

Mapping Evidence Of Patient-centered Care For Persons Living With Hiv: A Protocol For A Systematic Scoping Review

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Protocol

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Abstract

Background: The Human Immunodeficiency virus (HIV) is a global, chronic health challenge that warrants a multidimensional approach to treatment and care. Notwithstanding the strides made in suppressing the virus, evidence illustrates challenges in persons living with HIV (PLHIV) experiences of treatment and care. Such experiences threaten HIV patients' retention, adherence, mortality, comorbidities and the global community's efforts to end the AIDS epidemic by 2030. A patient-centred approach (PCC) to HIV care and treatment could improve patients' health care experiences, wellbeing, retention and adherence and strengthen patient-provider relationships. Hence, the aim of this scoping review is to comprehensively map existing evidence of PCC in HIV treatment and care. Additionally, the review will identify and describe gaps that could inform future research and interventional programmes or the need for systematic reviews.

Methods and analysis: As HIV PCC is a broad topic, a systematic scoping review, that includes peer-reviewed journal articles and grey literature will be conducted. Online databases: (Google scholar, Scopus, EBSCOhost, PsycINFO via ProQuest, PsycARTICLES via ProQuest, International Bibliography of the Social Sciences (IBSS) via ProQuest, UNAIDS databases will be accessed. Humanitarian databases such as the World Health Organization (WHO) and United Nations Educational, Scientific and Cultural Organization (UNESCO) will also be accessed to identify literature on PCC for PLHIV. Such literature will be published between 2009 and 2019. Two reviewers will independently extract data from relevant search engines, utilising specific inclusion and exclusion standards. Thereafter thematic content analysis will be performed, and a narrative account of the findings will be presented.

Discussion: As this is a scoping review, no ethical approval is required. Once the review is completed all summarized data will be disseminated in peer-reviewed journals, at national and international conferences, clinical settings and to policy makers. This is aimed at improving PLHIV's experiences in clinical settings, practice and care.

Keywords: HIV, patient-centred care, patient experiences, ART programme; ARVS; patients

Background

The Human Immunodeficiency virus (HIV) is a global, chronic health challenge with the United Nations 2019 fact sheet documenting 37.9 million people living with HIV (PLHIV) and 23.3 million PLHIV accessing antiretroviral therapy (ART) in 2018 (1). Additionally reporting 1.7 million new HIV infections and 770 000 individuals dying of AIDS-related illnesses in 2018 (1). Notwithstanding the monumental progress in suppressing the HI virus, the disease being rendered manageable and the global community's concerted efforts to end the AIDS epidemic by 2030, PLHIV articulate challenging experiences of treatment and care. Moreover, PLHIV are confronted with morbidities, co-morbidities and psycho-social factors with detrimental consequences (2,3). Furthermore, evidence illustrates barriers and challenges to

care such as patients' retention and treatment non-adherence, defaulting on ART and PLHIV articulating challenging treatment and care (4,5,6).

To sustain, improve and magnify the successes of ART programmes globally and end the AIDS epidemic by 2030, a multidimensional approach to HIV treatment and care is warranted (7). One such approach gaining momentum is patient-centred care (PCC) which entails a paradigm shift from traditional provider-centred care to a patient-centred focus (8). Patient-centred care positions patients at the epicenter of their care and treatment by incorporating their unique desires, needs, values and input in all interactions and discussions surrounding their health and wellbeing (9,10). This participative approach is achievable through comprehensive, consistent engagement by all healthcare stakeholders and systems involved in patients' healthcare journeys, decisions and discussions (11,12). The basic tenets of PCC include health promotion, effective reciprocal communication, partnerships and the effective use of resources (13). Moreover, PCC involves a robust partnership between patients and providers that facilitates the cocreation and implementation of care and treatment that best suits patients (14).

The benefits of PCC on clinicians, patients, health programmes and settings include reduced medical costs, improved adherence and health outcomes, strengthened and improved patient-provider relationships rendering improved patients' health care experiences, wellbeing, retention and adherence. (15,16,17,18). This is achieved by incorporating and respecting patients' individuality, preferences and needs through strengthened patient-provider relationships within warm, nurturing health environments (19,20). Improved HIV treatment and care that benefits the patient, their family, work life and the health environment is beneficial to achieving the goal to end AIDS by 2030. Moreover, it could encourage more PLHIV to access and adhere to ART.

In conclusion, a scoping review was chosen over a systematic review as a comprehensive range of literature mapping evidence of a broad topic such as PCC for PLHIV was required (21,22). Moreover, this information synthesis technique would summarise and disseminate existing literature findings, identify literature gaps and various types of evidence, preempt future research and determine the feasibility of conducting subsequent systematic reviews (23). Based on the research question, preliminary searches were conducted on various databases to ascertain evidence of HIV-related PCC literature (24,25). However, to the best of our knowledge few scoping or systematic reviews have been conducted on the topic (26,27). Hence, the relevance of conducting this scoping review. Furthermore, a review of evidence relating to patient-centred care rendered to PHIV will assist in the awareness of the various types of services, best practices, challenges and experiences of PLHIV and the roles that PCC can play in PLHIV's health journeys.

Methods

To ensure an updated, comprehensive scoping review, Arksey and O'Malley framework, Levac and associates enhancements, the 2015 Joanna Briggs Institute (JBI) and Tricco et al. guidelines informed this review (28,29,30,31,32). Peer-reviewed journal articles and grey literature on patient-centred care for

persons living with HIV will be included in this review. The following stages will frame this review 1) Eligibility of the research question 2) Identifying relevant studies 3) Study selection 4) Charting and extraction of data and 5) Collating, summarizing and reporting the results.

1. Identifying the research question

This study's research question is:

What literature exists on patient-centred care for people living with HIV?

Hence, the objective is to: To map existing evidence from literature on patient-centred care for people living with HIV.

Eligibility of the research question

A PCC (*Population, Context, Concept*) framework (Table 1) adequately addresses the eligibility of the research question.

2. Identifying relevant studies

All published and unpublished studies and grey literature pertaining to patient-centred care for persons living with HIV, will be included in the scoping review. Online databases: (Google scholar, Scopus, EBSCOhost, PsycINFO via ProQuest, PsycARTICLES via ProQuest, International Bibliography of the Social Sciences (IBSS) via ProQuest, UNAIDS database, World Health Organization (WHO) and UNESCO databases) will be utilized to identify literature written in all languages between 2009 and 2019 for relevance and currency. Manual searches from retrieved articles reference lists will be consulted for additional literature by DMM and SMN. In cases where articles are inaccessible, corresponding authors will be contacted to provide copies of same. Additionally, experts in the area of PCC and HIV will be consulted regarding the existence of relevant studies. Dissertations, theses and symposium abstracts will also be sources of grey literature. Search terms will include "patient-centred care", "persons living with HIV", "HIV-infected people", "HIV-positive patients", "HIV sero-positive".

A pilot literature search was conducted by DM and PN, a public health librarian, in November 2019 for articles from January 2009 to October 2019 on the University of KwaZulu-Natal online databases of MEDLINE via EBSCOHost, PubMed and ScienceDirect by DM and PB, a public health librarian. The search strategy included a combination of controlled vocabulary and Boolean-paired keywords. The table below indicates the databases, search string and keywords and the number of articles/studies retrieved. The study was restricted to humans with no language restrictions. Review and research articles were the limiters. The referencing software EndNote X9 was used to store literature. Table 2 contains the results of the pilot search.

3. Study selection

Studies will be selected by DMM and PN, independently based on the titles, abstracts and full articles and literature containing information that answers the research question and eligibility criteria. To test the selected databases and keywords a search plan was piloted by two screeners (DMM and PN) independently. However, the actual scoping review will consist of four (DMM, PN, MHP and a research assistant) team members. All relevant literature, excluding duplicates thereof, will then be uploaded to an Endnote X9 library exclusively created for this scoping review. Both DMM and PN will independently conduct comprehensive title and abstract screening and thereafter independently conduct full article screening. All discrepancies encountered by the two reviewers during the abstract and full article stages of the actual scoping review will be discussed and resolved by a third screener (MHP). To ensure all new relevant literature are included the research assistant will conduct weekly searches and update the database. The study selection process will be summarized using a PRISMA ScR flow chart attached (Fig. 1) (31). All studies that do not meet the inclusion criteria will be excluded.

Inclusion Criteria

Studies that meet the following criteria will be included:

- Literature written in all languages.
- Full text literature focusing on patient-centred care within a HIV-context.
- Full text grey literature (Government reports, policy statements, conference proceedings, theses and dissertations).
- Studies and articles published from 2009 to 2019.

Exclusion criteria

- Literature that focuses on patient-centred care and other illnesses.
- Literature which is unavailable in full-text.

4. Charting and extraction of data

To document the extracted data, a data charting table (Table 3) has been developed and will be piloted by DMM and PN and thereafter utilized throughout the data extraction process. The data charting table includes author names and publication date, title, study aim, study design, study setting, study population, concept, context, key findings, significant findings and key conclusions. This table will only contain literature that possesses variables or themes that comprehensively answer the research question. The data chart will frequently be updated by the research assistant. Discrepancies will be resolved in collaboration with the reviewers and the lead author (DMM).

5. Collating, summarizing and reporting the results

The extracted findings will be thematically grouped and analyzed using thematic content analysis using the NVivo version 12 software package. These themes will be examined in relation to: the aim of the study, validity of the research question and the suggestions from the findings for future research. Discrepancies will be resolved by consensus throughout this process.

Quality assessment

The quality of evidence will be assessed through utilizing the Mixed Methods Appraisal Tool (MMAT)– Version 2018 (33,34). The tool will assist in ensuring that the quality and aims outlined for the study are expansively presented to eliminate any risk of partiality. This will be achieved through examining author's names and year of publication, title, study aim, study setting, population, concept, context, significant findings and key conclusions. The quality of this study will be determined by the results, and only literature that possess a high score from the data extraction process will be approved.

Discussion

The proposed scoping review will map evidence of PCC for persons living with HIV as PCC is characterized as a value-adding process for patients and health systems within several health disciplines (35,36). The global community's goal to end AIDS by 2030, improve HIV programmes and increase the number of PLHIV on ART renders this review relevant and valuable. Moreover, although evidence has shown the benefits of PCC in most spheres of healthcare, little is known on the impact of PCC within the HIV arena. The reason for this review's extension of the context to include the global community over a ten-year period is to generate relevant findings pertaining to PCC for PLHIV in various health care settings over a substantial period. Results from this scoping review will generate significant data pertaining to patient-centred care for persons living with HIV, which will be useful to humanitarian organizations such as WHO, UNESCO, ACHPR, HRW, ILGA, UNHRC and UNAIDS.

The results of this scoping review could be four-fold, 1) summarise existing literature, map literature gaps that currently exist on this subject, offer suggestions on how further research can address these gaps and the relevance of conducting systematic reviews 2) promote dialogue around patient-centred care for PLHIV 3) contribute to the improvement of the care and treatment of PLHIV and 4) address the role of governments, community-based organization (CBO's), non-governmental organizations (NGO's), policies and awareness campaigns in addressing patient-centred care for PLHIV. This four-fold approach supports The Joint United Nations Programme on HIV/AIDS (UNAIDS), the Sustainable Development Goals (SDG's) and the End the AIDS Epidemic by 2030 universal agenda of eliminating violations against human rights and having zero discrimination and respecting the dignity of PLHIV. Furthermore, the strengths of this review are its importance for clinicians, healthcare systems, patients and policy makers. Moreover, its outcomes would be published in peer-reviewed journals and presented at international seminars.

Abbreviations

ACHPR: African Commission on Human and Peoples Rights

AIDS: Acquired Immunodeficiency Syndrome

ART: Antiretroviral therapy

ARV: Antiretrovirals

CBOs: Community-based Organisations

HIV: Human Immunodeficiency Virus

HRW: Human Rights Watch

ILGA: International Lesbian, Gay, Bisexual, Trans and Intersex Association

JBI: Joanna Briggs Institute

NGOs: Non-governmental Organisations

PCC: Patient-centred care

PCC: Population, Context, Concept

PLHIV: People living with HIV

SDGs: Sustainable Development Goals

UNHRC: United Nations Human Rights Council

UNAIDS: The Joint United Nations Programme on HIV/AIDS

UNESCO: United Nations Educational, Scientific and Cultural Organization

WHO: World Health Organization

Declarations

Ethics approval and consent to participate

Not applicable. This scoping review will not consist of human participants.

Consent for publication

Not applicable.

Availability of data and materials

All data generated or analyzed during this study will be included in the published scoping review article and will be available upon request.

Competing interests

The authors declare that they have no competing interests.

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Author's contributions

The scoping review protocol was conceptualized by DMM and developed by DMM, MHP and PN. The actual scoping review will be a collaborative effort of four (DMM, MHP, PN and a research assistant) team members.

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Tables

Table 1: PCC Mnemonic determining the eligibility of the research question

P- Population	<p>People living with HIV (PLHIV)</p> <p>Refers to all people living with the Human Immunodeficiency virus (1).</p>
C- Concept	<p>Patient-centred care (PCC)</p> <p>Refers to the process of positioning patients at the epicentre of their care and treatment by incorporating their unique desires, needs, values and input in all interactions and discussion surrounding their health and wellbeing (9).</p>
C- Context	Global

Table 2: Pilot database search results

Database	Search string and keywords	Number of articles/studies retrieved
ScienceDirect	patient-centred care AND persons living with HIV	4,830 results Review articles (1,357) Research articles (3,473)
ScienceDirect	patient centered care AND "HIV-infected people" OR "patients living with HIV" OR "HIV positive patients" OR "HIV seropositive"	3,580 results Review articles (964) Research articles (2,616)
ScienceDirect	patient centered care AND HIV-infected people OR patients living with HIV OR HIV positive patients OR HIV seropositive	45,817 results Review articles (13,256) Research articles (32,561)
Pubmed (1)	((Human Immunodeficiency Virus patient centred care) AND (("HIV patient centred care") AND ("2009/01/01"[PDat] : "2019/12/31" [PDat]) AND Humans[Mesh])) AND persons living with HIV	16
Pubmed (2)	(("Patient-Centered Care"[Mesh]) AND "HIV Long-Term Survivors"[Mesh]) OR "HIV Seropositivity"[Mesh] Review articles (13,256) Research articles (32,561)	5200 Review articles (13,256) Research articles (32,561)
EBSCOHost	Human Immunodeficiency Virus patient centred care) AND (("HIV patient centred care") AND Humans AND persons living with HIV	392606
The initial search query did not yield any results. However, using SmartText Searching, results were found based on the keywords provided.		

Table 3: Data charting table

Author and publication date
Title
Study aim
Study design
Study setting
Study population
Concept
Context
Interventions
Key findings
Significant findings
Key conclusions

Figures

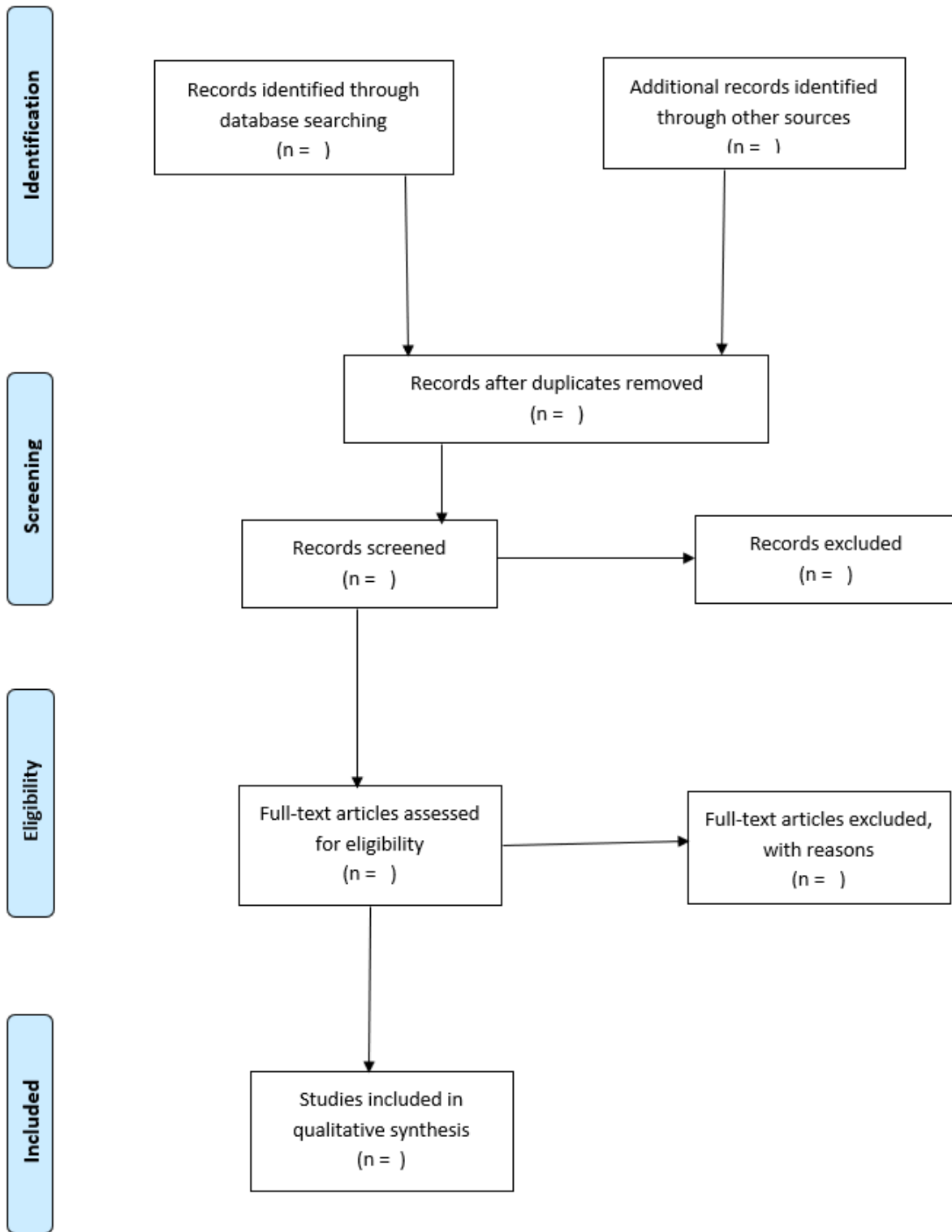


Figure 1

PRISMA ScR flowchart demonstrating literature search and selection of studies