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Title: Expanding the Target Audience for Management Guidelines: Co-Development of the Patient and Family Guide to the CANMAT and ISBD Bipolar Disorder Guidelines

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Key Message: Patient and family educational tools can encourage collaborative decision making and potentially enhance the delivery of, and adherence to, evidence-based recommendations. The Patient and Family Guide to the 2018 CANMAT and ISBD bipolar guidelines used a co-development model to ensure the highest levels of relevance and accessibility for knowledge users.

Discussion: The Canadian Network for Mood and Anxiety Treatments (CANMAT) and the International Society for Bipolar Disorders (ISBD) have continued their longstanding collaboration in developing new guidelines for the management of patients with bipolar disorder (BD) (1). These highly-cited guidelines have been published and translated into several languages, and are a key resource to clinicians, educators, and academics around the world. The guideline also serves as the backbone to a free point-of-care app designed for use by clinicians at the bedside to enhance the delivery of evidence-based care (2). While these traditional and novel methods of knowledge translation helped disseminate the CANMAT / ISBD guidelines, and have corollaries in efforts undertaken by BD guideline projects from other esteemed organizations and groups, it appears to us that one key group has been mostly left out, namely patients and families.

The CANMAT / ISBD bipolar guidelines manuscript is a 74-page publication that is written using academic language to effectively communicate the scientific rigour and methodological processes undertaken by the guidelines committee to arrive at the numerous recommendations. While well suited for an academic and clinical readership, this type of document is likely to be inaccessible and not easily digestible to patients or family members and supporters who are trying to learn and understand what constitutes evidence-based treatment for bipolar disorder.

Hence, the Patient and Family Guide to the CANMAT and ISBD Guidelines on the Management of Bipolar Disorder (3) was developed in collaboration with members from patient and advocacy groups, who helped tailor the information to the needs of consumers. This was accomplished by selecting and explaining the key messages and recommendations from the guidelines that were most relevant to experts by experience and their supporters.

Several principles were established for developing the Patient and Family Guide:

- A. Co-development methodology would be utilized at all phases. Representatives of CANMAT and ISBD worked alongside representatives of several professional and advocacy groups, including i) the Patient and Family Advisory Council of the Department of Psychiatry, Sunnybrook Health Sciences Centre, University of Toronto; ii) Hope + Me, the Mood Disorders Association of Ontario, Toronto, Canada; and iii) the International Bipolar Foundation, San Diego, United States.
- B. All content for the Patient and Family Guide would be derived from the 2018 overall guidelines publication. In order to ensure fidelity to the original precision and integrity of the guidelines, no additional information was added from outside of the guidelines.
- C. The Patient and Family Guide would not attempt to include all information contained in the guidelines, but content would be selected based on perceived value in enhancing the readers' understanding and appreciation of both the broad strokes and nuances of evidence-based mental health care for BD.
- D. The Patient and Family Guide would be formatted in an inviting manner, and use non-technical language that facilitates understanding for as large an audience as possible.

The specific co-development methodology used to produce the Patient and Family Guide was informed by the CHOICE-D document that emerged from the CANMAT MDD guidelines (4,5), and included the following steps:

1. A worksheet-like template was developed for each collaborating group / organization to facilitate the first stage of review of the overall BD guidelines. The template included a 5-point Likert rating of the importance of a particular section of the guidelines for the Patient and Family Guide, a section for comments and suggestions related to specific content from the guidelines, and then recommendations on the content that should or should not be included in the Patient and Family Guide.
2. One template was provided for each of the 8 sections of the BD guidelines, namely, Introduction, Foundations of Management, Acute Management of Bipolar Mania, Acute Management of Bipolar Depression, Maintenance Therapy for Bipolar Disorder, Bipolar II Disorder, Specific Populations, and Safety and Monitoring
3. Each participating group / organization received the template and instructions, and identified member representatives to complete the templates and solicit internal feedback.

4. Written and verbal communication with the study PI was used in order to address any queries.
5. Completed templates were then submitted by the participating groups / organizations
6. A Media Communications company (MDH Consulting Inc.) assisted in the collating and formatting of the first reviews into a working draft of the Patient and Family Guide
7. An iterative process of several rounds of edits and feedback with representatives of all participating groups / organizations were completed – focusing on content, language, and formatting.
8. Final formatting was completed and the Patient and Family Guide was finalized.

Following completion of the Guide, several dissemination efforts were launched. CANMAT, ISBD, IBPF and each participating organization published the Guide on their websites with full and free access. The Guide was professionally translated into French, and efforts are underway on additional translations. Participating organizations broadcast the Guide on social media platforms, and a short summary video was created and uploaded. Next steps may include evaluation of the potential impacts of such Patient and Family Guides on subjective and objective measures of patient care.

The overall goal for developing the Patient and Family Guide was to promote opportunities for enhanced collaborative decision making between patients, their families, and the clinicians involved in the delivery of care (Figure 1). Having all parties equipped with accessible information about evidence-based care for BD encourages a collaborative open dialogue and shared decision making. These are cornerstones to improving quality of care and both patient satisfaction and adherence. In the future, we would recommend similar Patient and Family Guides be co-developed as part of the Knowledge Translation and Exchange Plans for all Clinical Practice Guidelines.

Learning Points:

1. The clinical recommendations produced by clinical practice guidelines should be made readily accessible to patients, family members, and supporters who are eager to learn about best care practices
2. Patient and Family Guides may be an effective way for clinicians, educators, patients and their supporters to “all speak the same language” when discussing management for BD
3. Using a co-development model throughout the process can enhance the quality of Patient and Family Guides, making them more approachable, usable and relevant

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Figure 1: Model for Enhanced Knowledge Translation to Promote Evidence-Based Care

