Workshop Report

Incorporating consumer experiences into the planning and evaluation of collaborative care of depression in Canada

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St. Mary’s Research Centre
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WORKSHOP REPORT

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WORKSHOP REPORT

ABSTRACT

Collaborative care for depression describes a range of approaches in which consumers, their families and caregivers, together with health care providers from primary care and specialty mental health services, work together towards a goal of more coordinated and effective services for individuals with depression. These approaches are beginning to be implemented in primary care settings across Canada.

Although high-quality evidence from clinical trials demonstrates that the outcomes of depression in primary care can be improved by collaborative care, little research has focused on the extent to which these interventions are consumer-centered.

The objectives of this workshop were:
1. To review known efforts to incorporate consumers’ perspectives, preferences, and experience into the planning and evaluation of collaborative care of depression in family practice settings across Canada, and to learn from successes and failures;
2. To create an evaluation framework to guide evaluative research on collaborative care of depression that incorporates the measurement of consumer experiences;
3. To begin to develop a research agenda that will facilitate future research and evaluation efforts on consumer-centered collaborative care of depression in primary care.

The workshop brought together 41 consumer, providers, health care planners and researchers from across Canada.

The workshop identified 8 important attributes of collaborative care programs for depression that affect consumer experiences: respect; involvement of consumers as partners; information and communication; responsiveness to changing needs; whole person care; comprehensiveness; accessibility; and system coordination. Examples of each attribute contributed by workshop participants provide the basis for future improvements and for development of appropriate measures.

The revised evaluation framework that resulted from the workshop may help to inform research and evaluation of collaborative care initiatives.

The results of this workshop set the stage for future research efforts in the following areas:
- Development of operational measures of the 8 most important domains of consumer experience;
- Use of these measures to evaluate collaborative care programs for depression across Canada.
INTRODUCTION

Objectives

1. To review known efforts to incorporate consumers’ perspectives, preferences, and experience into the planning and evaluation of collaborative care of depression in family practice settings across Canada, and to learn from successes and failures;

2. To create an evaluation framework to guide evaluative research on collaborative care of depression that incorporates the measurement of consumer experiences;

3. To begin to develop a research agenda that will facilitate future research and evaluation efforts on consumer-centered collaborative care of depression in primary care.

Background

Collaborative care for depression is defined in various ways. For purposes of this document and the workshop, we proposed the following definition, adapted from one proposed by the Canadian Collaborative Mental Health Initiative:  

Collaborative care for depression describes a range of approaches in which consumers, their families and caregivers, together with health care providers from primary care and specialty mental health services, work together towards a goal of more coordinated, timely and effective services for individuals with depression.

High-quality evidence from clinical trials demonstrates that the outcomes of depression in primary care can be improved by collaboration between the family physician and other health professionals. Two elements of collaborative care for depression, in particular, are related to better consumer outcomes: 1) a “case management” - allied health professionals who support family physicians (FPs), for example, by helping to educate consumers about depression, and providing consumer follow-up and feedback to FPs, and 2) consultation by a psychiatrist who provides back-up and case-load supervision to the case manager, and may also provide clinical advice and decision support to FPs, focusing on consumers in whom depression is not improving as expected.

Despite this evidence, most depressed patients continue to be managed by family physicians without input from psychiatrists or other mental health providers, and while collaborative care models for depression are beginning to be implemented in some settings in Canada, little research is focused on the extent to which these interventions are consumer-centered. Measures of consumer experiences of collaborative care remain poorly-defined and unstandardized, impeding efforts to compare different initiatives. Many initiatives have assessed consumer satisfaction, but most of these studies do not tease out the specific strengths and weaknesses in sufficient detail to inform specific quality improvement efforts.

There is strong incentive to obtain input from patients and their families into the implementation of collaborative care initiatives for depression, as this can help to increase the acceptability and ultimate effectiveness of these interventions. Future efforts to assess and compare the strengths and weaknesses of Canadian collaborative care initiatives from the consumer perspective require a
common evaluation framework and a common set of measures. The aim of this workshop was to provide an opportunity for Canadian researchers, decision-makers, and health care users and providers to jointly develop such a framework and a research agenda.

THE INITIAL FRAMEWORK

1. Literature review
We conducted a preliminary systematic review of published studies of consumer experiences of collaborative care for depression in primary care to inform the framework we would propose to workshop participants. A total of 43 studies were identified in the initial search. Of these, 31 (72%) studies reported only a general measure of patient experiences, such as general satisfaction. Most of the studies in this preliminary review assessed general consumer satisfaction rather than specific aspects of these experiences. This limits their usefulness to identify program components that could be improved. Further, there was little to no standardization across studies in the measures of consumer experiences. Finally, none of the studies were conducted in Canada.

2. Proposed framework
The evaluation framework presented at the workshop comprised 3 components that contributed to consumer experiences:
- Collaborative care approach (e.g., types of staff, their roles, how they communicate with each other and with patient/family, types of treatment offered)
- Care setting (e.g., solo family doctor versus multidisciplinary group, rural versus urban setting, province)
- Population receiving care (e.g., seniors, immigrants)

THE WORKSHOP

1. Planning
The planning of the workshop was carried out by a team of researchers, clinicians, decision-makers, and consumer representatives from across Canada. See Appendix 1 for a list of planning committee members.

In August 2010, the group held a first teleconference to brainstorm the development of a Canadian research agenda on the management of depression in primary care and to explore innovations and change in policy and practice across the country. The team agreed to submit a proposal for a CIHR Meetings, Planning and Disseminations (MPD) grant to conduct a special session at the June 2011 Canadian Conference on Collaborative Mental Health Care (in Halifax) as a pan-Canadian round-up on this topic.
Discussions over weeks leading up to the application for funding allowed the group to refine the research agenda and moved focus towards measuring the consumer experiences of collaborative depression care.

Funding was received in late January 2011. While content of the workshop, and final speakers were being finalized, the team collectively built a list of relevant individuals to invite - sending invitations out progressively to ensure the 40 spots available for the workshop were filled without overbooking. The final list of participants is in Appendix 4.

2. Presentations

Following a review of conference objectives and an overview of proceedings, the workshop was given a broad range of perspectives through a number of formal presentations.

- Debbie X (last name withheld to protect identities of her children and ex-spouse), a mother of 3 children, living and working in Dartmouth, NS shared with participants her perspective on different models of mental health care delivery, having for many years cared for her ex-husband battling schizophrenia and daughter with depression. She spoke about being a strong advocate for the benefits of collaborative care, having witnessed firsthand the benefits of shared care after struggling through what she describes as disappointing and painful experiences in the healthcare system. The moving presentation encouraged further informal presentations from other participants with their own lived experiences who spoke about factors that contribute to a positive or negative experience with mental health care.

Discussion of individual experiences was followed by formal presentations from 2 national organizations.

- Gillian Mulvale spoke about patient-centered collaborative care of depression from the perspective of the Canadian Health Services Research Foundation, highlighting the importance of comprehensive primary health care, a shift from institutional to community settings and opportunity for greater patient involvement in decision-making.
- Joan Edwards Karmazyn from the National Network for Mental Health emphasized the importance of the recovery model, speaking about the model as a driving force for her work throughout her professional career in the mental health field.

The preliminary evaluation framework proposed by organizing researchers was presented briefly before participants heard reactions and perspectives on the framework from a panel of regional speakers.

- Dan Bilsker spoke about an initiative in British Columbia to measure consumer experience to inform collaborative mental health care and concluded that patient experience can critically inform collaborative mental health care but that we are only just learning how to utilize this source of knowledge.
- Nick Kates spoke about initiatives to involve consumers in evaluation of collaborative care for depression in Ontario, highlighting the challenge in always trying to learn from the experience of people using health services.
- Michel Gervais reviewed efforts in Quebec to develop collaborative care of depression, and insisted that the inherent complexity of collaborative work means that we must constantly remain open to emerging strategy throughout planning processes.
• Sabina Abidi described shared care in the context of the IWK Collaborative Mental Health Care Program in Nova Scotia, stating that collaborative care requires a shift in attitude and that mental health services must function as patients do: not in isolation but as members of family and community.

3. Feedback from participants

Workshop participants provided feedback in several ways: in the interactive session; in questions and comments on invited presentations; and in the “bottom line” comment sheet.

The interactive session allowed participants to work in groups to answer questions developed by the organizing committee. This allowed discussion about some of the more important aspects of collaborative care for depression in terms of the consumer perspective and to think further about the framework presented. Each group reported back to all participants in a plenary session, leading to a diverse and spirited plenary discussion during which 15 individuals took the microphone.

At the end of discussions, participants were given 10 minutes to complete a reflection sheet, allowing them to make note of the bottomline lessons drawn from the afternoon's proceedings. 18 participants completed these forms.

21 participants completed brief evaluations sheets at the end of the event. 90% agreed that the workshop content and format were designed appropriately to meet the objectives; 85% agreed that the day’s proceedings met expectations; 85% felt they were able to participate and give input as needed; and 95% were satisfied with the organization of this event.

THE REVISED EVALUATION FRAMEWORK

All feedback obtained was organized under the following 3 headings: A) domains of consumer experience; B) methods to elicit consumer experiences; and C) the framework for future research and evaluation.

1. A - Domains of consumer experience

In organizing the comments of workshop participants within domains of consumer experience, we were guided by themes identified in a Canadian consensus document on attributes of primary care, and a Canadian consensus conference that included consumer input on quality indicators for primary mental health care. We identified 8 primary domains (see below). The domains with a greater number of comments are listed first, but specific comments are not ordered by frequency of expression. Note that we have transcribed comments provided on what participants have experienced as well as what they want to experience.

1) Respect: (providers demonstrate respect for dignity of consumers and provide adequate privacy)

• Consumers’ values and experiences are incorporated into treatment planning.
• Consumers trust providers to support them.
• Providers give hope for recovery.
• Providers consider costs to consumers when making treatment recommendations.
• Consumer capacity for self-management is evaluated.
• Trusting, respectful relationship
• Consumers feel they are not alone.
• Consumers and their family members are listened to and taken seriously.
• Expectations and limits of confidentiality are explained to consumers and their family members.
• There is agreement on what information can be shared with others.

2) Involvement of consumers as partners: (Consumers and their family members are active partners in collaborative interventions, both when receiving care and in the design and evaluation of programs and services).
• Treatment options are discussed with consumers and their families
• Consumers and their family members are involved as partners and active participants in the care team.
• Not all consumers will be willing or able to participate in same way (e.g., stage and severity of illness may affect participation).
• Eliminate power imbalance and hierarchal management of health between consumers and providers
• There is openness to questioning and adapting treatment approach based on consumer and family preferences.
• Feedback on approach sought on a regular basis to ensure directions taken match consumer preferences.
• Cultural shift amongst provider group is necessary in order to normalize consumers having input into their care.
• Consumer feedback about their providers (including trainees) and quality of care.

3) Information and communication: (Providers elicit and understand consumer concerns, explain health care issues).
• There is sufficient time and lack of barriers for consumers and their family members to ask questions.
• There are opportunities for personal communication, not just pamphlets.
• Tools are needed to improve patient-provider engagement, e.g., to help consumers organize themselves before and after an appointment.
• Providers pace how they provide information to match the needs and interests of consumers/family members and demonstrate openness to questions, concerns, and need for clarification.

4) Responsiveness to changing needs: (Care is adjusted as patient needs change)
• Patients are followed and their depression is monitored over time.
• Patients are referred for collaborative care when their clinical situation warrants it.
• Treatment options are considered if their condition changes.
• There is ongoing support with feedback loops.
• There is increased communication during care transitions.

5) Whole person care: (Providers elicit and consider the physical, emotional, social, ethical, and spiritual aspects of a patient’s health)
• Providers integrate physical and mental health care (holistic care).
• Physical issues discussed in holistic way (as they relate to mental health issues).
• Patients are asked a broad range of questions (on history, contextual factors, social determinants of health, attitudes to health and illness).
• Religious values and cultural background are taken into account by providers.

6) **Comprehensiveness: (A full range of services is available to meet patient needs)**
   • Includes prevention and promotion of sense of wellness.
   • Peer support is available to consumers and their family members.
   • Self-management materials (e.g., books, manuals, audiovisual materials) are provided.

7) **Accessibility: (Consumers are able to contact providers and reach health care services).**
   • Treatment and support can be accessed by consumers in a timely way.
   • On-site psychiatrist increases access.
   • Services should be located close to consumers.

8) **Coordination: (There are plans to use resources efficiently, guide people to programs they need).**
   • Providers are knowledgeable about community resources and “other parts of system”.
   • Consumers and their families have the knowledge and tools to navigate the healthcare system.
   • Peer support is available to help with navigation.

2. **B - Methods to assess consumer experience**

Overall, there was strong endorsement for incorporating the input of consumers/ families as equals for research to be more meaningful. While participants recognized the complexity of this research, there was strong support for conducting it. Participants provided guidance on how programs and researchers can gather information on consumer experiences, perceptions, and preferences. The most important element is a trusting relationship in which consumers can be comfortable. Individual exploratory conversations and focus groups are both important approaches.

Several innovative approaches were presented:
   • Discrete choice analysis: a person is asked to choose between a number of variables that are grouped in different combinations to determine their preferences and specific factors that might affect their choices (i.e a physician would ask a patient whether they would prefer to receive coaching on depression self-care for a 3-month period, or start on an antidepressant medication).
   • Shadowing (consumers are shadowed by an observer).
   • Consumer images obtained by giving them cameras.
   • Bring together representatives of different agencies
   • Take consumer stories.
   • Map out care pathways – patients can add information at each step.
3. C - Evaluation framework

The revised evaluation framework reflects feedback from workshop participants as well as frameworks for improving the delivery of collaborative mental health care, for assessing contextual factors that affect the quality of collaborative care, and for a mental health recovery model (CMHA). The framework shows 3 groups of factors that contribute to consumer experiences of collaborative care of depression, and the outcomes of these experiences in terms of satisfaction and quality of life. Within each grouping, the components listed are not intended to be exhaustive, but illustrative of some of the important factors, derived principally from feedback at workshop.

The 3 groups of factors that may affect the 8 domains of consumer experiences identified in this workshop include:

1. **The type of collaborative care** provided. Two key components are the psychiatrist and the case coordinator/manager. Colocation of these key individuals with the primary care team is expected to improve outcomes. Provider education in collaborative care and policies (e.g., for remuneration) are other important factors.
2. **Personal resources** brought to the collaborative care process by those affected by depression. Greater severity of depression, comorbidity with other mental or physical health problems, and cultural factors may be barriers to effective care. Involvement in self-care on the other hand may facilitative and improve the experiences and outcomes.
3. **Community resources** available to individuals with depression. Support may be available from the circle of support (family and friends), peer support workers, community services, and sometimes from resources at work. The ability of the collaborative care team and the patient to access and coordinate these resources may have beneficial effects on outcomes.

This evaluation framework may be useful to decision-makers, managers, clinicians, and researchers who wish to improve the quality of consumer experiences of collaborative depression care. For example:

- Program planners may wish to identify components of this framework that might be improved in order to address one or more of the consumer experience domains.
- Program evaluators may wish to choose measures that reflect the experience domains that have been prioritized by patients.
- Researchers may wish to explore the use of common measures of each domain of experience so that different programs may be compared using common measures.

See diagram on the following page
Conceptual model showing factors contributing to consumer experience of collaborative care of depression

CONSUMER EXPERIENCES OF COLLABORATIVE CARE
- Respect – Involvement as partners – Communication – Responsiveness – Whole person care
- Comprehensiveness – Accessibility – Coordination

OUTCOMES
- Satisfaction – Quality of life – Recovery
CONCLUSIONS

This workshop brought together consumers, providers, and researchers from across Canada to develop recommendations on the incorporation of consumer experiences into the planning and evaluation of collaborative care of depression. The revised evaluation framework that resulted from the workshop may help to inform research and evaluation of collaborative care initiatives.

The workshop identified 8 important attributes of collaborative care programs for depression that affect consumer experiences: respect; involvement of consumers as partners; information and communication; responsiveness to changing needs; whole person care; comprehensiveness of services; accessibility; and system coordination. Examples of each attribute contributed by workshop participants provide the basis for future improvements and for development of appropriate measures.

Two recent consensus development initiatives, one of them being Canadian, incorporated consumers into consensus development exercises to identify measures of the quality of primary care mental health services.\(^9,13\) Several priority themes identified were similar to those identified in our workshop (information, comprehensiveness of treatment, respectful treatment of patients and families, and incorporation of patient and family preferences for treatment).

Some of these attributes have also been identified as important in the limited prior research on collaborative care of depression. Among the 12 studies identified in our systematic literature review that measured specific domains of consumer experiences, the following aspects were assessed (number of studies in parentheses): information received (8), accessibility (4), involvement of patient/family in treatment decisions (3), courtesy/respect (3), coordination/continuity (2), range of treatments provided (1). Unfortunately, the measures of patient experiences used in these studies were diverse, limiting the ability to compare outcomes between the studies. Notably, none of the studies were conducted in Canada.

A recent position paper developed by the Working group on Shared Mental Health Care of the Canadian Psychiatric Association (CPA) and the College of Family Physicians of Canada (CFPC),\(^10\) also recommends inviting feedback from consumers and families regarding effectiveness of collaborative interventions and access to essential services.

The results of this workshop have set the stage for future research efforts in the following areas:

- Development of operational measures to capture the 8 most important domains of consumer experience;
- Use of these measures to evaluate collaborative care programs for depression across Canada.
REFERENCES


## APPENDICES

1. **List of planning committee members**

<table>
<thead>
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<th>Name</th>
<th>Position and Affiliations</th>
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2. List of workshop participants

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