The concept of child-centered care in healthcare: a scoping review protocol

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Review question/objective: The objective of this scoping review is to identify and evaluate the concept of child-centered care (CCC) in healthcare in order to achieve greater clarity on the concept and its applicability, benefits and potential to inform the evidence base of children’s health care, policy and practice.

The questions of this review are:
• What constitutes the concept of CCC in healthcare?
• How has the concept developed?
• What is the applicability of CCC and what are its limitations?
• How does the concept of CCC benefit and inform children’s healthcare?

Keywords Child-centered; children’s health; patient participation; pediatric(s)

Introduction

In 1989, the UN Convention on the Rights of the Child acknowledged the status, role and rights of children, and contemporary health care standards, policies guidelines and practices are designed to reflect the convention.1 There has been a shift within many countries to acknowledge children as agentic beings with the potential to be actively engaged within their own community and in society.2 A child-centered care (CCC) approach in healthcare reflects this wider acknowledgement of children’s rights and their right to be involved in their own healthcare.3

Child-centered care situates children and their interests at the center of thinking and healthcare practice and involves the inclusion of children and young people as participants in their care and decision-making.4 The concept of CCC is becoming increasingly apparent in health literature and in shaping contemporary children’s healthcare.4,7

Described variously as an approach, a model, or as a way of working, the concept of CCC is often discussed in association with the more familiar and pervasive concepts in children’s healthcare of “patient-centered care” and “family-centered care” (FCC).4,8,9 Patient-centered care (also referred to as person-centered care) is defined as an approach to healthcare that is grounded in partnerships between health providers, patients and families and applies to patients of all ages.10

The concept of FCC emanates from work in the 1950s exploring the effects of hospitalization on children and the seminal Platt Report (Ministry of Health UK) on care of children in hospital.11,12 The definition of FCC has evolved over time and is described as a way of caring for children and their families that ensures health care is planned around the whole family, not just the individual child/person.13,14 In a family-centered approach, all family members are recognized as care recipients.15 Historically, health professionals and parents or carers have been recognized as the active members of the partnership in FCC, while children and young people have been allocated a passive role.7,16 While FCC has been widely embraced as a philosophy informing children’s health care, the implementation of FCC has remained problematic with studies indicating there is little evidence as to its effectiveness.17,18

Problems identified with FCC include: ineffective communication between health professionals, families and children; controlling access parents have to

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their child; parental needs being unmet; and differing expectations of the role parents have when their child requires health care.  

Child-centered care as a concept in health care has gained momentum in the 21st century. Its positioning in children’s healthcare follows on from the publication of the Bristol Royal Infirmary Inquiry Report and is about placing children and their families at the center of practice. The conceptualizations, definitions and applications of the three terms, patient, family- and child-centered care, lack clarity and there is considerable blurring and overlapping or even contradiction of meanings.

Some organizations providing children's health services draw upon the models patient- and family-centered care rather than CCC to describe their services. This appears to be in recognition that the term CCC does not clearly incorporate young people, whereas patient-centered care can be applied to all ages. In some commentaries the terms FCC and CCC are used almost synonymously and as a single concept. Coleman, for example, writes of FCC “that conceptualizes children as central to, and as active participants in their own care”. With such conceptual blurring it is impossible to ascertain whether CCC offers something unique to children or to healthcare practice/practitioners.

While there has been a considerable body of work, including systematic reviews pertaining to patient-centered care and FCC, less has been written about CCC in healthcare. The concept of CCC in health care has a more recent history than FCC and is still emerging or coming to maturity. However, the key concepts of CCC appear to be about childhood (defining thereof), the focus on the child in the context of the family, and not the other way round; the rights of the child as opposed to the family, or in combination with the family. There is a shift in hierarchy in CCC compared to FCC so that the child comes first.

A scoping review of CCC is timely in terms of clarifying the definition/s and the conceptual boundaries of CCC in relation to FCC; this in turn will assist clinicians to reconsider their understandings of CCC and FCC and, as appropriate, (re)orient their engagement with children within their everyday practice. Clarification about the concept of CCC will inform evidence-based children’s health approaches by being clearer about where the balance should fall between the child and their family (parents/carers and siblings) and where the emphasis should be placed in terms of the involvement of the child in care and decision making.

An initial search of the literature in preparation for this review protocol in the Cochrane Database of Systematic Reviews, JBI Database of Systematic Reviews and Implementation Reports, MEDLINE (PubMed), CINAHL, TRIP database and PROSPERO on January 10, 2017 identified that there are no scoping reviews or systematic reviews on the concept of CCC in healthcare.

Inclusion criteria

This scoping review will consider a wide variety of sources of literature including opinion pieces, reviews, policy documents, and qualitative and quantitative studies. All papers will refer to CCC in healthcare, in order to identify the current conceptualization of CCC.

Concept

This scoping review protocol has examined the concept of CCC. However, as CCC is an under-defined and emerging concept there are no pre-existing definitions for which there is consensus. However, for the purposes of this review our working definition of CCC is: any approach to or philosophy of care which is characterized by positioning the child at the center of the care (whilst acknowledging importance of parents/carers and family). In addition, this core definition would be linked to/underpinned by one or more of the following characteristics: a consideration of childhood and the developing child; an acknowledgement of children as agentic beings and the promotion of opportunities for children to be engaged actively within their care.

Context

This scoping review will consider CCC as it relates to any setting where healthcare may be provided (e.g. in-patient and out-patient settings; tertiary, secondary and primary care settings; respite and hospice settings; medical home, home-based care and school settings).

Types of studies

The scoping review will consider research papers of any kind, opinion papers, policy documents from governments, healthcare organizations, professional bodies and consumer advocacy groups.
Papers published in English from 1990 will be included. The year 1990 has been chosen as the cut-off date as this is the point at which the concept of CCC in health care appears in the literature, albeit that child-centeredness was originally only presented within discussions on family-centered care. The selection of 1990 as the cut-off also ensures that literature from the decade that predates the 2001 Kennedy Report is included, as this report was pivotal in starting the shift towards a more child-centric approach to service delivery.²¹

Methods
This scoping review will adopt the methodology for JBI scoping reviews as described in the JBI Reviewer’s Manual.²⁵

Search strategy
The search strategy will be comprehensive in order to identify both published and unpublished (gray literature) primary studies and reviews. A three-step process will be used as is recommended for JBI reviews. An initial limited search of MEDLINE, (PubMed) and CINAHL will be undertaken to identify articles on this topic, followed by analysis of all the text words and subject words contained in the titles and abstracts, and of the index terms used to describe these articles. This will inform the development of a second search strategy using all identified keywords and index terms across all included databases. Thirdly, the reference list of all identified reports and articles will be searched for additional studies. An example of a proposed detailed search strategy for one major database is detailed in Appendix I. The search strategy was conducted in CINAHL on the concepts of CCC and children’s participation in decision-making. For each concept, separate searches were undertaken for text words in the title (TI) and abstract (AB), and for CINAHL Headings exploded subject headings (MH+) and major subject headings (MM). This allows for the preliminary search strategy to be modified line by line as further articles with other terms are retrieved and for the strategy to be adapted to other database searches. The asterisk operator (*) was applied to find variant spellings and word endings in text word terms.

The reviewers intend to contact authors of primary studies or reviews for further information if it is considered relevant. Only articles in English will be included in this review.

Information sources
The following databases and search engines will be included: CINAHL, MEDLINE, Web of Science and Google Scholar. Search for gray literature will utilize Google Scholar, Open Grey, Dissertation Abstracts International and CINAHL Plus. Papers which refer to other papers (post 1990 as justified earlier) in terms of CCC will be hand searched to the point where no others emerge.

An initial list of keywords has been generated and will be expanded upon prior to the search process. This list includes, but will not be limited to: child-centered; child-centered care; children’s health care; rights; agency; engagement; choice; participation; decision-making.

We will set up alerts to ensure that we are made aware of any new papers that are published.

Data extraction
Data will be extracted from papers included in the scoping review using the draft data extraction tool listed in Appendix II. This is aimed to enable a logical and descriptive summary of the results that align with the objective and questions of the review and will facilitate the identification of the conceptualization and development of CCC and how it is applied. Review will be undertaken by two independent reviewers. The data extracted will include specific details about the authors, year and type of publication, country of origin, setting (e.g. inpatient, day-care, tertiary, home etc. as previously stated), speciality (e.g. surgery, rehabilitation, intensive care, neurology), aims/purpose, methodology and methods, sample (e.g. clinicians'/parents'/child’s perspectives) and key findings that relate to the scoping review question and objectives (e.g. applicability, benefits), and limitations/quality issues. Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer. Authors of papers will be contacted to request missing or additional data where required.

The draft data extraction tool will be modified and revised as necessary during the process of extracting data from each included paper. Modifications will be detailed in the full scoping review report.

Data synthesis
Depending on the literature identified, and due to the heterogeneity and descriptive nature of the literature, results will be presented to ensure that they
Effectively and clearly communicate the findings. Thus, we will translate our findings into different visual and text based formats, for example, infographics, tables and charts as well as a visual map that reflects the key findings and their relationship to each other. Where appropriate, overview graphics (presenting the macro picture) will be broken down to allow a more defined micro-presentation. As the core of these illustrative components, the descriptive/narrative text will be constructed to clearly align with the objective of mapping the applicability, benefits and potential of CCC to inform the evidence base of children’s healthcare, policy and practice.

References
Appendix I: Search strategy

Search conducted in CINAHL via EBSCOHost
October 24, 2017

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### Appendix II: Data extraction tool (proposed)

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