



The Delphi Consensus Consultation Method: Using Community Engagement to Identify Effective Self- Management Strategies for Bipolar Disorder

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Abstract

This case describes a study undertaken in 2012 by the collaborative research team to study psychosocial issues in bipolar disorder (CREST.BD) at the University of British Columbia. Our team used a community-based participatory research approach combined with the Delphi Consensus Consultation Method to explore self-management strategies that people with bipolar disorder use to prevent progression in manic mood states and to maintain wellness in daily life. Our study engaged academics, healthcare practitioners, and individuals who live with bipolar disorder in every aspect of the research, from inception, through implementation to knowledge translation. Extensive literature reviews on self-management strategies in bipolar disorder were followed by extraction and organization of self-management strategies. Our panel of participants ($N = 101$ individuals with bipolar disorder and 52 healthcare providers) rated the strategies in an online survey in two rounds. There were high rates of agreement between people who live with bipolar disorder and healthcare providers in terms of the most effective self-management strategies. Several factors were identified for stopping progression into mania: Forward Planning, Early Intervention, and Decreasing Stimulation. Factors relating to effective strategies for maintaining a balanced mood state included the following: Calming Activities, Medical Management, Physical Activity, and Maintaining Hope. This case study also describes how we used integrated knowledge translation to communicate the result of our study to academics, people with bipolar disorder, healthcare practitioners, and the wider community.

Learning Outcomes

By the end of the case, students should be able to

- Understand the importance of including various forms of expertise (academic, healthcare provider, and lived experience) in academic research
 - Evaluate the potential merits of using the Delphi Consensus Consultation methods and community-based participatory research Methods in their own area of inquiry
 - Develop an awareness of the issues faced by individuals who live with bipolar disorder and how self-management strategies can assist them in achieving and maintaining wellness
 - Acknowledge the importance of integrated knowledge translation as a key component of research
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Project Overview and Context

This case study describes a project that was undertaken by the collaborative research team to study psychosocial issues in bipolar disorder (BD) (CREST.BD), based out of the University of

British Columbia (UBC) Department of Psychiatry between 2012 and 2014.

BD is a mood disorder that is characterized by extreme highs and lows in mood, which can range from severe depression to mania. The symptoms of a manic mood state include euphoria, elation, grandiosity, and intense irritability (Goodwin & Jamison, 2006). It is estimated that 3.9% of the population lives with some form of BD, and according to the World Health Organization, it is the sixth leading cause of disability among people of ages 18-44 years (Kessler et al., 2005; Murray & Lopez, 1997). People living with BD experience high rates of hospitalization, relapse, and risk of suicide (Gitlin, Swendsen, Heller, & Hammen, 1995; Nordentoft, Mortensen, & Pedersen, 2011). In addition, BD is commonly associated with poor functioning (e.g., in employment, education, and relationships) and quality of life (QoL) (Michalak, Yatham, Kolesar, & Lam, 2006). Historically, research on BD has primarily focused on the biological causes of the condition and pharmacological treatments to address and alleviate BD symptoms. In recent years, however, research has shifted focus to examine the psychological and social factors in BD that can impact functioning and improve outcomes (Miklowitz, 2008).

Established in 2007, CREST.BD is a multidisciplinary international network dedicated to advancing knowledge regarding psychosocial factors in BD, in order to improve the health and QoL of people living with the condition. CREST.BD prioritizes four areas of research and knowledge exchange: Self-Management Strategies (SMSs), Psychosocial Interventions, QoL, and Stigma. As a network, we specialize in CBPR, an approach that involves partnering with members of the community who live with a particular health condition. Working collaboratively, CBPR includes community members in each stage of the research process through development, implementation, and finally sharing the results as a catalyst for social change (National Institute of Environmental Health Sciences, 2010). CBPR approaches aim to adapt to the needs of community members and engage them as active participants, rather than objects of research (Evans, Hole, Berg, Hutchinson, & Sookraj, 2009).

We view the contributions of empirical studies, the personal experience of individuals who live with BD, and healthcare provider expertise as equally sound and valuable (Sackett, Straus, Richardson, Rosenberg, & Haynes, 2000). As a result, our network is comprised of academic researchers and peer researchers (people who live with BD) from diverse backgrounds in order to encourage inclusivity, partnerships, and collaboration, and to share expertise.

In 2012, we initiated a new study to further explore one of our primary research areas: SMSs. Using a combination of a CBPR approach and Delphi Consensus Consultation Methods, the study sought to better understand how people use SMSs to manage psychiatric symptoms and

live well with BD.

Specifically, SMSs are the personal strategies that an individual uses to help improve their health and the quality of their daily life (Michalak et al., 2016). The strategies that people use to achieve this goal may be developed through trial and error by the individual or can be suggested by family and friends and mental health practitioners. Examples of common SMSs used by people with BD include eating a healthy diet, staying physically active, keeping a strict sleep routine, engaging in stress-reduction techniques such as meditation or yoga, and monitoring changes in mood or symptoms (Suto, Murray, Hale, Amari, & Michalak, 2010).

CREST.BD's first exploration of SMS was initiated in 2007, as part of our "Wellness Study." We conducted in-depth interviews and three focus groups with a total of 32 participants who lived successfully with the condition and asked them about what they felt contributed to their wellness. Their answers were categorized into six areas: (1) sleep, diet, and exercise; (2) monitoring and responding to early warning signs of the illness; (3) reflective, meditative, and spiritual practices; (4) understanding BD and educating others about the illness; (5) social support; and (6) having an action plan in case of recurrent illness.

The results were published in academic journals (Murray et al., 2011; Suto et al., 2010) and formed the basis of our resource-rich website <http://www.bdwellness.com>

The qualitative methods we used in the Wellness Study were appropriate to our aim of discovery and new insights; however, findings from a sample of 32 individuals cannot be generalized to a larger population. This awareness provided the impetus to initiate a larger study, in order to achieve a diverse, more generalizable understanding of effective strategies for managing BD, which tapped into the scientific, clinical, and personal expertise of our participants.

We chose the Delphi Consensus Consultation Method to expand our understanding of SMSs in BD, because it is a method used in health research to effectively answer practical research questions that require further exploration or where there are marked gaps in current knowledge (Michalak et al., 2016). The Delphi Consensus Consultation Method refers back to the Oracle of Delphi in Greece, an ancient site where people sought the wise counsel of a Priestess who was thought to commune directly with the Gods. In the modern world of scientific research, the Delphi Method is a way to consult widely with many individuals who have expertise in given area, resulting in a robust and valid form of "wise counsel." Delphi methods are characterized by a few main concepts including a focus on researching little understood topics, drawing on the opinion of experts and an interactive group process to elicit the opinion of the experts.

Typically, this is accomplished by surveying panels of experts over email or via web survey in a series of rounds. The final goal is the development of consensus between the experts. The responses of the panels of experts are statistically analyzed in a way that areas of agreement are highlighted (Amos & Pearse, 2008). Conclusions can then be drawn about the research question.

The Delphi Consensus Consultation Method was a good fit for CREST.BD's program of research because it allowed us to include the expertise of people who live with BD and front-line healthcare providers. In traditional research, academic expertise is often considered the gold standard. However, foundational to the CREST.BD philosophy is the idea that the knowledge of people who live with BD and the knowledge of those who support people with the condition (e.g., family members and healthcare providers) is highly valid and essential to our research.

Method in Action

Our aim was to identify effective SMSs that people use to manage their BD. Specifically, we wanted to discover more about how people (1) stopped hypomanic or manic mood states from becoming worse and (2) maintained their stability when already well.

First, we convened an exciting team to work on the project which included two peer researchers (people who live with BD), four academic researchers, a research coordinator, a knowledge translation specialist, and several student volunteers. Among us, we had a highly complementary skill set and a broad perspective that resulted in a rich learning environment in which to carry out our research.

The Delphi Method is a complex and labor-intensive research method. To guide us, we followed the steps of Morgan and Jorm's 2009 Delphi study on SMSs for mild depression and a Delphi study on supporting caregivers of those with BD (Berk, Jorm, Kelly, Dodd, & Berk, 2011). To help us map out all the tasks we had to accomplish in our multi-year study, we divided the project into four phases.

In Phase 1, we focused on the goal of generating a large list of potentially effective SMSs for BD from diverse sources. We accomplished this by doing two simultaneous literature reviews: one of peer-reviewed articles in academic journals and the other a "gray literature" search. Gray literature refers to sources of information that are not traditionally academic. It includes, but is not limited to, government and agency reports, website, blogs, chat forums, podcasts, videos, and books. For both literature reviews, we used a combination of terms related to self-management (e.g., symptom management, relapse prevention) and terms related to BD (e.g.,

mania, hypomania). In the academic literature search, we accessed the MEDLINE, PsychINFO, EMBASE, and PubMed databases. For the gray literature search, we used the Google search engine and accessed the first 25 links that appeared for each combination of search terms.

Once we had accumulated hundreds of academic papers and gray literature sources, we began a grueling process of reviewing each one and extracting individual SMSs from them. Concurrently, we reviewed the transcripts of the 32 interviews from our original 2007 Wellness Study, and similarly extracted each unique SMS from the data set. This extraction task was largely completed by the peer researchers and student volunteers, who put all of the SMSs into an enormous Excel spreadsheet. It was a fun job combing through blogs, chat forums, and articles and looking for SMSs in the text. By the time all the sources were analyzed, we had over 4000 individual SMSs!

In Phase 2, we came together as a team for a series of meetings. The purpose was to organize and categorize the SMSs into a manageable number. First, many of the 4000 SMSs were the same or similar, and we had to remove the duplicates we identified. For example, common SMSs like “use communication skills,” “limit alcohol and street drugs,” and “keep regular daily routines” appeared many times in our data. Once the duplicates were removed, we integrated the remainder into a master spreadsheet. We met almost weekly for 10 months (you’re getting a sense of the woman- or man-hours this project took now!), as we worked collaboratively to categorize them further. Some of the categories that emerged were sleep, diet, reflective and meditative practices (e.g., tai chi), mood monitoring, connecting with others, and cognitive strategies (e.g., positive self-talk, reframing). This helped us to organize the SMSs into manageable chunks, identify any remaining duplicate SMSs, and it also gave us a preliminary idea of the themes we could expect to see at the end of the study. Once all the strategies were organized, we worked as a team to decide on the wording. When we extracted the SMSs from the sources we found in our literature search, we kept the original wording, in order to be true to the source. However, some of them were not clear and concise or included more than one main idea, such as the following strategy, “talk about stressful events with a friend or therapist, by expressing them in artwork, by singing or dancing, or writing in a journal.” So, we combed carefully through each SMS and made sure each one was worded simply and consistently in preparation for presenting the SMSs to our panel of Delphi experts to rate. After many hours of discussion, our original 4000 strategies had been nicely honed to 493 unique statements, all of which represented potentially effective SMSs for BD.

Perhaps, the most challenging part of Phase 2 was keeping track of the number of SMSs we accumulated, discarded, and re-organized for the next step of the categorization process, while at the same time, maintaining each iteration of the search results, in order to track the origin of

each strategy. Confused? We certainly were! However, we were certainly thorough and housed multiple versions of various spreadsheets in the helpful file management tool Basecamp, which also allowed us to communicate with each other and keep track of things.

After the exhausting and cumbersome work of Phase 2, we were very excited to begin Phase 3, which involved building a web survey and recruiting participants.

It was our intention to recruit two panels of participants. One, to be comprised of healthcare providers and the other of people with lived experience of BD. We reached out to potential participants through a mail-out to approximately 500 people, through our CREST.BD newsletter, and to our network of contacts in the bipolar community. We also used our Facebook and Twitter social media sites for wider reach. We kept busy writing blogs on our website (<http://www.crestbd.ca/2013/06/04/introducing-the-delphi-consultation-method-a-study-redefining-what-it-means-to-be-a-bipolar-expert/>) , h o s t e d w e b i n a r s (https://www.youtube.com/watch?v=8P6M_u0oyJo), and the team filmed a video to recruit participants (<https://www.youtube.com/watch?v=nbnaDZvi14M>).

Central to the Delphi method is the use of an interactive group process to elicit expert opinion. Prior to the Internet age, Delphi studies used mail-out paper surveys or sometimes faxes! Thankfully, we have modern tools available to us; a web survey was a perfect way to make the study questionnaire accessible to our participants. We used the SurveyMonkey software to build a web survey that would house 493 SMSs in a user-friendly format. Participants were asked to rate the helpfulness of these strategies twice based on their own experience as a person living with BD or as a healthcare provider in their practice. The first time, we wanted them to rate the SMS based on the ability of the strategy to *stop progression into a hypomanic or manic mood state* and the second time to establish the helpfulness of the strategy in *maintaining a balanced mood*.

As we are an international research team with members in several countries, and the study was web-based, we targeted our recruitment efforts in Canada, the United States, Australia, and the United Kingdom. In the end, we successfully recruited 153 individuals: 101 were individuals with a diagnosis of BD and 52 were healthcare providers who had clinical experience in the treatment of BD.

Prior to opening up the survey to participants, team members had to complete the web survey themselves in order to test the system and identify any glitches. Finally, after over a year and a half of intensive work, we were ready to go! The web survey was launched in November 2013 and Round 1 was closed in February 2014.

The Delphi method stipulates that participants complete a series of two or more rounds, in order to statistically streamline the results and move the expert panel toward consensus. After we completed an initial analysis of the results from Round 1, strategies not meeting a threshold of consensus were eliminated. For Round 2, a streamlined version of the web survey was circulated in April 2014, with only the top 155 strategies included. Participants who completed both rounds of the survey were eligible to win a prize back of books on the topic of BD worth US\$500.

Results

Once the web survey was closed, we initiated Phase 4 and had our team members who are expert statisticians to analyze the results. Our primary paper on the study (Michalak et al., 2016) discusses the statistical analysis of the results in detail. In general terms, both panels of participants had high rates of agreement on which were the most helpful SMSs. In Delphi terms, this is called a “concordance” rate and supports the validity of the results. The statisticians grouped the highest rated SMSs into factors, that is, clusters of SMSs that were mathematically and thematically related. In terms of stopping progression into mania, the main themes related to Forward Planning (e.g., prioritizing important tasks, saying no, and setting boundaries socially); Early Intervention (knowing warning signs of an impending bipolar episode, seeking medical attention if needed); and Decreasing Stimulation (avoiding stimulating substances and activities, such as gambling or excessive Internet use, or stimulating social interactions). In terms of maintaining a balanced mood state, the SMSs that participants rated most highly were grouped into four factors or themes: Calming Activities (having a hot bath, engaging in relaxation or meditation exercises); Medical Management (getting an accurate diagnosis, keeping prescriptions on hand, attending regular appointments with a healthcare provider); and Physical Activity (having an active lifestyle, doing exercises you enjoy). One of our newest and most interesting findings that emerged was the theme of Maintaining Hope. Strategies such as believing in oneself, accepting emotions, and cultivating positive experiences were rated highly by our participants. One of our team members, Dr. Greg Murray referred to these SMS strategies as “hope-reinforcing behaviours.” After all of our hard work, it was very gratifying to see meaningful, reliable, results emerging from the huge amount of data we initially collected.

Knowledge Translation

Knowledge translation initiatives are important because the findings of research do not always get implemented or communicated beyond an academic setting. Knowledge translation refers to making the results of research accessible and understandable to the broader public. The

goal of knowledge translation is to synthesize, share, exchange, and apply research in ways that positively affects policy, the healthcare system, and the individual health of community members (Canadian Institutes of Health Research, 2015). Knowledge translation is built into all CREST.BD research projects, as we consider communicating the results of our research a critical part of the process. The results of the Delphi Consensus Consultation Study have been communicated to the broader community via our Bipolar Wellness Centre website www.bdwellness.com, which houses a robust collection of evidence-based information and SMSs that people with BD, their loved ones, and healthcare providers can access. We are engaged in an ongoing process of developing further blogs, videos, and written work based on the results of our Delphi study geared to a general audience. The academic community is typically engaged through published articles in peer-reviewed journals and conference presentations. As of this writing, we have two articles in submission to academic journals and a presentation planned at the International Society of Bipolar Disorders Conference in July 2016.

Summary

In our study, we used the Delphi Consensus Consultation Method combined with a CBPR approach to discover more about the SMSs that are effective for preventing manic mood states and maintaining a balanced mood state. The Delphi method was a perfect fit, as it is designed to elicit information on topics about which little is known. Our unique study integrated CBPR by engaging academics, clinicians, and people who live with BD each step of the way, from inception, data collection and analysis, through to knowledge translation. This was accomplished by putting together a diverse team of peer and academic researchers. We leveraged our community networks through our website and social media pages and used these same channels to disseminate our research as part of our knowledge translation initiatives. Despite challenges in managing an enormous data set and recruiting and retaining participants (see Suto et al., 2016), it was an enriched learning experience for everyone involved and we feel it makes an important contribution to the health and wellness of people who live with BD. Our research highlights the reality that individuals with BD use a diverse array of strategies to effectively manage their condition. Our findings validated previous knowledge about effective SMSs in bipolar disorder, such as the importance of physical activity and early intervention. We also uncovered new and unexplored ideas that may result in productive and exciting new programs of research for our CREST.BD team. Of particular interest is the idea that people engage in “hope-reinforcing behaviors.” Our participants identified specific strategies that help them maintain hope in the face of a condition that is often painful and highly stigmatized. The results of our study can inform clinical practice and allow healthcare providers to better support clients to engage in SMSs that will assist in maintaining balance and

prevent manic mood states. Through our website at www.bdwellness.com, individuals living with BD and their supporters can easily access a myriad of effective SMSs that have been validated by our panel of experts, and we hope the work our team has accomplished will contribute to a better QoL for those who live with BD.

Exercises and Discussion Questions

1. What are some areas of inquiry that might be particularly well-suited to the Delphi Consensus Consultation Method and community-based participatory research methods?
2. What are self-management strategies? How might this concept apply to help other communities of people who struggle with physical or mental health challenges?
3. We used both academic and gray literature in our study. What is gray literature and how does it differ from academic literature? Why might it be important to explore for research purposes?
4. Define knowledge translation. What means did we use to translate the knowledge we gained from our research to the academic and the bipolar community? What are some additional means of translating knowledge to a wider audience?
5. Consider writing a blog about your research. What makes a good blog? How do you convey scientific concepts in a way that is understandable and interesting to the average reader?

Further Reading

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Web Resources

CREST.BD website: www.crestbd.ca – the network’s main academic website

CREST.BD Bipolar Wellness Centre: www.bdwellness.com – an online resource center for people with BD and their healthcare providers

CREST.BD Quality of Life Tool: www.bdqol.com – an online QoL measurement tool for people with BD

CREST.BD blogs on the Delphi Study: <http://www.crestbd.ca/2013/06/04/introducing-the-delphi-consultation-method-a-study-redefining-what-it-means-to-be-a-bipolar-expert/>

Author and CREST.BD Team Member Sara Lapsley talks about Peer Research: <https://www.youtube.com/watch?v=WgjaTT5hgug>

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