Strategies for engaging patients and families in collaborative care programs for depression and anxiety disorders

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Review article

Strategies for engaging patients and families in collaborative care programs for depression and anxiety disorders: A systematic review

Matthew Meneara,b,⁎, Michèle Dugasb, Emmanuelle Careauc,d, Maud-Christine Chouinarded,
Maman Joyce Dogbaa,b, Marie-Pierre Gagonen, Michel Gervaisf, Michel Gilbertg, Janie Houleh,
Nick Katesi, Sarah Knowlesj, Neasa Martinj,k, Donald E. Nease Jr.l, Hervé Tchala Vignon Zomahounm, France Légaréa,b

a Department of Family Medicine and Emergency Medicine, Laval University, Quebec, Canada
b Centre de recherche sur les soins et les services de première ligne de l’Université Laval, Quebec, Canada
c Department of Rehabilitation, Laval University, Quebec, Canada
d Department of Health Sciences, Université du Québec à Chicoutimi, Chicoutimi, Canada
e Faculty of Nursing, Laval University, Quebec, Canada
f Centre intégré universitaire en santé et en services sociaux de la Capitale-Nationale, Quebec, Canada
g National Centre for Excellence in Mental Health, Quebec, Canada
h Department of Psychology, Université du Québec à Montréal, Montreal, Canada
i Department of Psychiatry and Behavioural Neurosciences, McMaster University, Hamilton, Canada
j NIHR Collaboration for Leadership in Applied Health Research and Care (CLAHRC) Greater Manchester, University of Manchester, Manchester, UK
k Neasa Martin and Associates
l Department of Family Medicine, University of Colorado Denver, Denver, US
m Quebec SPOR SUPPORT Unit, Quebec, Canada

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ABSTRACT

Background: Patients and families are often referred to as important partners in collaborative mental health care (CMHC). However, how to meaningfully engage them as partners remains unclear. We aimed to identify strategies for engaging patients and families in CMHC programs for depression and anxiety disorders.

Methods: We updated a Cochrane review of CMHC programs for depression and anxiety disorders. Searches were conducted in Cochrane CCDAN and CINAHL, complemented by additional database searches, trial registry searches, and cluster searches for ‘sibling’ articles. Coding and data extraction of engagement strategies was an iterative process guided by a conceptual framework. We used narrative synthesis and descriptive statistics to report on findings.

Findings: We found 148 unique CMCH programs, described in 578 articles. Most programs (96%) featured at least one strategy for engaging patients or families. Programs adopted 15 different strategies overall, with a median of two strategies per program (range 0–9 strategies). The most common strategies were patient education (87% of programs) and self-management supports (47% of programs). Personalized care planning, shared decision making, and family or peer supports were identified in fewer than one third of programs.

Limitations: Our search strategy was designed to capture programs evaluated in clinical trials and so other innovative programs not studied in trials were likely missed.

Conclusion: Most CMHC programs for depression and anxiety disorders adopted a limited number of strategies to engage patients and families in their care. However, this review identifies numerous strategies that can be used to strengthen the patient- and family-centeredness of collaborative care.

1. Introduction

In many countries, the bulk of care for common mental disorders such as depression and anxiety disorders is delivered in primary care (World Health Organization and World Organization of Family Doctors (WONCA), 2008). The prevalence of major depression in primary care settings is high, estimated to range between 10–20% (Craven and Bland, 2013; Mitchell et al., 2009; Wong et al., 2014).
Anxiety disorders are also encountered frequently and when considered together have been observed in 16–31% of primary care patients (Kroenke et al., 2007; Olariu et al., 2015; Vermani et al., 2011). For many patients with these conditions, a primary care provider will be their main and potentially sole source of mental health care (Vermani et al., 2011). Yet, despite how common these mental disorders are, important and long-standing gaps in quality of care persist with respect to their detection, treatment, and long-term management in primary care (Chapdelaine et al., 2018; Duhoux et al., 2011; Mitchell et al., 2009; Olariu et al., 2015; Stein et al., 2011). A better integration of care between primary care and mental health care providers is widely recognized as a solution for improving quality and patients’ experiences in care (Kwan and Nease Jr., 2013; Sunderji et al., 2018). There is now a considerable evidence base for a model of integrated care known as Collaborative Mental Health Care (CMHC). CMHC is a model of care in which primary care and mental health care providers share resources, expertise, and decision-making to ensure that primary care populations receive more effective, coordinated, and cost-effective mental health care (Kates, 2017). Over the past 25 years, CMHC programs have been examined in numerous clinical trials with effectiveness demonstrated in various populations, most notably those with common mental disorders (Archer et al., 2012; Sighinolfi et al., 2014).

While the strengthening of relationships between primary care and mental health care providers has been a focus of CMHC from the beginning, much less attention has been devoted to the relationships between providers, patients, and families. Some conceptualizations of CMHC clearly include patients and families as key partners in care (Kates et al., 2011; Katon and Selig, 2008; Thota et al., 2012) whereas others do not explicitly identify their engagement as a core component of the model (Bower et al., 2006; Farooq, 2013; Gunn et al., 2006). Even when patient and family engagement is valued, little guidance has been provided on how to translate this ideal into reality. Indeed, patient engagement in CMHC has historically been viewed in relatively narrow terms, such as through educational activities or individual supports for self-management (Katon et al., 2010). Meanwhile, the evidence base related to patient and family involvement in care has grown considerably over the past 20 years (Baker, 2014; Coulter and Ellins, 2007; Storm and Edwards, 2012; Tambuyzer and Van Audenhove, 2013). There is now a strong international consensus that partnering with patients and their families is both practically and ethically beneficial, not only during direct patient care but in other activities like service planning and evaluation, quality improvement, and policy development (World Health Organization, 2013).

The CMHC model is recognized as a best practice in clinical guidelines and a standard for how common mental disorders should be treated in primary care (Kates et al., 2011; Lam et al., 2016; National Institute for Health and Clinical Excellence (NICE), 2011). Empirical support for the model has spurred efforts to implement CMHC programs around the world (Archer et al., 2012; Farooq, 2013; Sighinolfi et al., 2014). It remains unclear, however, whether these programs are as patient- and family-centered as they could be. There is an urgent need to address knowledge gaps around the different strategies for engaging patients and families in collaborative care and provide guidance on how different members of the CMHC team can concretely support this engagement over the course of patient care. Our primary objective was thus to examine the range of patient and family engagement strategies used in collaborative care programs for depression and anxiety disorders. As a secondary objective, we sought to describe how and when different providers were involved in the engagement process.

2. Methods

The present systematic review is part of a larger realist review conducted by an interdisciplinary team including people with lived experience of common mental disorders. The protocol for the larger review has been published (Menear et al., 2016) and registered with PROSPERO, number CRD42015025522. We followed PRISMA guidelines in reporting results from this review (Liberati et al., 2009).

3. Search strategy

Our search strategy was designed to identify two types of articles: articles describing clinical trials of CMHC programs and ‘sibling’ articles on study protocols or quantitative or qualitative sub-studies linked to these trials. To retrieve the former, we performed a systematic review update of a previous Cochrane review on CMHC programs for depression or anxiety disorders (Archer et al., 2012). An information specialist replicated the Cochrane review’s search strategy, which included searches in the Cochrane Collaboration Depression, Anxiety and Neurosis Group (CCDAN) registers and CINHAL database. The CCDAN registers contain references for trials and other studies related to depression, anxiety and neurosis drawn from weekly systematic searches in MEDLINE, EMBASE, PsycINFO, and Cochrane CENTRAL (Archer et al., 2012). The CCDAN registers were searched from January 2011 until June 2016. The CINHAL database was searched from January 2009 until June 2016. We used the same search terms for depression, anxiety disorders, and collaborative care that were used in the Cochrane review (see the full list of CINHAL search terms in Supplementary File S1). To monitor the literature for ongoing or new CMHC programs published after our initial database searches, we searched three trial registers (ClinicalTrials.gov, WHO ICTRP, EU Clinical Trials Register) using search terms such as ‘collaborative care’, ‘integrated care’, ‘stepped care’, and ‘case management’. We also created monthly email alerts for new articles in MEDLINE, EMBASE, and PsycINFO based on our initial detailed search strategy. In both cases, the last verification of the literature was conducted in August 2018. None of the searches had language restrictions.

Considering that patient and family engagement strategies are not always fully described in the clinical trial articles for CMHC programs, we searched for ‘sibling’ articles that had the potential to contain additional relevant information. We adopted a ‘cluster searching’ approach (Booth et al., 2013), which included reference list searches of all eligible trial articles, author searches in Web of Science, reverse citation searches, and searches in Google Scholar using study trial names (e.g. IMPACT study).

4. Eligibility criteria

Articles on clinical trials of CMHC programs were included if they met the same inclusion criteria as were used in the 2012 Cochrane review. Participants were individuals of any age with a primary diagnosis of depression or anxiety disorder (including generalized anxiety, social anxiety, panic, phobias, post-traumatic stress, and obsessive compulsive disorder). Interventions were considered collaborative care if they met four criteria: (1) a multidisciplinary approach to care involving at least one primary care provider and another health professional, (2) a structured management plan (e.g. use of guidelines or algorithms, evidence-based treatments), (3) a systematic approach to patient follow-up, and (4) mechanisms for enhanced communication between providers (e.g. team meetings, consultation/supervision). Eligible study designs included randomized controlled trials (RCTs) or clinical controlled trials of CMHC programs. Eligible comparators included usual care or an alternative CMHC intervention. Articles had to report an outcome of interest – necessary for the realist review phase – including changes in depression or anxiety status, medication use, quality of life, or satisfaction with care. For ‘sibling’ articles, any published protocol or sub-study (quantitative or qualitative) directly related to an eligible CMHC program was included in the review.
5. Study selection

A team of five researchers and research professionals independently conducted the initial screening of titles and abstracts. Two review authors then independently reviewed the full-texts of relevant articles. For both initial and full-text screening, disagreements between review authors were resolved through discussion and, if necessary, by consulting the primary author (MM).

6. Data extraction

The data extraction process was piloted on a sample of 10 collaborative care programs where two review authors independently extracted data using a standardized extraction form. A codebook was developed to ensure a shared understanding of collaborative care components and engagement strategies. Next, a single review author (MD) continued the extraction, with full verification of accuracy of all extracted data conducted by the primary review author (MM). We extracted data on study, participant and CMHC program characteristics, including the types and roles of all health professionals and other stakeholders (e.g. researchers, peer or lay workers) involved in the programs.

We also coded and extracted data on patient and family engagement strategies, which we broadly defined as any strategy to consult, inform, involve, or partner with patients, families or their representatives in the delivery, organization, improvement or evaluation of healthcare (Carman et al., 2013). Coding and extraction of data on engagement strategies was an iterative process guided by a conceptual framework inspired by previous work by Carman (Carman et al., 2013), Pomey (Pomey et al., 2015), and Coulter (Coulter and Ellins, 2007). Our framework includes 27 potential engagement strategies occurring within 5 healthcare levels (Fig. 1). Engagement at the level of direct care occurs during interactions between patients and/or families, on the one hand, and healthcare professionals and/or clinical teams, on the other. It also includes the engagement of individual patients or families with health-related resources (e.g. educational materials, web-based portals). At the level of the organization of healthcare, patients or families are engaged in the planning, governance, improvement, or assessment of programs or services of a health organization, region or system. Patients and families can also participate in the design or delivery of training of professionals, either during their initial professional development or as part of their continuing education. They can similarly be involved in research on collaborative care, such as during the preparatory phase (e.g. defining objectives, ensuring relevance, seeking funding), the execution phase (e.g. designing the intervention, selecting and refining instruments, supporting data collection, interpreting data), or the translational phase (e.g. preparing scientific or lay communications, participating in knowledge translation activities). Finally, at the level of policymaking, patients, families, or their representatives can participate in shaping system-level policies, priorities, and resource allocation decisions related to collaborative mental health care. Strategies at each level fall along a continuum of engagement. At one end of the continuum, information flows in a unidirectional or asynchronous manner and patients and families are limited in their decision-making authority. At the other end of the continuum, information flows more bidirectionally and patients and families are viewed as partners or co-leaders that share in decision-making power and responsibility (Carman et al., 2013). The definitions for all engagement strategies are provided in Supplementary File S2.

Coding was based on directed and conventional content analysis approaches (Hsieh and Shannon, 2005), in which we deductively applied codes for pre-identified engagement strategies within our framework (e.g. self-management) but used inductive coding for newly identified strategies (e.g. simulated patients) and engagement strategy descriptors (e.g. types of providers involved, duration of supports). Some activities to engage patients or families were found to integrate multiple engagement strategies, such as when a peer support worker helped deliver a self-management program. In such multi-component activities, each component (for example, ‘peer supports’ and ‘self-management supports’) received a code as an engagement strategy. Similarly, an engagement strategy (e.g. ‘patient education’) targeted both patients and their families, codes for both the strategy (‘patient education’) and ‘family engagement’ were used. Coding was performed in trial articles first and then ‘sibling’ articles were searched for additional information. Information on engagement strategies was coded in Mendeley and then extracted within a structured spreadsheet.

7. Analysis

Given our review objectives, we used a narrative approach to data synthesis along with simple descriptive statistics. Following extraction of data on program characteristics and engagement strategies, results were summarized using descriptive statistics (frequency, median, average, range) and shared with the larger interdisciplinary research team, including our patient partners, to gather feedback on the identified strategies and descriptors used. Partners with lived experience supported the interpretation of results and the identification of implications and study limitations. We did not formally appraise the quality of studies included in the systematic review given that the objective at this stage was to identify and describe patient and family engagement strategies and not assess their effectiveness. An assessment of engagement strategy effectiveness is planned for the realist review phase of this study.

8. Results

8.1. Search results and description of CMHC programs

The systematic review update yielded 4643 articles after removal of duplicates. Screening of titles and abstracts led to the exclusion of 4339 articles, leaving 304 articles eligible for full-text screening. After the next round of screening, we retained 65 trial articles for inclusion in the review, which were linked to 51 new CMHC programs. We also identified 18 additional programs through trial registry searches and monthly email alerts that, together with the 79 programs identified in the 2012 Cochrane review, produced a total of 148 unique CMHC programs for depression or anxiety disorders (Fig. 2). We also identified 430 ‘sibling’ articles overall, including 317 articles listed in the 2012 Cochrane review and 113 articles retrieved through cluster searching.

Among the 148 CMHC programs included in the review, 105 programs were delivered in North America, including 99 in the U.S. and 6 in Canada. The remaining programs were located in Europe (33 programs), Australia (3 programs), Central or South America (4 programs), Asia (2 programs), or Africa (1 program). Most programs (79%) targeted people with depression, whereas 8% of programs targeted people with anxiety disorders, and 13% of programs targeted both people with depression or anxiety. Most programs (84%) also targeted adults (18 years or older), whereas 10% targeted older adults and only 6% targeted youth or mixed (youth and adults) populations. Finally, 53% of programs represented more traditional or stepped collaborative care interventions for depression or anxiety disorders, whereas the remaining programs represented a variation of these interventions (e.g. delivered mainly by telephone, telemedicine or via the Web, nurse- or pharmacist-based, delivered in the patient’s home, delivered in an integrated way for mental and chronic physical conditions). Characteristics for each program are provided in the Supplementary File S3.

8.2. Patient and family engagement strategies

Overall, programs used 15 different strategies to engage patients or families in care, with 15 different engagement strategies were identified
Table 1, with 96% (142 out of 148) programs reporting at least one engagement strategy. Programs adopted a median of two strategies, with a range of 0 to 9 strategies. The vast majority of strategies occurred at the direct care level where patients and families interact with professionals in the CMHC team. The most common engagement strategy across programs was patient education, described in 87% of programs (n = 129). Education covered a variety of topics (e.g. mental health conditions, treatments, importance of treatment adherence and relapse prevention, health promotion) and involved several and often multiple approaches, including education delivered verbally by professionals (n = 101 programs) or using written tools (e.g. books, brochures, manuals; n = 73 programs) or electronic tools (e.g. websites, videos, web applications; n = 27 programs). The next most common strategy was self-management supports, described in nearly half of programs (47%, n = 70). These supports included self-help or guided self-help approaches based on psychological treatments (n = 15 programs) or broader self-management interventions incorporating a range of activities aiming to help patients better manage their conditions and improve wellness (n = 55 programs). Self-management supports generally aimed to strengthen a variety of patients' skills (e.g. setting goals, coping with emotions and managing stress, managing and adhering to treatments, monitoring signs of relapse, communicating with clinical staff, adopting healthy behaviours) and were delivered in a variety of ways (e.g. verbally, manuals and workbooks, videos or web-based tools, individual or group sessions). After patient education and self-management, the strategies most frequently described were behavioural change interventions like motivational interviewing or behavioural activation (39%, n = 57), personalized care planning (32%, n = 48), shared decision making (SDM) (25%, n = 37), peer supports (9%, n = 13), and patient navigation (6%, n = 9). In two programs, investigators reported that patients had access to their health records or to a patient portal that they could use to find clinical information and communicate with their clinical team (Meglic et al., 2010; Simon et al., 2011).

There were also 22 programs (or 15% of all programs) that provided at least one form of support to families of people with depression or anxiety disorders. Strategies to educate families about mental illness or mental health treatments or resources were adopted in 18 programs, with this being the sole engagement strategy in 13 of these programs. Other programs included families in self-management supports (n = 5 programs), in shared decision making (SDM) (n = 3 programs), and in care planning (n = 3 programs). In one program, care managers provided instrumental supports to support mothers with depression with their child care needs (e.g. changing diapers, ensuring proper nutrition, help with clothing or schoolwork).

Beyond engagement at a direct care level, four programs described strategies for involving patients in the training of health professionals in collaborative care, one program described an engagement strategy at an

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**Fig. 1.** Patient and family engagement framework.
Fig. 2. PRISMA flow diagram.

4995 records identified through database searching

4643 records after duplicates removed

4643 records screened

4339 records excluded

304 full-text articles assessed for eligibility

239 full-text articles excluded due to ineligible:
- Populations (n = 12)
- Interventions (n = 45)
- Comparators (n = 6)
- Outcomes (n = 9)
- Study designs (n = 121)
- Settings (n = 15)
- Duplicate (n = 1)
- Language (n = 1)
- Already included in 2012 Cochrane review (n = 29)

65 trial articles describing 51 programs included in the synthesis

79 CMHC programs and 317 sibling articles from 2012 Cochrane review

148 total programs
148 primary trial articles and 430 sibling articles included in the synthesis

18 CMHC programs from trial registries and email alerts
113 sibling articles from cluster searching
Table 1
Patient and family engagement strategies adopted by collaborative care programs.

<table>
<thead>
<tr>
<th>Engagement strategy</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Direct care level</td>
<td></td>
</tr>
<tr>
<td>Patient education</td>
<td>Strategies or experiences designed to help individuals or groups improve health or prevent illness by increasing their knowledge or influencing their attitudes. May involve verbal educational strategies or the use of brochures, books, manuals, videos, websites, etc.</td>
</tr>
<tr>
<td>Access to health records or portals</td>
<td>Enabling individuals with a mental health condition to access their paper or electronic medical records or access personal health information or communicate with their providers through a secure online platform.</td>
</tr>
<tr>
<td>Behaviour change interventions</td>
<td>Interventions focused on bringing about direct behaviour changes in people with mental health conditions or addressing motivation, readiness or commitment to change. Includes interventions like motivational interviewing, behavioural activation, health coaching, etc.</td>
</tr>
<tr>
<td>Patient navigation</td>
<td>Patient navigation aims to help individuals with mental health conditions overcome health system or personal barriers to care. It involves helping people navigate an often fragmented health and social care system by informing them about the system and services available to them, improving communication with different agencies and services, and facilitating access to care by the right provider at the right time.</td>
</tr>
<tr>
<td>Personalized care planning</td>
<td>An anticipatory and negotiated discussion between a patient and one or more health professionals to clarify goals, options and preferences and develop an agreed plan of action based on this mutual understanding. The care planning process aims to ensure that patients’ values and concerns shape the way their mental health conditions are managed. Care plans can also outline the conditions for increasing or reducing treatment intensity, providers involved in the care, and a timeframe for providing services and reviewing the plan.</td>
</tr>
<tr>
<td>Self-management supports</td>
<td>Self-management refers to an individual’s ability to manage the symptoms, treatment, physical and psychological consequences and lifestyle changes inherent in living with a mental health condition. Self-management support is the care and encouragement provided to individuals with mental health conditions and their families to help them understand their central role in managing their illness, make informed decisions about care, build relevant skills and engage in healthy behaviours. Self-management supports can be delivered individually or in groups and can include use of tools such as books, manuals or workbooks, videos, web applications, etc.</td>
</tr>
<tr>
<td>Shared decision making</td>
<td>A process by which health decisions are deliberated upon and made jointly by the patient and one or more health professionals, taking into consideration the best available evidence, professionals’ clinical judgment, and the patient’s values and preferences. Shared decision making can be supported using tools such as decision aids.</td>
</tr>
<tr>
<td>Family supports</td>
<td>A family of interventions aiming to inform, consult, support or partner with family members of people with mental health conditions.</td>
</tr>
<tr>
<td>Peer supports</td>
<td>Involves people with lived experience of a mental health condition offering support to others with similar experiences. Peers can give and receive help founded on key principles of respect, shared responsibility and mutual agreement of what is helpful. Peer supports can be delivered individually, in groups, or in larger (usually online) communities.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Organization of healthcare level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Needs assessment</td>
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</table>

<table>
<thead>
<tr>
<th>Professional training level</th>
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</thead>
<tbody>
<tr>
<td>Simulated patients</td>
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<table>
<thead>
<tr>
<th>Research level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient consultations</td>
</tr>
<tr>
<td>Involvement in study phases</td>
</tr>
<tr>
<td>Research advisory groups</td>
</tr>
<tr>
<td>Co-leadership in research activities</td>
</tr>
</tbody>
</table>

Note. The strategies appearing in Table 1 are those that were adopted in the 148 collaborative care programs for depression and anxiety disorders included in this review. Definitions for all 27 engagement strategies identified in Figure 1 appear in Supplementary File S2.

organizational-level, and no programs described the involvement of patients or families in policymaking related to CMHC. With respect to professional training, all four programs (BRIDGE, COINCIDE, SmaRT Oncology-3, and SMADS) adopted the same strategy, i.e. to use simulated patients (live or in videos) to help physicians or care managers learn or practice new skills (Cooper et al., 2013; Coventry et al., 2015; Walker et al., 2014; Zimmermann et al., 2014). No programs reported the involvement of actual patients in the design or delivery of training. In the single program that engaged patients in the organization of care, researchers simply consulted patients through individual interviews, often to gather feedback on the content and delivery of the CMHC program or to explore potential barriers to its implementation during a pilot phase (Alegria et al., 2014; Curran et al., 2011; Simpson et al., 2008; Steel et al., 2011; Waitzkin et al., 2011). In the five other programs, patients were either in collaborator or co-leader roles. For example, in the Flinders Program delivered in Australia, investigators partnered with several patient organizations to support the recruitment of Vietnam veterans with comorbid alcohol use and mental disorders to the study (Battersby et al., 2013). In the PRISM-E, DIAMOND, and CASPER Plus programs, patients were involved in advisory or steering committees for the RCT and assisted with specific study stages (e.g. study design, developing patient-friendly data collection forms) (Bosanquet et al., 2017; Levkoff et al., 2004; Solberg et al., 2013). In the CADET program conducted in the UK, multiple engagement strategies were used, including having two patient representatives on the study trial steering committee and another patient and public involvement advisor as an investigator and full member of the trial management group overseeing the research (Richards et al., 2016).

8.3. Supports for patient and family engagement

Across programs, CMHC teams comprised a median of 4 health professionals or other stakeholders, most often including family
physicians (92% of teams) and psychiatrists (77% of teams) but also nurses (55% of teams), psychologists (40% of teams), social workers (26% of teams), or other mental health professionals (e.g. psychotherapists, mental health counselors) (17% of teams). These latter professionals often played the role of ‘care manager’ within their teams but in some programs were in mental health specialist roles. Non-professional CMHC team members included peer support workers or groups (9% of teams), research staff (5% of teams), and lay health workers (e.g. promotoras) (2% of teams).

When examining the engagement strategies occurring at a direct care level, we found that engagement was most often supported by a single CMHC team member, usually the care manager (Tables 2 and 3). Care managers were largely responsible for delivering patient education and family supports, supporting patients’ self-management, using motivational techniques, and helping patients navigate services. The involvement of multiple team members was relatively more frequent in the cases of personalized care planning, shared decision making, and peer supports (over 50% of the time delivered by two or more providers). For example, when patients were engaged in shaping their care plan, it was more common for both the family physician and care manager to be involved in the process, supported occasionally by a psychiatrist or other specialist (Table 3). Similarly, peer supports were always delivered by a peer support worker or group, but in nearly half of programs also included support from a care manager.

Most of the engagement strategies at the direct care level were delivered on multiple occasions over time (Table 2). Engagement occurred most often within the first 6 or 12 months following treatment initiation but in rarer cases extended to periods greater than one year. For strategies such as shared decision making and family supports, however, engagement occurred on only a single occasion (e.g. at the time of the initial treatment decision) in over one third of programs. With respect to other engagement strategies occurring at the levels of professional training or research, programs most often described the involvement of patients and families during a single stage of the CMHC initiative. This includes the stages of preparing for the program (e.g. assessing client needs), implementing the program (e.g. giving advice on intervention content or implementation barriers, supporting professional training, supporting patient recruitment), and evaluating the program (e.g. advising on data collection forms). In the CADET and CASPER Plus programs, authors specifically mentioned that patients were involved throughout the research process (Bosanquet et al., 2017; Richards et al., 2016). In the CASPER Plus program, the authors also stated that they aimed to involve patients in the dissemination of study results, though no details are reported on how this would be undertaken (Bosanquet et al., 2017).

9. Discussion

This study aimed to critically review strategies used to engage patients and their families in CMHC programs for depression and anxiety disorders and describe how and when different providers are involved in the engagement process. We found 148 unique CMHC programs, identifying at least one engagement strategy in 142 (96%) of these programs. Overall, 15 different engagement strategies were identified, including 9 strategies occurring at the direct care level, 4 strategies at the research level, and one strategy each at the levels of healthcare organization and training. CMHC programs individually adopted a median of two strategies (range 0–9), the most common being patient education and self-management supports. Across programs a diverse range of health professionals and other stakeholders contributed to supporting patient and family engagement. However, within programs such supports were typically provided by only a single member of the CMHC team, most often the care manager. Our findings led us to make the following observations.

First, CMHC programs have a strong potential to include a diverse range of patient and family engagement strategies; however, this potential is not being fully realized. Over half of programs adopted two or fewer engagement strategies, including educational approaches (often information provided orally or using printed materials, videos, websites, etc.) adopted in the majority of programs. Patients and their families have a range of informational needs related to mental illness, its treatment, and coping strategies (Tlach et al., 2015) and providing such
Table 3
Types of providers involved in patient and family engagement.

<table>
<thead>
<tr>
<th>Provider type</th>
<th>Education (n = 129 programs) N (%)</th>
<th>Self-management (n = 70 programs) N (%)</th>
<th>Motivational enhancements (n = 57 programs) N (%)</th>
<th>Care planning (n = 48 programs) N (%)</th>
<th>SDM (n = 37 programs) N (%)</th>
<th>Family supports (n = 22 programs) N (%)</th>
<th>Peer supports (n = 13 programs) N (%)</th>
<th>Patient navigation (n = 9 programs) N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary care physicians</td>
<td>4 (3)</td>
<td>1 (1)</td>
<td>0 (0)</td>
<td>28 (58)</td>
<td>21 (57)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Psychiatrists</td>
<td>1 (1)</td>
<td>0 (0)</td>
<td>2 (4)</td>
<td>21 (44)</td>
<td>9 (24)</td>
<td>1 (5)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Other physicians/specialists</td>
<td>1 (1)</td>
<td>1 (1)</td>
<td>1 (2)</td>
<td>4 (8)</td>
<td>3 (8)</td>
<td>0 (0)</td>
<td>0 (0)</td>
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Note.

* A score of zero on the types of providers involved for the strategies 'Education' and 'Self-management' indicates that patients were sent educational or self-management materials by mail with no obvious contact with or follow-up by any type of provider.
information is a foundation for greater involvement in care. Yet, information provision as a stand-alone intervention has minimal to small impact (Donker et al., 2009; Grudniewicz et al., 2015) and is widely considered a lower or passive form of engagement (Carman et al., 2013; Grande et al., 2014; Thompson, 2007). Supporting self-management offers a greater potential for active engagement by being centered on patients’ goals and aiming to enhance skills related to decision-making, problem solving, symptoms and treatment management, communication with health providers, or adopting healthy behaviours (Barlow et al., 2002; Lorig and Holman, 2003). Its effectiveness is demonstrated for various chronic conditions (Taylor et al., 2014; The Health Foundation, 2011) and positive results have been observed for common mental disorders (Cuijpers et al., 2010; Houle et al., 2013). Both patient education and self-management supports should be core elements of a broader patient and family engagement plan within CMHC programs. However, programs should consider incorporating additional direct care strategies that can strengthen patient-provider relationships and reflect the collaborative spirit of CMHC. For example, care planning should extend beyond clinician-centric treatment plans and instead represent a personalized and collaborative process in which patients and professionals work together to clarify and set goals based on patients’ priorities and needs for support, and subsequently establish a mutually agreed upon plan of action and process for reviewing progress (Coulter et al., 2015). Shared decision making is an essential process within care planning (Coulter et al., 2015) and is the crux of patient-centered care (Barry and Edgman-Levitan, 2012; Weston, 2001). Sharing in decisions is critical for common mental disorders because patients frequently face decisions that are preference-sensitive, such as about which treatments to initiate or which providers to involve in care, whether to discontinue or switch treatments, which self-care strategies to pursue, etc. (Slade, 2017). Shared decision making ensures that patients and families are aware of their options, have opportunities to discuss the risks and benefits of these options, and can collaborate with their clinicians to make choices informed by clinical advice, the best available evidence, and their own preferences and values (Legare and Wittman, 2013). Behavioural change interventions like motivational interviewing and behavioural activation should also be woven into the fabric of collaborative care for depression and anxiety as they can be brief, low intensity interventions that can produce a range of positive impacts on symptoms, concurrent alcohol or substance use, and engagement in treatment and care (Ekers et al., 2014; Lundahl et al., 2013; Martinez-Vispo et al., 2018; VanBuskirk and Wetherell, 2014). Peer supports are often highly valued by patients and are similarly associated with a range of benefits, from increased feelings of hope, motivation and self-efficacy, to greater social supports and quality of life, and reduced stigma, symptoms, and hospital admissions (O’Hagan et al., 2010; Pfeiffer et al., 2011; Walker and Bryant, 2013). Integrating such evidence-based engagement strategies within CMHC programs has the potential to enhance and broaden their impacts and promote patient-centeredness, yet most of these strategies were observed in less than one third of programs.

Second, care managers have an important role to play in ensuring that patients participate fully in their care but the responsibility for engagement should not fall on their shoulders alone. Rather, patient engagement at a direct care level should be a team effort and occur all along the patient care journey. Our analyses revealed greater evidence for the involvement of multiple care providers in care planning, shared decision making and peer supports, whereas patient education, self-management supports, behavioural change interventions, family supports, and patient navigation were largely delivered solely by care managers. Interprofessional approaches to care planning (Coulter et al., 2015; van Dongen et al., 2016a, 2016b) and decision making (Chong et al., 2013; Dogba et al., 2016; Stacey and Légaré, 2015) have garnered increased attention in recent years and reflect collaborative approaches that allow ‘the patient team’ and ‘the clinical team’ to each bring their complimentary perspectives and expertise to important care decisions and processes. Such interprofessional practices can reduce power differentials between participants, foster trust, and promote informational continuity and decisions informed by more complete information (Dunn et al., 2018; van Dongen et al., 2016a). This approach could be extended to other engagement strategies as well. Indeed, strategies like behavioural activation or self-management supports can themselves be multi-faceted interventions and team members could share responsibility over their multiple components. In the OPTIMAL program, for example, people with depression or anxiety and other chronic conditions participated in a six-week self-management group (Garvey et al., 2015; O’Toole et al., 2013). The group was led by occupational therapists and covered topics such as stress and fatigue management, healthy eating, communication strategies, and goal setting. In addition, a physiotherapist and pharmacist co-facilitated sessions on keeping physically active and on managing medications, respectively. In other programs, peer support workers have also led or facilitated self-management sessions and can bring a unique recovery-oriented perspective and serve as role models for participants (Battersby et al., 2013; Ludman et al., 2007, 2016). Moving forward, efforts should be made to capitalize on the diversity of knowledge and expertise within CMHC teams in order to support a team-based approach to patient engagement. Furthermore, consistent with our findings on the frequency and duration of engagement, this team-based approach should be initiated at the earliest stages of care and be sustained throughout acute and maintenance phases as long as required by the patient.

Third, we were struck by the limited involvement of family members in CMHC programs. Family involvement was observed in only 15% of programs and often consisted of the simple sharing of written educational materials with family members. An emerging literature suggests that families want an active role in care and can participate in care planning, decision-making, self-management, and other forms of support for loved ones (Doody et al., 2017; Haine-Schlagel and Walsh, 2015; Hamann and Heres, 2019; Tambuyzer and Van Audenhove, 2013). Their involvement may be particularly essential in programs targeting youth or older populations. Our findings suggest, however, that only 2 of 16 programs for older adults and 4 of 8 programs for youth reported any form of family involvement in care. Overall, few CMHC programs have explicitly aimed to be both patient- and family-centered. This represents a critical gap in the evidence base for CMHC and an issue that should be reflected upon by current and future program leaders.

Finally, it seems plausible to link the relatively narrow use of engagement strategies at the direct care level to the limited involvement of patients and families in the design, implementation and evaluation of CMHC programs. Out of 148 programs, 10 programs involved patients in the research process and in only 5 programs were patients in collaborator or co-leader roles. When programs did partner more actively with patients, their involvement was reported to have several benefits. For example, Richards and colleagues involved patients with depression at multiple stages in the development of their collaborative care program. They conducted interviews with patients during the initial design of their intervention and then again with patients participating in a phase II pilot trial for their program. Feedback from patients led to an improved understanding of the acceptability of the intervention and how to support patients’ educational needs on medications, better tailor their behavioural activation program to patients’ circumstances, and deliver effective case management services over the phone (Richards et al., 2006; Simpson et al., 2008). In their phase III CADET program trial, a patient and public involvement advisor was a full member of the research team and helped develop patient-facing materials, treatment manuals, and questionnaires and supported project management and data collection (Richards et al., 2016). These examples highlight the value added by partnering with patients in research and quality improvement and are consistent with benefits described in the broader literature, including research being more
relevant and grounded in people's daily experiences, study materials that are more culturally appropriate and suitable for lay audiences, and improved interventions and services (Bombard et al., 2018; Brett et al., 2014; Shippee et al., 2013). Furthermore, according to Bombard, while lower forms of engagement can facilitate the development of user-friendly tools and materials, more collaborative approaches (e.g. co-design) are often needed to produce meaningful changes to service delivery or structures (Bombard et al., 2018). Future CMHC programs should create opportunities for patients and families to be actively involved in program design, implementation, and evaluation to ensure that services are responsive to their needs and priorities.

Some limits of this review should be noted. Our literature searches captured CMHC programs that were evaluated in clinical trials and not other innovative programs that were not subject to formal evaluations with experimental designs. Also, our initial searches for CMHC programs within the CCDAN and CINAHL databases were performed until June 2016 and while we used additional search strategies to capture more recent programs (e.g. searches of ongoing trials in trial registries, monthly alerts) it is possible that some recent CMHC programs were missed. Our review did however include more than a dozen programs appearing in the literature from 2016 and beyond and there was no distinguishable trend with respect to higher levels of engagement over time, thus allowing us to be confident in our findings and conclusions. With respect to identifying engagement strategies, it would have been beneficial to contact study authors to gather additional information on the strategies adopted in programs and validate our findings. These strategies are not always recognized as core components of CMHC programs and are thus not always well described in the articles presenting trial results. That said, we mitigated this problem by performing cluster searches that enabled us to identify a large number of other articles tied to each program, providing us with a larger pool of data to extract and use to characterize patient and family involvement. Our analyses of engagement strategies were also very detailed and involved breaking down engagement activities into their individual components, a strength of our review. Finally, this systematic review was descriptive in nature and did not focus on the effectiveness of strategies for engaging patients and families in their care. Advancing knowledge about which engagement strategies are effective for which patients and under what circumstances is an important next step and will be the focus of the realist review phase of our study.

10. Conclusion

Collaborative mental health care has emerged as the dominant model of team-based care for common mental disorders in primary care. Patient and family engagement should be viewed as a core component of this model that contributes to the patient- and family-centeredness of his care. Indeed, for collaborative care to be truly patient-centered, patients should be regarded as respected and autonomous partners in care and receive timely access to useful information, support, and encouragement to be active participants in care planning, decision-making, and self-care. Collaborative care should also be family-centered, recognizing that families can be crucial allies in the care of their loved ones and, along with patients, essential members of the collaborative care team. Such partnerships with patients and families are important not only at the level of direct care delivery but also in the planning, improvement, and evaluation of programs and policies and in the education of professionals in collaborative care teams. What our review found is that patient and family engagement remains limited in the majority of CMHC programs for depression or anxiety disorders; however, there are clear opportunities for programs to incorporate new strategies to strengthen the patient- and family-centeredness of collaborative care. This review identifies a large number of strategies that program leaders may adopt to encourage engagement at the level of direct care as well as other levels of program planning, delivery or evaluation. Many of these engagement strategies benefit from their own evidence base and their implementation can serve to optimize and broaden the impacts of collaborative care. Program leaders should further recognize that CMHC programs offer ideal settings for the delivery of new and innovative interprofessional approaches to patient and family engagement. Such approaches have the potential to foster relationships that are more positive, trusting, and supportive of patients and families – helping them to feel part of the team throughout their journeys in care and recovery.

11. Contributors

All authors contributed to the design of the study. MM and MD designed the search strategy with team feedback and participated in article selection and data extraction. All authors contributed to the interpretation of data. MM drafted the manuscript and all authors critically revised the manuscript for intellectual content. All authors read and approved the submitted version of the manuscript.

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Declaration of Competing Interest

None.

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Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.jad.2019.11.008.

References


