Towards a framework for patient-centred care coordination: a scoping review protocol

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ABSTRACT

Introduction Patient-centred care and care coordination are each key priority areas for delivering high quality healthcare. However, the intersection between these two concepts is poorly characterised. We theorise that greater advancements in healthcare quality could be realised when care is organised in a way that aligns with patients’ preferences, needs and values across every level of the healthcare system. There is currently no published review that describes the intersection of patient-centred care and care coordination. We will undertake a scoping review that will be foundational to the development of a conceptual framework for patient-centred care coordination that integrates and synthesises the overlap between these two concepts and describe how it manifests across levels of the healthcare system.

Methods and analysis A multidisciplinary team of reviewers will conduct a scoping review of published and grey literature to identify and synthesise key concepts at the intersection of patient-centred care and care coordination, following Preferred Reporting Items for Systematic Reviews and Meta-analyses extension for Scoping Reviews guidance for scoping reviews. Databases we will use in our search include PubMed, CINAHL, Embase, Social Sciences Abstracts, Nursing and Allied Health Premium, Health and Medical Collection, and PsycINFO. Articles will be included that are English-language; published during or after 2001; describe a theory, conceptual model, theoretical framework or definition that addresses both patient-centred care and care coordination. Articles will be excluded if they do not address the intersection of patient-centred care and care coordination; discuss a patient-centred medical home without discussion on patient-centred care concepts; or discuss a paediatric, inpatient or palliative care setting. A data extraction template will facilitate qualitative thematic analysis and findings will be synthesised into a conceptual framework.

Ethics and dissemination This work does not require ethics approval. A preliminary framework will be presented to a group of patient stakeholders for refinement before dissemination through a peer-reviewed journal and conference presentations.

STRENGTHS AND LIMITATIONS OF THIS STUDY

● A scoping review approach is well suited to our research as it is an effective, rigorous and systematic method for synthesising key concepts, types of evidence and research gaps related to a relatively unexplored area.

● The review will be conducted by a multidisciplinary team with expertise in research in patient-centred care, care coordination and scoping reviews, as well as in clinical care.

● Patient stakeholders will contribute to interpretation of results to inform subsequent development of a conceptual framework of patient-centred care coordination.

● The review may miss relevant grey literature or models implemented in practice but not described in the current literature.

● This scoping review is limited to descriptions of outpatient adult healthcare.

INTRODUCTION

In 2001, in response to mounting concerns about insufficient quality of care in the nation, the Institute of Medicine (now the National Academy of Medicine) made an urgent call to fundamentally change how healthcare is delivered in the US. Their seminal Crossing the Quality Chasm report1 identified patient-centred care as one of six top priorities to achieve quality care. Concurrently, care coordination was identified as a cross-cutting priority area by the Institute of Medicine and the National Quality Strategy.2 These calls to action energised the already-ongoing grassroots efforts to improve patient–provider relationships, enhance health outcomes and satisfaction with care, and decrease healthcare costs.

In research and practice alike, patient-centred care and care coordination are often treated as separate entities, yet this approach has limitations. Patient-centred care is typically understood as care consistent...
with the patients’ preferences, needs and values.\(^1\) While providing a useful starting point, such definitions generally do not attend to the wider continuum of healthcare delivery, focusing instead on the patient–clinician dyad.\(^3\) By contrast, care coordination definitions emphasise the organisational dimension. For example, the original definition by the US Agency for Healthcare Research and Quality defines care coordination as ‘deliberately organising patient care activities and sharing information among all of the participants concerned with a patient’s care to achieve safer and more effective care’.\(^4\) While explicitly referencing safety and effectiveness, this conceptualisation overlooks patient-centredness, that is, integrating patient preferences, needs and values into the development, execution and coordination of care plans. A few models integrate patient-centred care concepts into care coordination and vice versa.\(^5\) \(^7\) Yet a preliminary search of the literature yielded no published review describing the concept of patient-centred care coordination as a single construct.

Despite the recommendations outlined in the Institute of Medicine report, healthcare quality in the USA continues to lag behind its counterparts.\(^8\) The USA spends more on healthcare than other high-income nations yet demonstrates lower scores on several key health measures including life expectancy, chronic disease burden, hospitalisations and deaths from preventable causes,\(^9\) and patient satisfaction. Care coordination\(^10\) \(^11\) and patient-centred approaches\(^12\) \(^13\) have each been shown to improve such outcomes. Even greater advances might be achieved when care is organised across the health system in a way that aligns with patients’ preferences, needs and values; that is, when patient-centred care coordination occurs at every level of the healthcare system.

We aim to draw across existing frameworks that include both patient-centred care and care coordination concepts, to develop a single construct that can span multiple levels of healthcare delivery. Until that is done, we cannot know what will be required to achieve patient-centred care coordination nor what the outcomes of good patient-centred care are. In this paper, we describe the protocol of a scoping review that will clarify and develop the concept of patient-centred care coordination. Our results will serve as the foundation of a new conceptual framework for patient-centred care coordination, which will describe how patient-centred care coordination manifests at the patient–clinician level, between the patient and their healthcare team, between care teams and at the organisational level.

**Study objectives**

Our objectives are to: (1) describe the relationships between patient-centred care and care coordination; and (2) develop a conceptual framework for patient-centred care coordination at the patient–clinician level, patient–healthcare team level, between care teams and at the organisational level. In this work, our goal is to articulate how the overlap between patient-centred care and care coordination can be understood as a single construct. We believe that a framework that describes patient-centred care and care coordination as a single construct may help to target research and quality improvement efforts that may improve the quality of care.

**METHODS AND ANALYSIS**

**Study design**

We will conduct a scoping review of the literature. A scoping review is an effective, rigorous and systematic method for synthesising key concepts, types of evidence and research gaps related to a relatively unexplored area.\(^14\) \(^15\) This type of review is an especially useful approach to provide clarity on concepts, develop working definitions and to inform future research, policy and practice.\(^16\) \(^19\) This methodology is an excellent fit for our objective of developing a conceptual framework for the intersection of patient-centred care and care coordination and mapping it to the different levels of care.

Our methodology will be guided by the widely recognised evidence-based framework for scoping reviews outlined by Arksey and O’Malley,\(^19\) Levac et al\(^20\) and the Joanna Briggs Institute.\(^18\) \(^21\) \(^23\) We will identify both published and grey literature to ensure that we are including a broad range of contexts for our search. ‘Patient-centred care’ and ‘care coordination’ are both terms with multiple definitions and constructs that may make it difficult to elucidate the intersection between the two concepts. We will address this challenge by using key terms used to inform previous systematic reviews of patient-centred care or care coordination. We will only include articles that explicitly outline theories, models or frameworks pertinent to both concepts. This approach will allow us to capture all sources that explicitly engage with the concepts at hand, while also keeping the review scope manageable.

**Stage 1: identifying the research questions**

The two questions that will guide this scoping review are:

1. In what ways are patient-centred care and care coordination related concepts?
2. How is the intersection of patient-centred care and care coordination manifested at the levels of patient–clinician, patient–healthcare team, between care teams and patient–organisation?

**Stage 2: identifying relevant studies**

We based our search strategy on established scoping review methodologies.\(^18\) \(^20\) \(^23\) We will identify both published and grey literature to ensure that we are including a broad range of contexts for our search. ‘Patient-centred care’ and ‘care coordination’ are both terms with multiple definitions and constructs that may make it difficult to elucidate the intersection between the two concepts. We will address this challenge by using key terms used to inform previous systematic reviews of patient-centred care or care coordination. We will only include articles that explicitly outline theories, models or frameworks pertinent to both concepts. This approach will allow us to capture all sources that explicitly engage with the concepts at hand, while also keeping the review scope manageable.

An experienced research librarian (JGS) will assist us in...
searching databases and will provide input on our three-step search strategy.

Search strategy
The first step in our search will be to complete an initial search of the PubMed and Embase indexes to identify titles and abstracts of studies that include key terms related to both patient-centred care and care coordination. In consultation with our librarian, we selected PubMed and Embase to conduct our initial search as these indexes are high-yield databases. In this preliminary search, we will use key terms previously used in existing systematic reviews that define patient-centred care and care coordination as unique concepts. These key terms include those that are related to either patient-centred care or care coordination (eg, integrated care, patient-centred medical home, multidisciplinary team). As patient-centred care and care coordination have been widely discussed in the literature with inconsistent use of terminology, using a wide range of terms will allow us to capture relevant literature. In this first step, we will identify any additional key terms or search criteria to be incorporated in a subsequent and more comprehensive search.

Consistent with established scoping review methodology, we will then search a broader range of electronic databases for published literature. Since patient-centred care and care coordination have been conceptualised across a variety of disciplines, the databases we search will include multidisciplinary research. Databases we will use in our search include PubMed, Embase, CINAHL, Proquest Health and Medical Collection, SociINDEX with Full Text, and PsycINFO. Online supplemental appendix file 1 details the proposed search syntax we will use for each database. Resulting articles and citations will be imported into a web-based platform called Covidence to facilitate organisation of articles, team collaboration, ease of review and agreement with the PRISMA-ScR criteria.

The last step in our search strategy will be to supplement our database search with grey literature. We will search the websites of agencies and foundations known by our author group to have published relevant content. These websites were selected for our search as they are frequently comment on patient-centred care or care coordination and may offer an improved understanding of patient-centred care coordination.

Stage 3: study selection
We will screen titles and abstracts of articles resulting from our search followed by a full-text screening to identify articles for inclusion in our review.

Inclusion and exclusion criteria
Inclusion and exclusion criteria will be iteratively developed to guide our scoping review. These proposed criteria will be used in our search strategy and in study selection. For manageability and relevancy, we will include articles published during or after the year 2001 that are focused on routine outpatient care for adult populations. The year 2001 was selected as our search start date to align with the release of the Institute of Medicine’s Crossing the Quality Chasm report. Articles will be included in the next step of full-text screening if they meet the following inclusion criteria:

- Article describes a theory, conceptual model, theoretical framework or definition for patient-centred care or care coordination.
- Article is published in English.
- The focus of the article discusses both patient-centred care and care coordination. This means that the article discusses patient preferences, needs and values alongside care coordination or a related term (eg, integrated care).

Articles will be excluded if they:
- Do not address the intersection of patient-centred care and care coordination at any level of care.
- Discuss a patient-centred medical home without including a discussion on patient-centred care concepts (ie, shared decision-making, patient–provider relationships, or patient goals, preferences or priorities for care). The patient-centred medical home is a model of healthcare that is not inherently focused on patient-centred care, though it is important.
- Base discussion on a paediatric population, inpatient setting or palliative care setting, since these have different conceptualisations of patient-centred care and care coordination.

Screening abstracts and titles
Two lead reviewers (GF and VV) will screen a random sample of 20 titles and abstracts using the above criteria and refine if necessary. These 20 articles will serve as a pilot to evaluate inter-rater reliability in selecting articles for full-text screening. Screening decisions will undergo a consensus building process, whereby all articles with disagreement will be reviewed and consensus will be reached to include or exclude in full-text screening.

Following this pilot screening, eight members of the research team will screen the remaining titles and abstracts in pairs. The two lead reviewers will demonstrate how to apply the inclusion and exclusion criteria to a sample of 10 articles. This will help reviewers become familiar with how the criteria should be applied in abstract/title screening. Reviewers will then screen 30 articles each. Each article will be screened by two randomly assigned reviewers. The lead reviewers will hold meetings with the full team to meet to resolve conflicts and ensure fidelity to the screening criteria. Reviewers will screen the remaining articles in randomly assigned pairs, with regular team meetings to ensure that discrepant decisions undergo a consensus discussion and that decisions are made consistently.

Screening full-text articles
Two members of the research team will independently screen the same 10 full-text articles for eligibility.
Discrepancies will be resolved in a consensus discussion. Then, six reviewers will work in pairs to screen full texts of articles and determine whether inclusion criteria are met. Ten per cent of articles will be checked by lead reviewers to ensure fidelity to eligibility criteria. Articles that are retained in the review will undergo data extraction (step 4 below).

A PRISMA-ScR flow chart will be used to outline the screening decision process and track the number of studies that are included at each phase of our study selection. The PRISMA-ScR flow chart and finalised inclusion/exclusion criteria will be included in a manuscript detailing the results of our final scoping review.

Stage 4: data extraction
A data extraction form developed by the research team will be tested independently by two reviewers on 10 randomly selected articles. Initial data items to be included will be study characteristics (eg, first author, year of publication, journal, title, type of article, aims/methods) and key content that relates to the research questions of interest. The data extraction form will be revised iteratively as needed.

Stage 5: data summary and synthesis of results
Findings from our scoping review will be presented in a table and summarised in narrative form. Articles will undergo a frequency analysis for quantitative description of relevant literature to capture characteristic such as the number of articles, types of articles, discipline, figures and other visual representations of patient-centred care coordination. We will also conduct a thematic analysis for qualitative description of relevant literature to highlight how the intersection of patient-centred care and care coordination have been described at each level (patient–clinician, patient–healthcare team, between care teams and patient-organisation).

Stage 6: consultation with patient stakeholders
We will consult with patients as part of developing a framework for patient-centred care coordination. Inherent in the definition of patient-centred care is having patients at the centre. Patient feedback will inform this review. Further, the US Department of Veterans Affairs (VA) prioritises patient engagement in health services research, and provides financial and other structured opportunities to support Veteran engagement. We will use the Veteran Stakeholder Council available at our VA research centre—the Centre for Healthcare Organisation and Implementation Research (CHOIR)—for feedback both on our proposed conceptual framework for patient-centred care coordination and dissemination plan. The Veteran Stakeholder Council meets regularly to provide ad hoc feedback on research projects across the centre. We will prepare a presentation for the quarterly Veteran Stakeholder Council that will cover the rationale underlying our scoping review, an overview of the literature and a preliminary model. We will then ask Council members for feedback, including their interpretation of the findings and what elements we may have missed in the resulting conceptual framework. We will also ask stakeholders about additional grey literature or models of patient-centred care coordination that are implemented in practice of which they may be aware.

Patient and public involvement
Patients and the public were not involved in the design of this scoping review. We plan to elicit patient stakeholder feedback on our conceptual framework after conducting the review of the literature, which will be published in a subsequent manuscript.

ETHICS AND DISSEMINATION
This study does not require ethics approval, as data will be reviewed and collected from publicly available materials. A preliminary framework will be presented to a group of patient stakeholders for refinement before dissemination. Dissemination will occur through peer-reviewed journals, conferences and other channels, according to a plan to be co-created with our Centre’s Veteran stakeholder council.

DISCUSSION
Our protocol will use robust methods to review the literature. Further, engaging with patient stakeholders to develop our conceptual framework is a highly patient-centric approach to research, which makes our study both theoretically grounded and highly relevant for practice and policy. Our multidisciplinary study team comprises researchers who have backgrounds in medicine, anthropology, psychology, health policy, public health, social work and nursing. A multidisciplinary team is strongly suited for this work as concepts pertinent to patient-centred care and care coordination are found across a range of social, behavioural and medical science fields.

Our protocol has some limitations. A common limitation with scoping reviews is the possibility that some literature may be missing relevant studies. For our protocol in particular, this concern is most relevant for our search of the grey literature. Guidance on searching grey literature is not straightforward nor systematised, which may make it likely that grey literature is missed. The websites we have selected to include in our search strategy publish a high volume of articles on patient-centred care and care coordination, but our internet search may not be comprehensive. A second limitation is that there may be current models of patient-centred care coordination that are implemented in practice, but that have not yet been published in the literature or grey literature and so will not be identified in our search.

Although decades of clinical practice and policy-making have yielded considerable advancements, the
US healthcare system is still plagued with high costs, quality deficits and disparities. Certainly, greater conceptual clarity around patient-centred care and care coordination alone will not solve this challenge. Yet, the conceptual framework for patient-centred care coordination to be yielded by this scoping review will fill a long-standing gap in the literature and shape future research, health policy and clinical practice guidelines that may contribute to advancements in healthcare quality in the USA and other nations.

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