best treatment experiences included access to information. Participants commonly sought further information online to understand their diagnosis or prescription, demonstrating insufficient information given professionally.

The experiences of our participants show that youth with suicidal ideations, depression and anxiety have had variable experiences seeking support. Positive experiences were interactions characterized by recognition, respect, choice and information. Participants desired their supports to believe the degree of their distress without “evidence” (such as self harm). Based on participants’ experiences with their personal and professional support systems we suggest that responses to participants fell on a continuum from dismissal of the condition (minimization) to stigmatization (depicted in figure 1). Participants considered neither of these end responses to be acceptable or appropriate.

Respect and understanding were of paramount importance in support for recovery. Individuals supporting youth with depression or anxiety may decide to use the theoretical spectrum proposed above to gauge their own responses when providing support. It is suggested that a person in this position should endeavor to respond by recognizing an individual’s distress and continuing to support them by facilitating access to more information and multiple treatment strategies.

The homogeneity of this sample is a limitation, as it consists primarily of highly educated women residing in an urban center. Different perceptions and experiences with the mental health system may exist for other youth demographics such as men, youth with other mental illnesses, youth with less education, or those in remote areas. In light of these limitations, further investigation of this area is warranted.

Bibliography

Bradley, Kristina L, Patrick J McGrath, Cyndi L Brannen, and Alexa L Bagnell. “Adolescents’ Attitudes and Opinions about Depression Treatment.” *Community Mental Health Journal* 46(2010): 242–51. doi:10.1007/s10597-009-9224-5.

Cheung, Amy H, and Carolyn S Dewa. “Mental Health Service Use among Adolescents and Young Adults with Major Depressive Disorder and Suicidality.” *Canadian Journal of Psychiatry* 52(2007): 228–32.

Eisenberg, Daniel, Marilyn Downs, Ezra Golberstein, and Kara Zivin. “Stigma and Help Seeking for Mental Health among College Students.” *Medical Care Research and Review* 66(2009): 522–541. doi:10.1177/1077558709335173.

Gulliver, Amelia, Kathleen M Griffiths, and Helen Christensen. “Perceived Barriers and Facilitators to Mental Health Help-Seeking in Young People: A Systematic Review.” *BMC Psychiatry* 10(2010) doi:10.1186/1471-244X-10-113.

Jaycox, Lisa H, Joan Rosenbaum Asarnow, Cathy D Sherbourne, Margaret M Rea, Anne P LaBorde, and Kenneth B Wells. “Adolescent Primary Care Patients’ Preferences for Depression Treatment.” *Administration and Policy in Mental Health and Mental Health Services Research* 33(2006) 198–207. doi:10.1007/s10488-006-0033-7.

Merikangas, Kathleen, Jian-ping He, Marcy Burstein, Sonja Swanson, Shelli Avenevoli, Lihong, Cui, Corina Benjet, Katholiki Georgiades, Joel Swendsen. “Lifetime Prevalence of Mental Disorders in U.S. Adolescents: Results from the National Comorbidity Survey Replication–Adolescent Supplement (NCS-A)” *Journal of the American Academy of Child & Adolescent Psychiatry* 49(2010). 980-989. doi: 10.1016/j.jaac.2010.05.017.

Nguyen, Cat Tuong, Louise Fournier, Lise Bergeron, Pasquale Roberge, and Geneviève Barrette. “Correlates of Depressive and Anxiety Disorders among Young Canadians.” *Canadian Journal of Psychiatry* 50(2005): 620–8.

Pine, DS, P Cohen, D Gurley, J Brook, and Y Ma. “The Risk for Early-Adulthood Anxiety and Depressive Disorders in Adolescents with Anxiety and Depressive Disorders.” *Archives of General Psychiatry* 55(1998) doi:10.1001/archpsyc.55.1.56.

Rickwood, Debra, Frank Deane, Coralie Wilson, and Joseph Ciarrochi. “Young People’s Help-Seeking for Mental Health Problems.” *Australian E-Journal for the Advancement of Mental Health* 4(2005): 2–34.

Sheenan, DV, Y Lecrubier, KH Sheehan, P Amorim, J Janvas, E Weiller, T Hergueta, R Baker, and GC Dunbar. “The Mini-International Neuropsychiatric Interview (M.I.N.I.): The Development and Validation of a Structured Diagnostic Psychiatric Interview for DSM-IV and ICD-10.” *Journal of Clinical Psychiatry* 59(1998): 22–33.

TenHave, Thomas R., James Coyne, Mark Salzer, and Ira Katz. “Research to Improve the Quality of Care for Depression: Alternatives to the Simple Randomized Clinical Trial.” *General Hospital Psychiatry* 25 (2003): 115–123. doi:10.1016/S0163-8343(02)00275-X.

Waldrop, AE, RF Hanson, HS Resnick, DG Kilpatrick, AE Naugle, BE Saunders. "Risk factors for suicidal behaviour among a national sample of adolescents: implications for prevention. *Journal of Traumatic Stress* 20(2007) 869-79.

Appendix 1- Qualitative interview schedule

Theme – point of support

Experiencing mental challenges, who is the person you turn to? Is there somewhere/someplace you find helpful and you feel you can contact? What would you recommend to a young person with suicidal ideation or other mental challenges?

Theme – healthcare

You mentioned that you experienced a mental health crisis and suicidal ideations:

- What support did you look for?
- Have you been to a doctor or therapist to talk about these issues? (Try to see if any diagnosis?)
- (If yes) Have you received care/support/help for this?
- (If no) Have you received any other form of help for this?
- Do you think the help you received was supportive and sufficient?
- What did you do on your own to improve your situation?
- What did you experience as helpful with your suicidal ideations?

Theme – Internet usage

(This can be for them selves, for a friend, or family member)

- Have you ever searched for information on mental health online?
- How did you proceed?
- What programs did you use?
- Are you aware of any specific websites?

- Was this helpful?
- Did you ever use interventions or treatment online? (eg. group therapy, online counseling, CBT programs etc.)

Theme – expectations for online support

If there was a website available for individuals with mood disorders or anxiety what would you like it to look like.

- Any specific features? ...
- Who would be able to access it?
- Who would be the best host for it?
- How would you search for it?
- Would the most useful page be online information/knowledge?
- Would it be a discussion forum? Or a specific type of treatment?

References

- 1 Kathleen Merikangas et al. "Lifetime Prevalence of Mental Disorders in U.S. Adolescents: Results from the National Comorbidity Survey Replication-Adolescent Supplement (NCS-A)" *Journal of the American Academy of Child & Adolescent Psychiatry* 49(2010). doi: 10.1016/j.jaac.2010.05.017. 981
- 2 Cat Tuong Nguyen et al. "Correlates of Depressive and Anxiety Disorders among Young Canadians." *Canadian Journal of Psychiatry* 50(2005): 620
- 3 DS Pine et al. "The Risk for Early-Adulthood Anxiety and Depressive Disorders in Adolescents with Anxiety and Depressive Disorders." *Archives of General Psychiatry* 55(1998) doi:10.1001/archpsyc.55.1.56. 56
- 4 AE Waldrop et al. "Risk factors for suicidal behaviour among a national sample of adolescents: implications for prevention. *Journal of Traumatic Stress* 20(2007) 89

Appendix 2 – Code Book

Free Nodes	
First Point of Contact – General	General first point of contact (e.g., the first person they told about the problem- including school counsellors)
First Point of Contact – Healthcare System	First point of contact to the healthcare system (e.g. first time seeking help from a healthcare professional; GP, counsellor etc)
Medication	Experiences and thoughts around taking medication, including whether they wanted medication prescribed or not
Mental Health Concern	Self-identified concern or official diagnosis given by a health professional (e.g., depression, anxiety)
Other methods of coping	Methods of coping with problems/emotions; not including medication (e.g., using a diary, exercising, expressing emotion through artwork, taking a break to sleep)
Recommendations to a friend	What a participant would recommend to a friend if they were going through the same issue or had the same mental health problem(eg., coping, resources, visiting healthcare professionals)
Search Terms	How the participant looked for online information related to their mental health concern, searched for information (e.g., what search terms or words did they use to search for information) Includes if they did not look online.
Stigma	Experiences and thoughts around stigma (e.g., did they feel stigma from friends, family, or healthcare professionals), thoughts around how to reduce stigma for themselves or others
Triggers	Events or experiences that the participant perceived as initiating episodes of distress

- 5 Amelia Gulliver, Kathleen M Griffiths, and Helen Christensen. "Perceived Barriers and Facilitators to Mental Health Help-Seeking in Young People: A Systematic Review." *BMC Psychiatry* 10(2010) doi:10.1186/1471-244X- 113
- 6 Amy H Cheung, and Carolyn S Dewa. "Mental Health Service Use among Adolescents and Young Adults with Major Depressive Disorder and Suicidality." *Canadian Journal of Psychiatry* 52(2007): 230
- 7 DV Sheenan et al. "The Mini-International Neuropsychiatric Interview (M.I.N.I.): The Development and Validation of a Structured Diagnostic Psychiatric Interview for DSM-IV and ICD-10." *Journal of Clinical Psychiatry* 59(1998): 25
- 8 Daniel Eisenberg et al. "Stigma and Help Seeking for Mental Health among College Students." *Medical Care Research and Review* 66(2009):.doi:10.1177/1077558709335173. 535
- 9 Gulliver, Griffiths, and Christensen. "Perceived Barriers and Facilitators to Mental Health", 116
- 10 Kristina L Bradley, et al. "Adolescents' Attitudes and Opinions about Depression Treatment." *Community Mental Health Journal* 46(2010): 242-51. doi:10.1007/s10597-009-9224-5. 249
- 11 Debra Rickwood et. al., "Young People's Help-Seeking for Mental Health Problems." *Australian E-Journal for the Advancement of Mental Health* 4(2005): 16
- 12 Lisa H Jaycox et. al., "Adolescent Primary Care Patients' Preferences for Depression Treatment." *Administration and Policy in Mental Health and Mental Health Services Research* 33(2006). doi:10.1007/s10488-006-0033-7. 203
- 13 Thomas R. TenHave et al., "Research to Improve the Quality of Care for Depression: Alternatives to the Simple Randomized Clinical Trial," *General Hospital Psychiatry* 25, no. 2 (March 2003): 119.