

BMJ Open Mapping Evidence of Patients' Experiences in Integrated Care Settings: A Protocol for a Scoping Review

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ABSTRACT

Introduction Integrated care (IC) models have emerged to address gaps in care for individuals with complex healthcare needs. Although the clinical and cost-effectiveness of IC models are well-established, our understanding of whether IC models facilitate a patient-centred care experience from the patients' perspective is not well understood. This scoping review aims to comprehensively map the literature to provide a broad overview of patients' experiences in IC settings with a focus on the experiences of complex patients with comorbid mental and physical illnesses. It also aims to describe current gaps identified in the literature in our understanding of aspects of care that are often unrecognised.

Methods and analysis Using established scoping review frameworks and guidelines, we will perform a comprehensive search in the following databases: MEDLINE, EMBASE, PsycINFO, CINAHL, AMED and the Cochrane Library to identify relevant studies on patients' experiences in IC models. Grey literature sources and studies bibliographies will also be searched to identify relevant studies and documents. Data will be extracted and summarised using descriptive statistical and qualitative analyses. We will also consult with stakeholders from various backgrounds to enhance the comprehensiveness of this review.

Ethics and dissemination This review requires no ethical approval. Findings from this study will be disseminated through publication in a peer-reviewed journal, clinical conferences and in knowledge translation settings, aiming to improve clinical practice and care delivery.

INTRODUCTION

Gaps in the healthcare of people with comorbid mental and physical health conditions are well-established resulting in increased costs and poor patient outcomes.¹ Recognising the need to address these gaps in mental and physical care concurrently, several healthcare systems paradigms are currently shifting towards implementing integrated models of care to help achieve the 'Quadruple Aim': improve patient outcomes and experience of care, minimise costs as well as improve care-providers' experiences.^{2 3} Integrated

Strengths and limitations of this study

- This scoping review will be the first review to summarise evidence on patients' experiences in integrated care settings.
- Scoping review methodology will allow us to examine a broad range of outcomes that are not feasible to be measured quantitatively.
- This review will exclude studies that measure patient experience based solely on satisfaction surveys.
- We will not assess the methodological quality of available evidence on patients' experiences which is consistent with scoping review guidelines.

care (IC) comprises a number of established models of care such as the (colocation, collaborative care and fully IC) models based primarily on the level of behavioural health integration within primary care.^{4 5}

IC is defined as care that results from a one-practice team composed of primary care and behavioural health clinicians, who use a systematic and a cost-effective approach to provide patient-centred care for a defined population.^{6 7} Whereas the collaborative care model (CCM) "is a specific type of integrated care that operationalizes the principles of the Chronic Care Model (E. Wagner 2001) to improve access to evidence-based mental health treatments for primary care patients." (APA, p10)⁸ There is increasing evidence for the clinical-effectiveness of the CCM improving patient outcomes and quality of care for patients with chronic illnesses, including mental health.^{9 10} For example, a recent systematic review analysed data from 79 randomised-controlled CCM trials involving 24 308 patients and showed an improvement in anxiety and depressive symptoms both short and long terms.⁹ Collaborative care can also involve providers from different specialties, disciplines or sectors to provide a complementary service and support to serve a defined population.¹¹⁻¹³ According

to the American Psychiatry Association (APA) definition of collaborative care, "there is an expert consensus that all collaborative care models share four fundamental principles: 1) team-driven, 2) population-focused, 3) measurement-guided, and 4) evidence-based." (APA, p10)⁸

Despite the mounting evidence for the effectiveness of IC models, little is known about patients' experiences in IC settings.¹²⁻¹⁵ Reviews on IC outcomes have not clearly articulated patient experience measures.^{16 17} A recent systematic review evaluating the quality of measures used in IC models demonstrated that some quality measures such as clinical-effectiveness, cost-effectiveness and patient satisfaction are overemphasised, whereas other vital domains of patient experience (patient safety, equitability, patient-centredness, accessibility or timeliness of care) are often unaddressed.¹⁸ These results align with Wolf's narrative review, which underscored the need to move beyond satisfaction surveys as patient experience is more than patient satisfaction.¹⁹ In this review, patient experience was defined as a broader concept shaped by important domains such as organisation/culture, lived emotional and physical experience, personal interactions, active involvement, continuity of care, person-centredness, perceptions, information and responsiveness.¹⁹ Therefore, there is a need, as we move towards implementing a more patient-centred approach, to comprehend how the patient experience has been described and evaluated in the literature in IC settings. Specifically, addressing what aspects of IC are meaningful to patients and service users will help ensure that these IC models are effectively implemented and supported to build effective healthcare systems whose engaged workforce can address complex population needs and improve their experience of care.^{1 2 20-22}

Based on these gaps in our understanding of patient experience within the IC models, we aim to conduct a scoping review to explore the breadth of knowledge around patients' experiences in IC models. Since patient experience is a broad and multidimensional concept, not a circumscribed and well-defined outcome, a scoping review was selected as the appropriate method to comprehensively map the existing literature, identify important themes and ascertain gaps in our knowledge.²³ This review will provide a comprehensive review of patients' experiences in various IC settings to offer unique insights and knowledge about the quality of care from patients' perspectives and identify evidence around patient-centred care experiences in IC settings. As such, evidence from this review should allow knowledge users, such as providers, researchers and policy-makers, to identify important outcomes for patients and service users and to deliver whole-person care from the patient's perspective.

Given the complexity and heterogeneity of patients' experiences, we will use a scoping review methodology to examine studies exploring patient experience from the patients' perspectives and to surface the breadth and depth of issues that impact the quality of patients' experiences. Although there are many definitions of what

constitutes the 'patient experience', we aimed to use the most widely adopted and operationalised definition by the Beryl Institute for the purpose of this scoping review, defining patient experience as 'the sum of all interactions, shaped by organization's culture, that influence patient perceptions, across the continuum of care'.²⁴

The objectives of this scoping review are: (1) to describe the existing evidence on patient experience in IC models, (2) to determine what dimensions of patient experience are influenced by receiving care in IC setting and (3) to understand which elements of IC patients value the most.

PROTOCOL DESIGN

This scoping review follows the scoping review framework developed by Arksey and O'Malley and enhanced by Levac *et al.*^{25 26} The review adheres to the recommended scoping review guidelines by the Joanna Briggs Institute (JBI) aimed at improving the clarity and rigour of the review process.²⁷ According to the Arksey and O'Malley framework, the recommended six stages are: (1) identifying the research question that will address the main purpose of the study, (2) identifying relevant studies balancing breadth and comprehensiveness, (3) selecting studies using an iterative team approach to refine search strategy, improve clarity in decision-making for study selection and data extraction, (4) charting the data will involve using appropriate numerical summary and qualitative thematic analysis to illustrate key issues and themes, (5) collating, summarising and reporting the results as they relate to the study purpose and implications of the study findings for policy, practice and research and (6) consulting with relevant stakeholders and key informants.

Stage 1: identifying the research question

One of the three primary goals outlined by the APA guidelines for evidence-based IC models (eg, collaborative and fully IC models) is to provide a patient-centred care experience in addition to improving patient outcome and being cost-effective. According to the APA 2016 dissemination report, patient-centred care, based on the chronic care model (CCM), is defined as proactive care that facilitates patient outreach to engage, activate, promote self-management and treatment adherence and coordinate services.⁸ The objectives of this review are: (1) to map the evidence on the experience of patients in IC settings to understand whether care from *patients' perspectives* is indeed patient-centred and (2) to identify gaps in our understanding of patients' needs and preferences for a patient-centred care experience. Much uncertainty still exists around the experience of patients with complex care needs. As such, this review will focus primarily on patients with coexisting mental and physical illnesses given the increased prevalence of mental and physical comorbidity and complexity of care in this population. This review will also consider the experience of patients with a chronic mental or physical illness to enhance the

comprehensiveness of this review given the paucity of research in this area.

Based on our described objectives, this review primary question is:

‘What is the breadth of existing evidence on the experience of patients with co-occurring physical and mental illness in integrated care models?’

In addition to this primary research question, we developed the following secondary research objectives for this scoping review:

1. What dimensions of patient experience (such as continuity of care, waiting time and interprofessional relationship with primary care provider) are affected when receiving care in an IC setting?
2. What elements of IC have the greatest value and importance to patients?

Stage 2: identifying relevant studies

Identification of relevant studies for this review will be accomplished by searching the following six electronic databases: MEDLINE, EMBASE, Psyc INFO, CINAHL, AMED and the Cochrane Library. To enhance our search strategy for this scoping review, we will consult with an expert health research librarian at our institution to develop a searching protocol that will be used to retrieve relevant papers from the six specified databases systematically. Based on the JBI scoping review guidelines, a three-step strategy will be used to develop our search strategy. First, a preliminary search will be conducted initially in the two main databases (MEDLINE and EMBASE). The goal of this initial search will be to identify the relevant (MeSH and Emtree) terms and keywords by analysing the text words contained in the title and abstract of retrieved papers and of the index terms used to describe related articles (online supplementary appendix). Second, using all identified terms and keywords, we will create a search protocol that will be undertaken across all included databases. The designed search strategy will be saved into MEDLINE to ensure reproducibility of our search results. Third, we will conduct a wide hand and grey literature search through Google Scholar and our institutional database to identify any relevant studies, conference abstract or reviews that are relevant to this scoping review. Finally, the reference list of all identified articles will be screened to locate any other relevant studies. While developing our search protocol, we will frequently seek feedback from our research team to refine our search strategy. We will also assess the quality of our search protocol using the PRESS 2015 Evidence-based Checklist guidelines.²⁸ The scoping review search strategy for the databases will be reported in the online supplementary appendix as outlined in a Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement.²⁹

Stage 3: study selection

Two independent reviewers (AY and RC) will apply a two-step approach to screening. The first step will involve that each reviewer independently screens studies by

title and abstract to identify potentially eligible studies. Study eligibility will be based on satisfying the inclusion and exclusion criteria developed in consensus by the research team. In the first phase, a citation would be relevant to include if the study abstract indicates evaluation of patient experience in an IC model whether (shared, colocated, coordinated, collaborative or fully IC model). The second phase will then involve a full-text review of all identified citations from phase one to confirm study's eligibility for analysis. In this step, we will use the Patient-Centered Integrated Behavioral Health Care Principles & Tasks Checklist developed by the AIMS Center at the University of Washington.²⁹ The rationale for using this checklist is to identify studies whose model of IC explicitly or implicitly aligns with the IC guidelines developed by the APA that are evidence-based. Any study that includes one or more of the core collaborative care principles described in the checklist mainly patient-centred care, population-based care, measurement-based treatment, evidence-based care or accountable care will qualify for the analysis phase. All eligible studies for analysis bibliography will be searched to identify any additional studies that might be eligible for inclusion. At both phases, each reviewer will work on the screening process independently. At the end of each phase, a third reviewer (SS) will review (AY and RC) documented search results to ensure results validity and resolve any identified discrepancies. Search process progress and results will be discussed during our regular meetings. We will use the PRISMA flow diagram to outline our search results, depicting the number of studies to included or excluded from the data analysis phase.³⁰

Inclusion criteria

- ▶ Patient experience, in this study, is defined as patients narratives describing their experience of receiving care through observational or descriptive studies, focus groups, or semi-structured interviews.
- ▶ IC models including: shared, coordinated, collaborative care and IC.
- ▶ Patients of all ages will be included.
- ▶ Patient population includes patients with comorbid mental and physical illness, patients with chronic mental or physical illness seen in primary care, community settings or hospital settings.
- ▶ Articles of all kinds (conference abstract, grey literature, reports and research articles) and all study design whether quantitative or qualitative studies will be included except for viewpoint articles such as editorials.

Exclusion criteria

- ▶ Studies evaluating patient experience based solely on patient satisfaction measures or using the Patient Assessment of Care for Chronic Conditions form.
- ▶ Editorials.

Table 1 Data extraction for the scoping review research questions

Summary	<ul style="list-style-type: none"> ▶ Author(s) ▶ Title ▶ Citation ▶ Type of publication: original, review or grey ▶ Location: country and region
Characteristics of integrated/collaborative care model	<ul style="list-style-type: none"> ▶ Population characteristics (age, sex, demographics, culture and racial or ethnicity-specific factors) ▶ Settings: inpatient, outpatient, community-based or primary care ▶ Inclusion/exclusion sampling criteria ▶ Model of care ▶ Characteristics of the intervention (any adaptations) ▶ Titles of service providers and description of roles ▶ Infrastructure (proximity, medical records, communication, philosophy and values) ▶ Components of integrated/collaborative care: team-based characteristics
Measurement, evaluation and outcomes	<ul style="list-style-type: none"> ▶ Aim of the study ▶ Study methodology: quantitative and/or qualitative including (phenomenological, ethnographical or grounded theory-based studies) ▶ Interview strategies ▶ Outcome measure or major findings

Stage 4: data charting

A data-charting form will be developed and reviewed by the research team before data extraction commence. The form will also be used to pilot results from two to three studies to ensure that the form captures all relevant themes to the scoping review question and objectives. Then, the two independent reviewers (AY and RC) will apply the developed approach consistently to extract relevant data from the identified studies. Any disagreement in extracting results will be resolved with a third reviewer (AL) opinion. Since a scoping review aims to provide a comprehensive view of the literature, data extracted from relevant studies will include but not be limited to the following information (see [table 1](#)):

1. *Descriptive study information*: authors, title and citations, geographical location and type of publication (review, original study or grey literature).
2. *Characteristics of integrated/CCM*: model of care (IC vs collaborative care), titles of service providers and roles, characteristics of the examined population (age, sex, physical and/or mental condition and inclusion/exclusion criteria), clinical settings (eg, acute, primary healthcare, community and long-term care), cultural, racial or gender-specific factors relevant to patient experience and barrier/facilitators to perceiving a patient-centred care experience.
3. *Major themes relating to patients' experiences*: study aims, methodology (focus group vs ethnography) and key findings that relate to the scoping review question.

Stage 5: synthesising and results presentation

Data extracted from the identified studies by members of the reach team (AY, RC and ZKC) will be analysed and presented quantitatively using descriptive numerical summary analysis and qualitatively through thematic

analysis. We will present the descriptive summary analysis in a table that outlines each study's first author, year of publication, intervention, settings and studies' main findings. These tables and charts will provide an overview of the extent, nature and distribution of the studies included in this review. Further, themes identified from all the studies will be organised, coded and thematically analysed to convey dominant themes, contradictions or variability in evidence linked to patient experience in integrated/collaborative settings. Likewise, in other stages, data analysis will constantly be refined with research team contributions and insights.

Stage 6: consultation

Scoping review guidelines underscore the value of consulting stakeholders and knowledge users as their contribution to the review process can provide unique insights beyond what is evident in the literature.^{25 26} The aim of this scoping review is to provide a comprehensive overview of the current evidence on patient-centred care experience in IC settings to highlight the existing gaps in the literature and limitation to implementing a patient-centred care approach from the patients' perspectives. Therefore, we believe that consulting with various stakeholders will further enrich the comprehensiveness of this review. For the purpose of this review, we will conduct 2–3 consultation meetings with the formed advisory committee comprised of patients with both physical–mental health conditions who are advisors for medical psychiatry programme at our institution, healthcare providers working in IC programme, organisation stakeholders (eg, programme leaders and administrators) and researchers. Using feedback from this advisory group, we will triangulate identified themes from the literature, elucidate divergent perspectives among

stakeholders and incorporate further feedback on the data analysis.

DISCUSSION AND DISSEMINATION

This scoping review aims to contribute to this growing area of research by exploring the evidence in the existing literature around patient experience in collaborative/IC settings. This scoping review will provide further insights into the aspects of care that matter to patients as well as highlight relevant quality indicators to IC implementation that may not be measured at present.¹⁸ A limitation to this review might be quality assessment of included studies. Nevertheless, results from this study will inform practitioners, knowledge users and researchers of the current gap in our knowledge these evolving models of care. As such, findings from this review could be valuable for organisations, practitioners and knowledge users interested in translating and implementing a sustainable model of IC that truly addresses important needs for patients and caregivers.^{1 18 31}

Knowledge from this review will be disseminated through presentations at clinical conferences, organisations involved in transforming patient experience, community and knowledge users and through publication in a peer-reviewed journal.

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Contributors AY, DW, MM, and SS contributed to the conceptual design of this review. AY conducted the literature review, search strategy design, and drafted the protocol. RC, ZKC, and AL reviewed and contributed to the finalization of this manuscript. All authors have read and approved this manuscript. SS is the guarantor of this work.

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Competing interests None declared.

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