

Original Research

Developing an Evaluation Framework for Consumer-Centred Collaborative Care of Depression Using Input From Stakeholders

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Objective: To develop a framework for research and evaluation of collaborative mental health care for depression, which includes attributes or domains of care that are important to consumers.

Methods: A literature review on collaborative mental health care for depression was completed and used to guide discussion at an interactive workshop with pan-Canadian participants comprising people treated for depression with collaborative mental health care, as well as their family members; primary care and mental health practitioners; decision makers; and researchers. Thematic analysis of qualitative data from the workshop identified key attributes of collaborative care that are important to consumers and family members, as well as factors that may contribute to improved consumer experiences.

Results: The workshop identified an overarching theme of partnership between consumers and practitioners involved in collaborative care. Eight attributes of collaborative care were considered to be essential or very important to consumers and family members: respectfulness; involvement of consumers in treatment decisions; accessibility; provision of information; coordination; whole-person care; responsiveness to changing needs; and comprehensiveness. Three inter-related groups of factors may affect the consumer experience of collaborative care, namely, organizational aspects of care; consumer characteristics and personal resources; and community resources.

Conclusion: A preliminary evaluation framework was developed and is presented here to guide further evaluation and research on consumer-centred collaborative mental health care for depression.



Élaboration d'un cadre d'évaluation des soins de la dépression en collaboration centrés sur le client, avec l'apport des intervenants

Objectif : Élaborer un cadre pour la recherche et l'évaluation de soins de santé mentale en collaboration pour la dépression, qui comprenne des attributs ou des domaines de soins importants pour les clients.

Méthodes : Une revue de la littérature sur les soins de santé mentale en collaboration pour la dépression a été menée et utilisée pour guider la discussion lors d'un atelier interactif avec des participants pancanadiens, parmi lesquels des personnes traitées pour dépression par des soins en collaboration, ainsi que des membres de leur famille,

des médecins des soins de première ligne et de santé mentale, des décideurs, et des chercheurs. L'analyse thématique des données qualitatives de l'atelier a identifié des attributs clés des soins en collaboration qui importent aux clients et aux membres de leur famille, ainsi que des facteurs qui peuvent contribuer à de meilleures expériences pour les clients.

Résultats : L'atelier a dégagé le thème prédominant du partenariat entre clients et médecins engagés dans des soins en collaboration. Huit attributs des soins en collaboration ont été jugés essentiels ou très importants pour les clients et les membres de leur famille : le respect; la participation des clients aux décisions concernant le traitement; l'accessibilité; l'offre d'information; la coordination; les soins de la personne prise comme un tout; la réceptivité aux besoins changeants; et l'intégralité. Trois groupes de facteurs inter-reliés peuvent influencer sur l'expérience des soins en collaboration pour le client, notamment, les aspects organisationnels des soins; les caractéristiques et les ressources personnelles du client; et les ressources communautaires.

Conclusion : Un cadre d'évaluation préliminaire a été mis au point et est présenté ici dans le but de guider d'autres évaluations et recherches sur les soins de santé mentale en collaboration pour la dépression centrés sur le client.

Depression is one of several mental health conditions that are predominantly managed in primary care, sometimes with support from mental health providers. Its high prevalence, impact on morbidity, mortality, quality of life, and health care costs make it a significant public health concern.¹⁻¹⁴ Optimal management of depressive disorders requires collaborative care; that is, a well-coordinated, effective range of services provided by planned interaction between primary care and mental health professionals.¹⁵ By 2005, all Canadian provinces had either created or were creating local primary care programs that attempted to integrate mental health.¹⁶ A typical model included a family physician, a psychiatrist, and (or) a social worker or a mental health nurse. Many initiatives appeared to be moving toward the co-location of mental health and primary care providers and the expansion of the range of disciplines involved in the collaborative team.¹⁷

While collaborative care involves interaction between primary care and mental health providers, it is logical for the preferences, values, and cultural traditions of consumers to be incorporated into treatment planning.^{16,18} However, there is little empirical evidence on whether and how this occurs in practice. Both the evolution and evaluation of consumer-centred care may benefit from a framework that identifies not only those attributes of care that are valued by consumers but also specific care processes that may improve consumer experiences.¹⁹ Accordingly, our 3 objectives were to identify the attributes of collaborative care that are considered by consumers to be important, the consumers' experience of collaborative care interventions, and the methods that can be used to elicit and understand consumers' perceptions of collaborative care approaches.

Methods

A preliminary literature review was undertaken to identify attributes of consumer-centred collaborative care of depression and to develop a discussion framework for an interactive workshop with pan-Canadian stakeholders. At this gathering, we listened to viewpoints of participants and sought their perspectives as consumers, providers,

Clinical Implications

- Clinicians should focus on ways to develop meaningful and active partnerships with patients and their families.
- Clinicians should inquire about the person's experience of the care provided and use this information in the overall treatment and management of depression.
- The 8 key attributes of care identified in this project should be further studied in the context of different collaborative mental health care initiatives for depression.

Limitations

- The views and experiences of our workshop participants may not be representative of all Canadian stakeholders in collaborative care of depression; there were also a limited number of family physicians and consumers in our study.
- The sample size for the rating of the attributes was small in our study.
- The literature review may not have identified all relevant studies; we did not rate the quality of the methodologies in the studies that we reviewed.

health care planners, and researchers on key attributes of collaborative care to make revisions to the literature-based evaluation framework. Workshop participants later provided feedback on the revised framework and rated the importance of the key attributes identified.

Literature Review

Relevant studies that identified or measured attributes of collaborative care for depression based on consumer perspectives were located primarily from published reviews,^{15,20} supplemented by a limited search of electronic databases from 2007 to 2011 (MEDLINE, PsycINFO, and Embase) using the following keywords: primary health care; depressive disorder; depression; mental disorders; treatment; patient satisfaction; outcome assessment; and program evaluation. To identify additional pertinent studies, we consulted reference lists and solicited input from team

members and workshop participants. Using a checklist, we ascertained the following eligibility criteria: original study or review (qualitative or quantitative) of interventions that involved some form of collaboration between primary care and mental health providers (excluding drug trials) for care of people with depression or depressive symptoms (not necessarily exclusively); different ambulatory care settings (primary care, mental health clinics); outcomes that included measures of consumer experiences of the care received; and language (written in either English or French). In the final step, we reviewed the outcome measures of consumer experiences used in each eligible study and excluded studies that reported only on general satisfaction with care. Using a standard abstraction form, we extracted the following information from each study: author(s) and year of publication; country and region where the study was conducted; study setting; study design; intervention description; control and comparison group description (if relevant); measures of consumer experiences; and results.

Workshop

The workshop was held as part of pre-conference activities at the June 2011 Canadian Conference on Collaborative Mental Health Care in Halifax, Nova Scotia. To promote broad participant representation, no workshop fees were required for attendance. The 12-member workshop planning committee comprised researchers, members of national mental health organizations, primary care and mental health providers, and decision makers. We invited a spectrum of stakeholders to participate, aiming to have roughly equal representation of 4 groups: primary care providers, mental health providers, decision makers, and consumers. To further reach as broad a group as possible, we used different types of information sources to identify potential participants: conference website, conference posters, snowballing, and scanning of conference registration lists.

Our team proposed a preliminary framework, adapted in part from the realist review evaluation framework²¹ and from an evaluation framework for the quality of collaborative mental health care in Ontario family health teams,²² to stimulate presentations and group discussions. Our framework comprised 3 groups of factors presumed to impact consumers' experiences: the collaborative care approach (for example, types of staff, their roles, how they communicate with each other and with consumers and families, and types of treatment offered); the care setting (for example, solo family doctor, compared with multidisciplinary group; rural, compared with urban, setting; and province); and the population receiving care (for example, older adults and immigrants).

Presentations were made by people with lived experience of depression, representatives of national mental health organizations, and providers or decision makers from 4 Canadian provinces (British Columbia, Ontario, Quebec, and Nova Scotia) who were familiar with the unique regional delivery of collaborative care of depression in

their province or region. Presenters were asked to address 2 questions:

1. In future research or evaluation of collaborative care for depression in Canada, what consumer experiences should be measured?
2. What particular approaches to collaborative care influence consumer experiences, either positively or negatively?

In an interactive session that followed the presentations, participants commented on the presentations and on the preliminary evaluation framework. This was followed by small group discussions, with participants assigned to 1 of 5 discussion tables, each table comprising a mix of stakeholders. The discussion was led by one of the workshop planners, who also took notes. In a final plenary debriefing session, the discussion leaders from each table presented a summary of the points raised, and there was an opportunity for general discussion. Participants were invited to complete a bottom-line sheet to record comments about what researchers should retain as the most important issues covered during presentations and discussions, as well as to share any experiential perspectives not previously vocalized.

Four months after the workshop, following qualitative analysis of workshop proceedings (see below), a first draft of the workshop report (including a revised evaluation framework, the proposed attributes of care, and a list of workshop participants) was distributed by email to participants for feedback. Modifications were incorporated into a revised draft of the revised evaluation framework. Five months after the workshop, a final draft of the report was circulated by email to all participants and planning committee members. Participants were asked to anonymously rate the 8 key attributes generated at the workshop as to their importance in the routine collaborative care of depression (essential, very important, important, less important).

Ethical Issues

The protocol was approved by the St Mary's Hospital Research Ethics Committee. Participants provided oral but not written consent to participate. Permission was requested at the workshop for the proceedings to be audio-recorded and photographed, and for the participants' names and affiliations to be listed in the final report. As one person did not agree to audio recordings, no recordings were made.

Qualitative Data Analysis

Team members took notes on all questions and comments made during the presentations and discussions. Analysis of these qualitative data was carried out in 3 stages.^{23,24} First, all recorded points, comments (including comments from the bottom-line sheets), presentation notes, and slides were coded for ideas that fell under 3 predetermined themes: attributes of consumer-oriented collaborative

care; evaluation framework factors; and, methods to elicit consumer experiences.

Second, we analyzed ideas generated about the attributes of consumer-centred collaborative care. Comments regarding consumers' experiences were grouped into preliminary, descriptive, and interpretive categories. We further refined the categories in light of the literature and a Canadian consensus document on attributes of primary care.²⁵ At this stage of the analysis, workshop participants were invited to review the categories for accuracy, comprehensiveness, and clarity, resulting in further refinements.

Third, the initial framework was reconsidered in light of the attributes emerging from the qualitative analysis (stage 2) and the specific comments made at the conference regarding the framework (stage 1).

Results

Literature Review

We retrieved 66 potentially relevant studies based on the title or abstract. Among these, 45 met all initial eligibility criteria; in the final step, 34 studies were excluded because the only patient experience outcome measure was general satisfaction. The 11 remaining studies are shown in online eTable 1. We also found 2 reports on consensus development initiatives that incorporate consumers in developing indicators for the quality of primary care mental health services.^{26,27}

The majority ($n = 6$) of the original studies were conducted in the United States, 4 in Europe, and 1 in Australia. Eight were randomized controlled trials, 1 was a before–after study, and 2 were descriptive program evaluations. The study samples comprised consumers with depression ($n = 5$) as well as mixed mental health problems including depression ($n = 6$). Interventions were varied, but most included some form of care management or care coordination. Control or comparison groups (if applicable) received either usual care or minimal intervention.

Most studies used validated scales to measure consumer experiences,^{28–34} but the attributes of collaborative care were defined differently and measured in diverse ways. Seven of the 9 studies that included a comparison group reported significant effects on consumer experiences, including provision of information about depression and care^{35–37}; access^{38,39}; participation in care^{38,40}; courtesy³⁸; continuity and coordination³⁸; personal aspects of care, listening and acknowledgement of consumer concerns, advice, and follow-up³⁵; delivery system, goal setting, and problem solving⁴¹; and length of consultation.³⁷

Workshop

The workshop involved 40 participants (excluding the lead investigator), 9 other members of the planning committee, and 31 invited stakeholders.

Attributes of Consumer-Centred Collaborative Care. Overarching themes identified in the qualitative analysis were the development of a meaningful partnership between consumers and providers, and hope for recovery. According to participants, development of a partnership would require a culture shift among professionals and consumers alike, to make consumer participation in the collaborative team a standard expectation for all. Some participants also suggested an analysis of shared power in the collaborative partnership. It was acknowledged that this type of shared approach is complex and must also be accessible for people with varied capacity for decision making. The second overarching theme—hope for recovery—points to a recovery model for treatment of depression.^{42,43}

Our thematic analysis identified 8 attributes that are important to consumers and their families in consumer-centred collaborative care: respectfulness; involvement of consumers in treatment decisions; accessibility; provision of information; system coordination; whole-person care; responsiveness to changing needs; and comprehensiveness (Table 2).

The final survey was completed by 21 of 42 (50%) participants, of whom 9 were consumers ($n = 4$) or family members ($n = 5$), and 2 were planning committee members who were unable to attend. Table 3 shows the mean ratings of the 8 attributes and the relative ranking of each with the respondent group. Consumers and family members rated respectfulness and involvement highly, whereas other respondents rated information provision and coordination highly. The differences between the ratings of consumers and family members and those of others were not statistically significant. Notably, the mean ratings indicated that all 8 attributes were considered to be essential or very important by both groups.

Revised Evaluation Framework. To reflect the overarching themes of partnership and hope for recovery, we adapted a recovery framework,⁴⁴ which considered recovery and quality of life as the ultimate outcomes (Figure 1). The 3 groups of factors that could have a positive impact on consumer experience of care were revised and expanded from those in the preliminary framework, based mainly on qualitative analysis of the workshop.

The first and central group of factors—consumer resources—includes characteristics and personal resources of consumers that are important to consider when linking with formal collaborative care and contextual resources. Certain characteristics of consumers (for example, greater severity of depression, comorbidity with other mental or physical health problems, and cultural factors) may present challenges to effective care, while the ability to be involved in self-management may facilitate and improve consumer experiences and outcomes of care.

The second group—collaborative care resources—represents organizational and human resources within the formal collaborative care program. Key components are training of providers to think differently about care delivery,

Table 2 Attributes of consumer-centred collaborative care

Attribute	Description
Respectfulness	Collaborative care providers demonstrate respect for the dignity of consumers, provide adequate privacy and confidentiality, and support and guide consumer choices in care.
Involvement of consumers in treatment decisions	Consumers and family members actively participate in designing plans for their care and in the analysis and evaluation of health services and treatment programs.
Accessibility	Consumers are able to contact providers and reach health care services when they need them
Provision of information	Providers take the time needed to explain health care issues and treatments in understandable language; consumers have access to all relevant information about their own care.
System coordination	Delivery of services is managed so that different elements of care are easily accessed when needed and supported by effective working relationships, reliable methods of communication, and follow-up.
Whole-person care	Practitioners elicit, understand, and integrate biological, psychological, social, relational, and spiritual aspects of each person's presentation into the care plan.
Responsiveness to changing needs	Providers are able and willing to modify care plans to suit the changing needs of consumers and their families.
Comprehensiveness	A range of services intended to support whole-person care (including psychosocial services, support for self-management, and pharmaceutical interventions) is accessible and available.

Table 3 Ratings of importance of attributes of consumer-centred collaborative care, by consumer and family member status

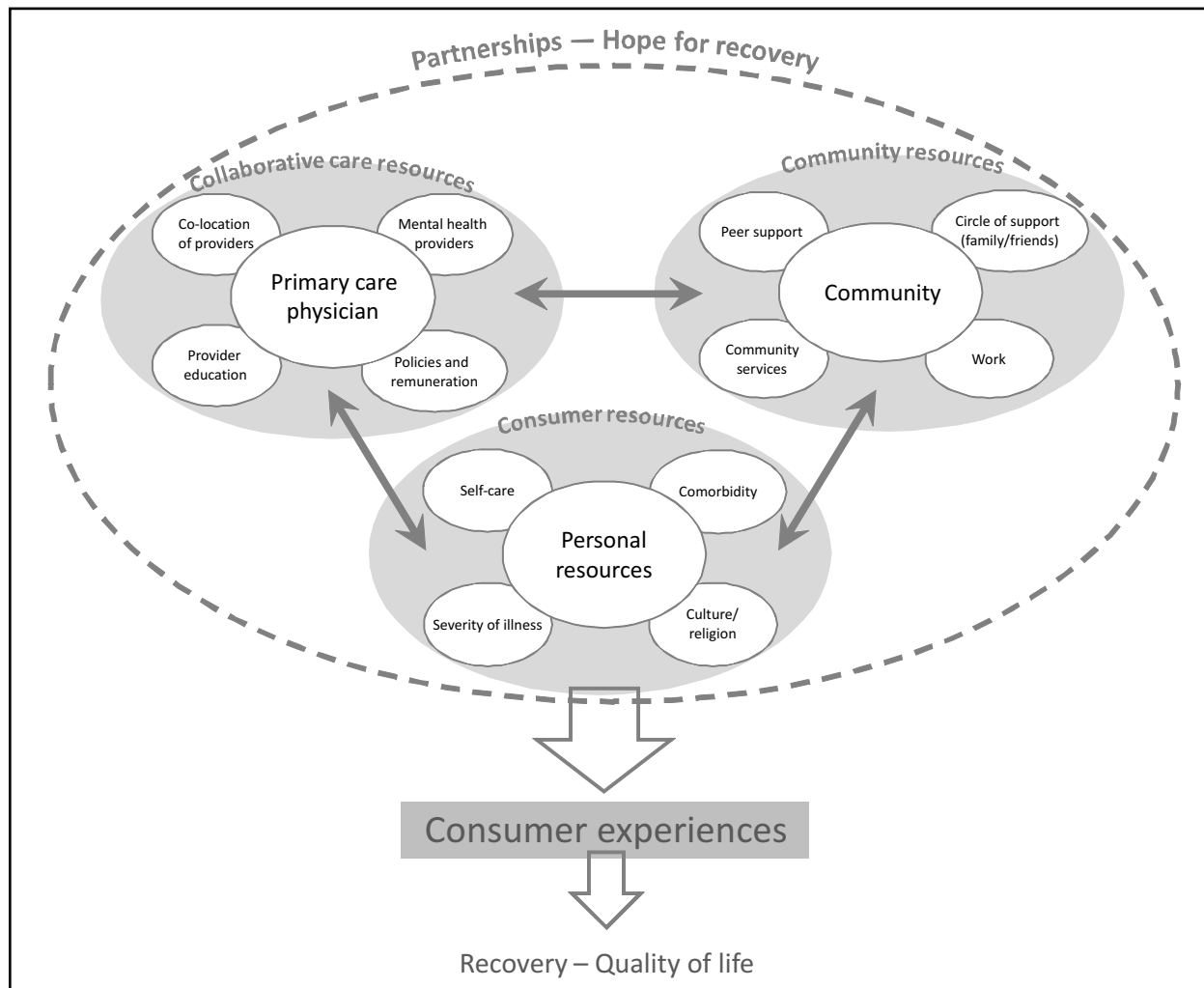
Attribute	Consumer and family, <i>n</i> = 9		Other, <i>n</i> = 12	
	Mean (SD) ^a	Rank	Mean (SD) ^a	Rank
Respectfulness	1.1 (0.3)	1 ^b	1.6 (0.8)	6
Involvement of consumers in treatment decisions	1.1 (0.3)	1 ^b	1.5 (0.7)	3 ^b
Accessibility	1.2 (0.7)	3	1.5 (0.5)	3 ^b
Provision of information	1.3 (0.5)	4	1.3 (0.5)	1 ^b
System coordination	1.4 (0.5)	5 ^b	1.3 (0.7)	1 ^b
Whole-person care	1.4 (0.9)	5 ^b	1.9 (0.9)	8
Responsiveness to changing needs	1.4 (0.9)	5 ^b	1.8 (0.5)	7
Comprehensiveness	1.6 (0.7)	8	1.5 (0.5)	3 ^b
^a Attributes were rated as follows: 1 = essential; 2 = very important; 3 = important; 4 = less important				
^b A tie				

engaging in collaborative partnerships with consumers and families, co-location of key individuals within the primary care team, and supportive policies such as remuneration for collaborative work. One workshop attendee spoke about the tremendous impact of having a psychiatrist in his son's family physician's office, which led to immediate consultation. Other attendees noted that training and proper remuneration would encourage the treating team to develop and engage in collaborative partnerships.

The third group of factors comprises community resources available to the consumer. Many conference attendees spoke of the importance of a small, consistent circle of support that actively participates alongside consumers and

providers in the promotion of recovery. Others spoke of the importance of positive peer support, and some suggested that peers may benefit from guidance, teaching, and provider back-up. Most also spoke of the need for various community resources that can match the individual needs of consumers and their families, that are located close to home or work, and are easily accessible.

Methods to Elicit Consumer Experiences. Participants presented approaches used to gather information about consumer experiences, perceptions, and preferences, including discrete choice analysis, in which consumers are asked to choose between numerous variables grouped in different combinations⁴⁵; shadowing of consumers by an

Figure 1 Evaluative framework for consumer-oriented collaborative care showing processes that affect consumer experiences^a

^a Some information based on Trainor et al.⁴⁴

observer⁴⁶; care pathways, in which the experience of care is mapped out, with input from consumers at each step⁴⁷; and the use of consumer images or photovoice methods, where consumers are given cameras to record images of their care.⁴⁸ Many participants emphasized the importance of presenting patient narratives alongside quantitative outcome measures, and suggested using approaches such as individual exploratory conversations and focus groups.

Discussion

This project synthesized information from a literature review and stakeholder input to develop an evaluation framework for consumer-centred collaborative care of depression. The framework is based on a model for treatment of mental illness that gives hope to recover meaningful engagement in life (for example, reintegration in work, finding meaning, or feeling connected), with or without clinical recovery.^{42,43} The evaluation framework also incorporates the overarching themes of partnership among consumers, their families, and providers, and hope for recovery.

We identified 8 key attributes of consumer-centred collaborative care of depression. Comparison with a Canadian consensus document²⁵ on the attributes of primary care showed concordance with 3 of our attributes (whole-person care, respectfulness, and comprehensiveness). We also found similarities with provision of information and involvement of consumers in treatment decisions (subdimensions within the attribute of interpersonal communication); accessibility (similar to accessibility–accommodation); and system coordination (similar to management continuity). Responsiveness to changing needs was the only attribute not represented in the consensus document. Several priority themes identified in other primary mental health care consensus initiatives were also similar to those identified during our workshop (information, comprehensiveness of treatment, respectful treatment of consumers and families, and incorporation of consumer and family preferences in treatment).^{26,27} A recent pan-Canadian survey⁴⁹ highlighted concerns when such consumer-centred attributes are absent (for example,

lack of access to treatment, lack of comprehensive funding support for treatment, and lack of respect for dignity shown by some front-line health care workers). Future research should evaluate and refine these 8 key attributes.

Three important limitations of this project should be noted. First, the views and experiences of our workshop participants may not be representative of all Canadian stakeholders in collaborative care of depression. As the workshop was conducted as part of a collaborative mental health care conference, those professionals with specific interest in collaborative care were represented more than others. Further research and evaluation is required to explore whether the attributes identified in our study are also important to consumers and workers in different settings. Second, the sample size for the rating of the attributes was small. Third, the literature review may not have identified all relevant studies, and it did not include unpublished (grey literature) studies.

Although the results of our project must be viewed as preliminary, they suggest strategies for improving consumer-centred collaborative care of depression and for the selection of attributes to measure consumer experiences.

Improving Consumer-Centred Collaborative Care of Depression

Our framework links 3 groups of factors that are of potential importance to improving consumer-centred collaborative care of depression. This framework views the consumer as central; the extent to which consumers are integrated into the collaborative care team and the context-relevant resources harnessed by the team are seen as critical to improving consumer experiences of collaborative care and promoting recovery. Some research evidence supports certain linkages within the framework. For example, positive consumer experience of care correlates with improvement in the quality of depression care, which may lead to improved outcomes.³⁴ Involvement of consumers in decision making tailors the care of depression to suit the consumer. It can also increase the likelihood that guideline-concordant treatment is used and adhered to by both health practitioners and consumers, leading to improvement in depressive symptoms.⁵⁰

Despite the importance of involving consumers as partners in care, implementation may prove challenging. Practitioners may view consumer involvement primarily as a means to improve adherence to medical recommendations, rather than working to integrate fully the priorities identified by consumers.⁵⁰ It is anticipated that clinicians will require education and preparation to enable them to participate in comprehensive consumer-centred collaborative care.^{20,51,52} Tools to assess consumer treatment preferences⁵³ and to assist consumers in informed decision making may also be helpful.⁵⁴

Measurement of Consumer Experiences of Collaborative Care

Our review of the published literature revealed a lack of standardized measures to qualify and quantify consumer-centred collaborative care approaches to treatment of depression in primary care. Because the collaborative care of depression involves care by a team of primary care and mental health practitioners, usually coordinated by the family doctor, the attributes of collaborative care identified in this study overlap substantially with the attributes of primary care in general, as described in a consensus report.²⁵ Despite this overlap, several of the attributes that we describe contain nuances that are of particular relevance to people with mental health problems. The attribute of respectfulness, as conceptualized in this project, may capture the extent to which consumers with mental health problems are taken seriously and are not treated differently or stigmatized. However, it may not capture the nuances of internal and external stigma.⁵⁵ This attribute also includes the dimensions of privacy and confidentiality, of particular importance in mental illness, which may need to be rated independently.

Two scales used in prior studies may be useful for evaluating collaborative care for depression, given that they contain items that address some of the attributes prioritized by our workshop participants, and, based on single studies, may be sensitive to collaborative care interventions. The Patient Assessment of Chronic Illness Scale,²⁹ a validated measure to assess consumer experiences of chronic illness care (including components of the Chronic Care Model), was sensitive to the provision of a case management intervention for depression.⁴¹ A scale developed to measure Participation In Care³⁴ was effective in measuring improved quality of depression care.⁴⁰

Other validated scales that assess consumer experiences of primary care may also be appropriate to evaluate collaborative care of depression.⁵⁶ A recently published study compared the psychometric performance of primary care instruments that measure respectfulness,⁵⁷ accessibility,⁵⁸ coordination,⁵⁹ interpersonal communication,⁶⁰ and comprehensiveness.⁶¹ Recent research suggests that instruments that ask consumers to report on problems they have experienced with their care may be more sensitive than traditional satisfaction scales in measuring quality improvement interventions.⁶² A newly developed instrument measuring coordination problems and information transfer gaps reported by consumers found that these problems were predictive of a sense of abandonment or emotional or physical health suffering.⁶³

Qualitative methods of evaluation may be useful, particularly in areas about which little is known (for example, the particular care processes that improve consumer experiences).⁶⁴ Future research will require the active involvement of consumers in identifying appropriate measures.¹⁹ Approaches that enable family members, peer groups, educators, and employers to provide feedback on their experiences during the consumers' illness and recovery should also be considered in future research.

Conclusions

The evaluation framework and attributes of consumer-centred collaborative care for depression developed in this project provide a first step in developing a foundation for future program development and research. Although some empirical evidence is available to support this framework, further research is needed to evaluate the effects of collaborative care initiatives on consumer experiences. With increasing use of collaborative care in the management of mental health and addictions in primary care, there will be more opportunity to apply this framework to different collaborative care settings and thus validate the attributes that are important to consumers in consumer-centred models of care.

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