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“I Could Be on Facebook by Now”: Insights from Canadian Youth on Online Mental Health Information Resources

« Je pourrais déjà être sur Facebook »: points de vue de la jeunesse canadienne sur les sources d'information en ligne concernant la santé mentale

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Abstract: The goal of this research was to learn from Canadian youth how they look for online information about mental health and to explore how they would prefer to receive information. Saturation was reached within four focus groups with a total of 21 youth participants, including 5 male and 16 female participants from various regions in Canada. Focus group participants were heavy users of social media but acknowledged the problematic aspects of using these sites to discuss or access mental health information. There was in general a lack of knowledge about mental illnesses and a high level of concern over stigma associated with seeking or providing mental health information online. Youth expressed a desire for interactive elements and youth-related material on mental health sites in order to engage and inform them.

Keywords: information seeking, youth mental health, online credibility, information literacy, social media

Résumé : L'objectif de cette recherche était d'apprendre des jeunes Canadiens comment ils cherchent des informations en ligne sur la santé mentale et d'explorer sous quelles formes ils préféreraient recevoir ces informations. Nous avons atteint la saturation dans les quatre groupes de discussion avec un total de vingt-et-un jeunes participants, dont cinq hommes et seize femmes provenant de diverses régions du Canada. Les participants aux groupes de discussion étaient de grands utilisateurs des médias sociaux, mais ils ont reconnu les aspects problématiques de l'utilisation de ces sites quand il s'agit de discuter ou d'accéder à des informations sur la santé mentale. D'une manière générale, les jeunes manquaient de connaissances sur les

maladies mentales et montraient un niveau élevé d'inquiétude concernant la stigmatisation associée au fait de demander ou de fournir en ligne des informations sur la santé mentale. Les jeunes ont exprimé le désir de trouver sur les sites de santé mentale des éléments interactifs et du matériel concernant la jeunesse susceptible d'éveiller leur intérêt et de les informer.

Mots-clés : recherche d'information; santé mentale des jeunes; crédibilité en ligne; compétence informationnelle; média sociaux

Introduction

Concern about the mental health of young people is significant and increasing. An estimated half of Canadians aged 19 to 24 with depression or suicidal tendencies have not sought mental health treatment (Cheung and Dewa 2007). One major barrier to seeking mental health treatment is stigma; young people usually perceive mental illness as socially unacceptable and therefore are reluctant to seek professional help. One avenue to addressing this problem is developing a deeper understanding of naturalistic mental health information-seeking behaviours. For instance, if psychologists better understand clients' information-seeking behaviour, they will be in a better position to mobilize their knowledge regarding diagnosis and treatment and to transfer this knowledge in order to assist individuals in making informed health decisions.

This qualitative study engaged Canadian youth aged 12 to 18 to investigate their attitudes about mental health and preferences for mental health information. The purpose was to identify and help overcome barriers to the use of high-quality online mental health resources. Unlike quantitative research, qualitative work does not attempt to count in its observations; rather, it stresses "the socially constructed nature of reality, the intimate relationship between the researcher and what is studied, and the situational constraints that shape inquiry" (Denzin and Lincoln 2005, 10). It was necessary to conduct this research qualitatively because the authors wanted to understand how youth socially construct their opinions about mental health and mental health information, and these are not quantifiable in a traditional sense. Although clinicians and information professionals likely would prefer that people access "authoritative" sources of health information rather than what they find independently, it is unrealistic and perhaps impossible to regulate natural health information-seeking preferences and behaviours in the Internet age. Unfortunately, relatively little qualitative health research exists, so this study has few precedents to follow. Health and medical researchers widely favour quantitative approaches, such as randomized controlled trials, over developing theory based on meaning and holistic understanding. Each approach has its merits and drawbacks, and the authors view them as complementary.

Youth mental health disorders

Canadian statistics on the prevalence of youth mental health disorders are troubling, and service uptake for those problems is equally concerning (Cheung and

Dewa 2007). Young people in Canada aged 15 to 24 (especially young, single men with low income and low education), are most likely to have negative attitudes toward seeking help for mental illness (Jagdego et al. 2009). This may be in large part why less than half of youth under the age of 18 with mental disorders seek needed mental health services (Kessler, Avenevoli, and Merikangas 2001). When young people do access support, it is most often from informal sources such as friends or family, yet many Canadians lack knowledge about options available for help about mental health concerns other than medical help (Bourget and Chenier 2007).

Corrigan and Wassel (2008) identify three types of stigma that act as barriers to seeking help for mental illness: public stigma, which is what the public does to people who are marked with mental illness; self-stigma, the internalization of public stigma that has cognitive and behavioural impacts; and label avoidance, whereby individuals who have not yet been diagnosed with a mental illness avoid mental health care in order to not be marked with the label.

The Internet has a strong appeal to people who wish to seek advice on important but stigmatized and sensitive illnesses (Klein and Wilson 2002; Berger, Wagner, and Baker 2005). Anonymously seeking information online about mental illness may be one way that young people can avoid some forms of stigma. However, young people (as well as the larger general population) may not necessarily have the skills or interest to carefully evaluate the online information they encounter (Fields 2005; Van de Vord 2009).

Online credibility

Rieh (2009, 1338) defines credibility as "people's assessment of whether information is trustworthy based on their own expertise and knowledge." According to Wathen and Burkell (2002), the credibility of a message is generally agreed to result from an interaction of source characteristics (such as expertise and trustworthiness), message characteristics (including factors such as plausibility, internal consistency, and quality), and receiver characteristics (such as cultural background and previous beliefs). When it comes to online messages, an important factor is what Wilson (1983) coined "cognitive authority." Cognitive authority is described by Rieh (2002) as the extent to which users think that they can trust information as being current, good, useful, and accurate. Cognitive authority decisions are "the result of underlying cognitive processes ... based on the information seeker's interpretation of source characteristics in light of a body of beliefs and attitudes that the information seeker has developed from an initial childhood stock" (McKenzie 2003, 262). Olaisen (1990) connects cognitive authority to influence, and influence to credibility.

Credibility and cognitive authority assessment are ongoing, iterative processes rather than discrete evaluation events (Rieh 2009). In two studies examining the cognitive authority and quality ratings used by scholars for information presented on the Internet, Rieh and Belkin (1998; 2000) found that the quality checks used by scholars for print material – presence of peer review, refereeing, and publisher reputation – were still applied to Web sources. They found source

credibility markers included aspects such as suffixes to URL addresses (.edu for educational sources, .org for non-profit sources, and .gov for US government sources were seen as more credible than .com for commercial sites) and statements of the authors' credentials and institutional affiliations. Rieh and Belkin conclude that there are multiple criteria that affect credibility of online information sources, including the source, content, presentation, currency, accuracy, and speed of loading. Eysenbach et al. (2002) carried out a review of health website evaluations and concluded that the most frequently used quality criteria included accuracy, completeness, readability, and design.

However, skill is required not only in evaluating online resources but also in finding useful online resources. A recent survey of university students aged 18 to 25 reveals that most are unaware of online mental health education modalities, including serious games, online chat services with psychologists, and self-directed online therapies (Neal et al. 2011). This lack of awareness is unfortunate considering the existence of reliable online mental health resources that have demonstrated usefulness for psychological education and as an adjunct to face-to-face therapy (Eysenbach 2001; Wootton, Yellowlees, and McLaren 2003; Efstathiou 2009). Neal et al.'s (2011) research demonstrates that most of those seeking online mental health information use Google and do not progress beyond the first page of search results; as a consequence, many if not most online mental health resources are not accessed by those who need them.

Method

University researchers and employees of a national youth mental health program (**mindyourmind.ca**) engaged youth to conduct this study. A national organization contracted the authors to do the work. The basis for this study began with user-centred design principles and youth engagement approaches. User-centred design "refers to how easy a product, web site or computer-based system is to use based on the users' perceptions" (George 2008, 3). An essential part of this methodology is substantial input from potential users *at every stage* throughout the design process. This contrasts with a more traditional "systems analysis" approach, in which the development team gathers user requirements at the onset of the project, develops the product without user consultation, and returns at the end with a finished product. This approach is problematic because it can be difficult for people to describe what they would like to see in a system without the existence of drafts or plans to guide their conceptualization of the finished product, and it frequently results in user dissatisfaction.

In addition to user-centred design principles, the project team drew on the expertise in youth engagement methods developed by **mindyourmind.ca**, an organization that has managed the growth of a comprehensive and responsive online and offline program with the goal of reducing the stigma and discrimination young people with mental illness experience. **mindyourmind.ca** is careful to engage youth and young adults in all aspects of each project they undertake, from inception to evaluation, and their developed expertise in youth engagement was used in identifying focus group participants and engaging participants in

discussion. **mindyourmind.ca** defines the process of "youth engagement" as follows:

Young people who are engaged affectively, cognitively and behaviourally participate fully and become co-creators with adult as partners. They are loyal, invested and because of this will be more likely to talk to their peers about their involvement. Interactions and communications are delivered in a manner that reflects a young person's world view and incorporates pillars of youth culture in the delivery and presentation.

Focus groups

The complementary youth engagement and user-centred design approaches were realized through focus groups. Focus groups began in marketing circles but are frequently used in social science research (Wildemuth and Wilkins 2009). The strength of focus groups lies in the ability of participants not only to convey their thoughts and experiences, but also to compare their thoughts and experiences with the others in the group. They are best used when research is at an exploratory phase of development. Since people often create their opinions socially (especially young adults who place a great deal of importance on their peers' opinions), the social environment of a focus group provides an ideal situation to explore the strengths and weaknesses of online mental health information.

The disadvantages of focus groups were also taken into consideration. These include the potential for one person to monopolize the conversation or impose her or her opinion on other participants (Wimmer and Dominick 2011), the potential for participants to portray themselves as more thoughtful, rational, and reflective individuals than they actually may be (Krueger and Casey 2009), and a tendency toward conformity (Morgan 1997). The moderators were aware of these disadvantages and did their best to encourage honest participation from all participants. Focus groups were chosen over individual interviews because they provided a more natural environment for youth, as participants would be influencing and influenced by others, just as they are in life (Krueger and Casey 2009). Focus groups have been found helpful in assessing needs and generating information (Krueger and Casey 2009), which is why this method was well suited to the purposes of this study.

As the team developed the focus group interview guide, the members aimed to ask questions only about the participants' (1) perception of what "mental health" is and their attitudes toward it, (2) how they would go about finding mental health information, and (3) the formats in which they would prefer to receive mental health information. These topics arose from several meetings involving the contracting agency and the researchers in which they articulated their jointly shared interests in young people's perceptions of mental health and preferences surrounding mental health information. The initial interview guide can be found in Appendix 1. However, the specific topics addressed in each focus group were determined in part by this guide as well as by the interests of each focus group's participants. Thus, the topics covered varied from group to group in response to the discussion that ensued in the context of the group.

This method is in keeping with grounded theory, which was used in this study (Charmaz 1990; 1991; 2000).

Recruitment

Due to the age group of the participants and the nature of the research, participant recruitment procedures required significant negotiations with the university's Research Ethics Board (REB). It took six months and three rounds of revisions to receive ethical approval for this study, which negatively impacted the contracting agency's timeline for receiving the deliverables. **mindyourmind.ca**'s project recruitment calls typically return dozens to hundreds of responses, as recruitment posters are designed by youth in youth-friendly language that they recognize and respond to. Details on the posters usually include any reimbursement they will receive since **mindyourmind.ca** recognizes that many youth have expenses to consider and feel valued when they are offered some type of compensation for their contribution. However, REB regulations do not allow for these recruitment approaches. Providing compensation details, such as "You will receive a \$10 iTunes card for your time," was viewed by the REB as too manipulative for recruiting young people. These REB requirements posed barriers during recruitment.

Upon eventual approval by the Research Ethics Board, an informational poster was distributed to approximately 3,000 contacts on the **mindyourmind.ca** e-mail list. Those who received the electronic copy of the recruitment poster were asked to circulate it, either by printing it and posting it or by electronically distributing it to their contacts. There was also a recruitment call posted on the **mindyourmind.ca** website's home page. Focus group recruits self-identified their interest by contacting **mindyourmind.ca** by phone or e-mail. Potential focus group participants were contacted by phone or e-mail after they made initial contact with **mindyourmind.ca** and expressed their interest in participating. Eleven youth and 12 parents or professionals made initial inquiries about the recruitment call, asking for details and expressing interest. For example, a public health nurse in eastern Canada expressed interest in the focus groups and shared the information with local youth. Focus group dates, times, and places were chosen to accommodate the locations and schedules of interested individuals.

Data collection

The only inclusion criteria were that the participant was 12 to 18 years old, lived in Canada, had appropriate parental consent, and could commit to participate in an in-person or teleconference focus group. Focus groups were conducted until saturation was reached—that is, the point at which no new themes emerged from the data (when participants' responses largely confirmed insights gained in prior focus groups). This point was reached after four focus groups. In qualitative research, it is standard practice to end data collection at this point (Morse 1995).

Three of the four focus groups were carried out in person and were audio-recorded, and one of the focus groups was carried out by teleconference. Two of the face-to-face focus groups were conducted in London, Ontario, and the other

Table 1: Age and gender of participants

	Female	Male	Total
12 to 14	4 (19.0%)	1 (4.8%)	5 (23.8%)
15 to 18	12 (57.1%)	4 (19.0%)	16 (76.2%)
Total	16 (76.1%)	5 (23.8%)	21 (100%)

Table 2: Geographical distribution of participants by region

	Western Canada	Ontario	Northern Canada	Quebec	Eastern Canada	Total
12 to 14	0 (0%)	5 (23.8%)	0 (0%)	0 (0%)	0 (0%)	5 (23.8%)
15 to 18	5 (23.8%)	3 (14.3%)	0 (0%)	0 (0%)	8 (38.1%)	16 (76.2%)
Total	5 (23.8%)	8 (38.1%)	0 (0%)	0 (0%)	8 (38.1%)	21 (100%)

one was conducted in Fredericton, New Brunswick. The teleconference focus group was conducted with youth living in Victoria, British Columbia. All four focus groups took place during the summer of 2011. Each group lasted from 60 to 90 minutes. All participants received a \$10 iTunes card for their participation. Through the sessions, all participants conveyed their thoughts and experiences about topics such as attitudes about mental health and stigma, seeking mental health information, and preferred modes of mental health information. Across the four focus groups, there was a total of 21 participants, including 5 male and 16 female participants (see Table 1). The team collected information about age, gender, and province of residence (see Table 2). Participants differed in other characteristics, including cultural background, but this information was not formally collected from the participants.

Audio recordings of the three in-person sessions were made using a digital recorder, and facilitators took notes at all sessions. The teleconference focus group was not recorded due to a technical problem, but both facilitators took detailed notes of the discussion, including key quotations from the participants. Important portions of the in-person focus groups were transcribed, but it was not possible to transcribe all of them due to time and budget concerns. The principal investigator, who was also the only one who attended all four focus groups, read the notes, listened to the recordings, and wrote reflective memos immediately following each session. She then revised the directives of each subsequent focus group accordingly; this is in keeping with the grounded-theory approach to qualitative research (Charmaz 1990; 1991).

Although the data collection sounds relatively straightforward, a host of issues surrounding the previously-mentioned REB considerations in this study impacted data collection. There was a great deal of compromise made between satisfying the university REB versus employing the youth engagement model designed by **mindyourmind.ca**. For example, opportunities for participants to root the focus group conversations into their real-world contexts, such as asking them

“What is your favourite web site, and why?” at the start of the session, were not considered relevant by the REB. At the same time, these are essential components to **mindyourmind.ca**’s youth engagement model as discussed above. In this instance, youth are not seen as objects, where research is happening to them, but as fully engaged participants and future knowledge users.

This raised the issue of how researchers interact with participants. Is it truly *unethical* to make participants feel comfortable and engaged in the research even if it means asking questions and having discussions that are not directly related to the research topic in order to develop a rapport with the participants? It became clear in this study that how researchers connect to participants has an important influence on data collection. The team came to question the typical ethical standards outlined by university REBs. The format privileges research performed in the hard sciences, and it impacts the effectiveness of the qualitative data-collection approaches used in research such as focus groups, one-on-one interviews, and usability studies.

Data analysis

As previously noted, this study used a grounded-theory approach. Specifically, the team used constructivist grounded theory, which assumes that “people create and maintain meaningful worlds through dialectical processes of conferring meaning on their realities and acting within them” (Charmaz 2000, 521). In a constructivist grounded-theory study, the categories form researchers’ interactions with the participants and the data. In other words, the reality that emerges from the research is “discovered” via meanings created by the researchers and participants as well as the participants’ stories (Charmaz 2000, 525). The principal investigator chose to use grounded theory to avoid encounters with preconceived notions that the team members might have had about the participants’ potential responses.

Using this lens, the principal investigator analysed the notes and recordings immediately following each session and wrote memos. This allowed her to determine the key issues that emerged as well as to refine the questions and discussion topics that the team presented to subsequent focus group sessions. She also debriefed with the members of the team that helped her facilitate the focus groups. In addition, research assistants who assisted with the partial transcriptions provided insight into the data. The data were coded for the participants’ thoughts, feelings, opinions, and experiences. The notes written throughout data collection, comparisons made between participants and groups, and the concepts created as a result of this work led to a smaller set of focused codes (Charmaz 2000).

Results (focused codes)

The codes that emerged from the analysis of the focus group discussions follow. In accordance with the use of grounded theory, these categories are not meant to be interpreted as ultimate answers but rather as ways of considering the general ideas that emerged from the focus groups (Charmaz 2000).

Social media: popular, problematic

The most popular websites were social media sites: YouTube, FMyLife (more popularly known as FML), and Facebook. A sizable amount of discussion was raised about Facebook use, such as status updates, activities such as "stalking people" and creating groups, and factors in their decisions about when to appear online or offline. The participants worried about being judged across many fronts and discussed the connections between social media, bullying, and stigma. For these interconnected reasons, they did not think that social media was a preferable venue for accessing mental health information.

In the focus group that took place in Fredericton, youth talked extensively about the widespread prevalence of bullying and cyber-bullying. In fact, all of the Fredericton focus group participants indicated that they had been either bullied in person or cyber-bullied. The Fredericton youth said that bullying was more physical in elementary school and middle school but that in high school bullying had become more emotional and frequently cyber-based. Participants in general did not think schools were doing a good job of addressing the widespread problem of bullying. For example, one youth explained that schools hold auditorium sessions telling students not to bully, but the underlying causes or results of bullying are not addressed, so the issue is not resolved.

Little agreement on online credibility

When asked how they determine whether an online source of information was credible, focus group participants provided a wide range of responses. Many did not know what qualities to look for when searching for information online and they emphasized how difficult it is to determine whether a site is credible, as illustrated in thoughts such as "(It's) really hard to decide if [a website is] credible," and "You can't consult with the website to know if it is legit or not."

Due to this uncertainty over credibility, not everyone trusted online health information but instead preferred authoritative figures such as doctors. Speaking about the unpredictable quality of online information, one participant stated, "I looked for 'bipolar' online and thought I was going to die in seven days. Wikipedia is not always correct because information is changed. I change facts on Wikipedia too." Another participant stated the following:

"Youth search for info, but wind up in sites that are bad for them, like pro-ana/mia [pro-eating disorder] or pro-s.i. [pro-self-injury] sites that claim to give support and valuable resources, but end up being a horrible influence on them. As the Internet is filled with valuable info, it is also filled with harmful info, and I think that it's worth noting that as well."

Other participants were more trusting and were satisfied with the information found on sites such as Yahoo! Answers.

Indicators of potentially credible online information that participants mentioned included a .org, .gov, or .ca domain suffix; the writing style; referrals from trusted adults; potential for interaction; easy navigation; pages with many visits; and pages in which the text is not too dense. As one participant stated, "I

look for .org as better information. I have a better sense if it is true; I can tell by the way it's written." Another participant simply stated: "I look for an author." Participants responded with surprise when the moderators discussed Google's manipulation of result lists and when depressionhurts.ca was revealed to be a pharmaceutical company's site. One participant exclaimed, "You would think it [depressionhurts.ca] was ok if it was advertised on TV!"

An overarching theme in this research was that of credibility through lived experience. People who have been through mental illness are considered to be reliable. Summarizing this sentiment, one participant stated, "It's hard to trust someone who hasn't had the experience." People with lived experience are also very good candidates for providing information online about mental illness. In the words of one participant, "They're the only ones who understand." Personal stories enhanced digital credibility and helped in assessing trustworthiness for the participants: "Someone who has been through it is important. You can't be helped by somebody who doesn't know what it's like. Someone who has been hurt inside knows what it's like." Another participants similarly responded, "I would like to hear from people who have been there. You need a variety of perspectives from different people – people who are my age, stars ..."

Personal stories are not necessarily factual but are the "truth" in the experience of a person and can be considered more relevant than evidence-based information (Eysenbach 2008). Young people in this project were willing to talk about issues related to mental health and, in some instances, shared their own lived experience.

Poor mental health literacy

There was misinformation about what constituted specific mental illnesses among focus group participants, especially with the younger youth (ages 12–14). Many were not familiar with the definitions of mental illness terms as they are clinically defined. Medical language did not describe or inform youth of what was happening to their peers or themselves. They thought of people with mental illness as those who are developmentally disabled or people who "others don't want to be around." The older participants were more familiar with mental health terms but did not use clinical terms such as "anxiety" to talk about mental health. The terms they used were in plain, lay language, such as "feeling like everyone is against you" or "someone who needs help." They attempted to differentiate between people who are going through difficult times ("troubled," "confused") and people who truly suffer from mental illness ("depressed," "nervous breakdown," "long-term"). Participants acknowledged that mental illness is much more difficult to discuss in society than other forms of illness. According to some, this may be true because "if you have a mental illness, people can't see it." This observation ties in with concerns surrounding mental illness stigma.

Mistrust and stigma

Participants were wary of going to certain authoritative people in many cases. With parents, it depended on the closeness of the relationship between the youth and parent. Teachers and counsellors were considered to be potential

contacts and positive sources of help in some cases, but only if they were willing "to really listen." General Practitioners received mixed reactions; in some cases, youth did not feel talking to doctors would be a comfortable situation. Some thought that General Practitioners were primarily interested in prescribing medication and then moving on to the next patient. There was a general concern that if people were not trustworthy, they would judge youth for their problems. One participant stated, "It can be difficult to share with people because you are afraid of being rejected when issues are shared." Strangers were somewhat concerning to participants, as they would rather talk to someone they knew. For this reason, despite the fact that many participants knew about a national youth helpline due to its extensive marketing, it was not a place they would contact because they felt talking to strangers about problems was "awkward." Participants widely recognized stigma as an issue, although they did not label it with this term. They agreed that people who have mental health problems are viewed as "weird" or "treated like they are nothing." They felt that schools could play a role in decreasing stigma surrounding mental illness by increasing awareness, but participants stated that they did not feel schools were doing an adequate job providing mental health education or addressing stigma.

Keep it simple

Participants said they were not likely to look for mental health information unless there was a motivating factor to do so, such as a friend in crisis, or a personal experience involving difficult feelings. When it came to the preferred formats of online mental health information, the participants stated that effective mental health-related websites would need to have digestible chunks of content in multiple formats, be safe (factual and ethical), be interesting, be concise, have short videos, display user ratings, offer quizzes, and be easy to search and navigate. It was also important to participants that online platforms are available at all times and can be anonymous. In terms of the critical characteristics for website credibility, participants stated that personal experiences of those with lived experience would increase trustworthiness of a resource, as would inclusion of a diverse range of culturally relevant youth content, all combined with recognizable experts. Participants thought these characteristics could decrease the isolation that youth with mental health concerns experience. They also suggested that campaigns and online resources should be easily recognizable through relevant branding co-created by youth. Obtaining information specific to local resources was also important.

A national mental health website unaffiliated with this study, while regarded around the country as an authoritative source of mental health information, was not a preferred resource for participants because the text on the site was too dense. Broadly speaking, participants did not want to read dense text to "get to the point." As one participant stated, "If it's not interesting online, I don't want to read about it." Participants viewed **mindyourmind.ca**'s technique of providing reliable mental health information very favourably, as it involves youth engagement and an interactive presentation of information.

When it came to serious online games that provided educational material, participants stated that they only found these sources acceptable in certain cases: “If I’m trying to find information for my friend, I don’t want to play a game.” Games that presented personal coping mechanisms, such as ways of handling stress, were acceptable and useful to some participants. Short, fun quizzes about mental health were discussed. One participant said, “They should be less than 10 questions. Otherwise, I would think, ‘I could be on Facebook by now.’” Some participants thought Facebook apps for mental health would be useful, but others would not want to interact with mental health apps on Facebook because their friends would then know about it. Videos were perhaps the most widely mentioned preferred modality of online mental health information, but this preference came with a few caveats. Online videos must be “interesting” (some perceived this as involving humour) and they must not be overly long. As one participant described it, they should be “about the length of a song.” Youth would also prefer to watch videos that feature celebrities talking about mental illness, as well as peers who have experienced it and found ways to handle it. Watching videos featuring psychologists or other authorities did not interest them. The youth focus groups in this study indicated that youth culture attracts youth and this becomes a potential way to refer peers to credible sources. A quote from one of the male focus group participants validates this approach:

“This band I like [Christofer Drew Ingle/Never Shout Never], they try to get people to open up about their problems. They are like you guys [mindyourmind.ca] that way. Try to get people to talk. Searching for bands can get you to mindyourmind.ca.”

Discussion

From this research it was evident that social media sites are popular websites, but there was some ambivalence among youth on how a mental health page would be received by “friends” on Facebook. [Thackeray and Hunter \(2010\)](#) show how social networking sites strengthen existing networks. Strengthening networks can yield strong advocacy networks when youth can manage the balance between privacy of personal details and a more public presence.

The focus group participants’ emphasis on hearing from those with lived experience of mental illness supports the conclusions made by [Hughes and Cohen \(2011\)](#), who conducted a study and comparison of discussions on effects of psychiatric medications on two professionally controlled commercial health websites and on two consumer-generated websites. They found that consumer reviews generated in the two non-professionally controlled health sites provided abundant concrete descriptions and situational examples; this suggests that online reviews and discussions from those with lived experience offer meaningful information to people with similar conditions.

This ties into the concept of affective authority, defined by [Neal and McKenzie \(2011\)](#) as “the extent to which users think the information is subjectively appropriate, empathetic, emotionally supportive, and/or aesthetically pleasing” (131). [Neal and McKenzie \(2011\)](#) analysed blogs written by women who have

the chronic gynecological illness known as endometriosis. They found that a user-centred approach to evaluating online health resources needs to take into account broader community standards, as affective authority can be a determining factor in how people seek health information. Traditional notions of credibility for online information do not take into account the role that affective authority may play in determining the credibility of a source. Yet clearly the participants in these focus groups indicated that hearing from others with lived experience was important to them and a credible source of information. The boundaries of what constitutes credible information online are quite blurry, and, as [Neal \(2010\)](#) explains, "what meets one person's needs for mainstream empirical research based on randomized controlled trials will not match another's desire for learning about complementary treatment options or peer-based discussion boards" (37).

Engaging Web users through design can be simple yet is often overlooked. Content or message credibility is essential. Focus group participants commented on simple ways to build trust in a website, such as displaying user-ratings, displaying number of visitors, ensuring easy navigation, and designing simple uncluttered pages with well-distributed, concise text. In these ways interactive Web-based media can be more engaging than traditional media for some youth ([Ryan-Nicholls et al. 2009](#); [Eysenbach 2008](#)). Poor web-design and navigation can have a negative impact, putting the website's credibility into question. It became clear through the group discussions that time was an important factor for participants when looking for information online. More content is not always better. Participants wanted to access the information they were looking for quickly and did not want to spend a lot of time looking through text-dense websites and reading medical jargon.

This confirms the findings of [Sillence et al. \(2007\)](#), who found that "[v]isual appeal, plus design issues relevant to site navigation appeared to exert a strong influence on people's first impressions of the site" (707–8). They followed up with an additional study (2007) on online health advice and again found that the number-one trust marker was that "the site was easy to use" (404). They concluded that if people are not able to "move beyond the poor design then the quality of the content becomes irrelevant" (404).

The majority of participants identified reducing stigma and discrimination (expressed as feeling alone or bullied) and improving mental health literacy (i.e., how to recognize mental health problems for what they are, how to stay safe, and how to get help for themselves or their friends) as areas to address. This shows that young people continue to be concerned about what others might think about them if they reach out for help in traditional ways.

Finally, this research reveals that youth are not clear on definitions of mental illness in general. To increase the mental health literacy of Canadian youth, using plain language to describe the variations of mental illness is critically important.

Limitations and future research

Technically speaking, grounded theory is constructed through sustained involvement with the participants by returning to them repeatedly to close holes in

developing theories. In this study, repeated engagement was not possible due to time, budget, and ethics constraints; however, as previously noted, refinements took place after each focus group.

Although the researchers were not concerned with obtaining a representative or statistically significant sample in this qualitative study, the participants' demographics are limited in scope. For example, only one group contained members from the younger (12 to 14 years) age group; it is difficult to recruit people in this age group due to ethics constraints as well as their limited understanding of mental health. Also, the contracting agency wanted focus groups from throughout Canada. Since Canada is a large country and difficult to define (Mackey 1999), it was difficult to determine how to represent the culturally and geographically diverse Canadian youth population. The team responded to this desire by conducting focus groups in three different provinces as well as various rural and urban settings, but these groups cannot be said to "represent Canada."

Future research could potentially address these limitations. Designing a longitudinal study including a broader sample of Canadian youth in terms of geographic location, age, and cultural background would address some of the focus group sample limitations. Additional future research could potentially seek youth input on the preliminary stages of design for a youth mental health Web resource, and document the periodical return to these youth focus groups for each stage of development through to the resource's full implementation. This research would be in line with user-centred design principles mentioned earlier.

Conclusions

Youth participation in the development of spaces for mental health knowledge transfer is important. Peer-to-peer approaches would likely be effective, as youth can naturally become advocates and guides for their peers. Youth benefit when they feel ownership of projects and have power to influence decision making. At the same time, adults' interactions have to demonstrate effective management of power roles, consistency, transparency, and intentionality (Messias et al. 2005). The result is psychological involvement and significant youth engagement. Young people who are engaged in an activity are occupied affectively, cognitively, and behaviourally. Engagement ensures sustained involvement in a project.

The ideas the youth participants came up with to address mental illness stigma included embedding mental health education into the school curriculum and placing information in schools (such as pamphlets or posters to raise awareness and knowledge). They also suggested a similar approach could be taken in places where youth spend free time: A kiosk in the mall or an advertisement in a movie theatre could supply mental health information. A coordinated nationwide campaign that is deployed in areas frequented by youth and designed to engage them could have significant impact on reducing stigma. The collective action of a larger group is generally more effective at bringing about change than the isolated actions of small groups (Thackeray and Hunter 2010); however, a recent study found pointed out that as few as four or five constituents can

impact a politician's position on an issue (March of Dimes 2001). It is easy to see how the coordination of many young voices on the topic of mental health literacy and stigma reduction aimed at Canadian youth could have a substantial impact.

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Appendix 1: Focus Group Discussion Guide

1. Attitudes and stigma

- How are people with mental health issues treated by their peers?
- How is mental illness perceived or described by others?
- What could be done to reduce the stigma of mental illness?

2. Seeking mental health information

- What circumstances or experiences would lead someone to seek mental health information?
- Would people seek help for themselves? For others?
- What kind of help would someone be looking for when they seek mental health information?

3. Preferred modes of mental health information

- When your peers (friends, schoolmates) are looking for health information, including mental health information, where do they go?
- What would be the best way to deliver mental health information?