

# BMJ Open Adapting to, integrating and self-managing HIV as a chronic illness: a scoping review protocol

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## ABSTRACT

**Introduction** The process of adapting to a life with a chronic illness, is a well-researched phenomenon for a number of common chronic illnesses. The construct, adaptation, embeds the notions of integration of the chronic illness into identity and self-management. Integration precedes self-management and is key to living positively with a chronic illness. Adaptation is an important concept in understanding trajectory and outcomes of living with a chronic illness. Applicability of these concepts to HIV as a chronic illness; when suppressive adherence has been achieved, however, is unknown. Specifically, the adaptation process to living with HIV as a chronic illness, the integration of HIV into identity and the resulting self-management behaviours by adults living with HIV are relatively unexplored. We describe a protocol for a scoping review of adaptation to living with HIV, we structure the enquiry around integration of HIV into identity and self-management and interrogate theories, models and frameworks that have been proposed and studied and we evaluate them for relevance and usefulness in the care and management of HIV.

**Methods and analysis** Methods proposed by the Johanna Briggs Institute will be followed. The protocol was drafted using the Preferred Reporting Items for Systematic Reviews and Meta-analysis extension for Scoping Reviews and was registered with the Open Science Framework. MEDLINE, SCOPUS, Cochrane Library, CINHAL and SocINDEX databases will be searched. A search in Social Science Research Network eLibrary and Open Access Theses and Dissertations will gather grey literature and reference lists of included sources will be screened. Study selection process will involve a title and abstract review and full text review, guided by clearly defined inclusion and exclusion criteria.

**Ethics and dissemination** Ethical approval is not required because this is a proposed review and collection of data on publicly available materials. The results will be published in a topic relevant journal and presented at related scientific events.

## INTRODUCTION

The efficacy of antiretroviral therapies (ART) in reducing HIV-related mortality and morbidity and ubiquitous availability of and access to ART treatments both in income rich and low-income and middle-income

## Strengths and limitations of this study

- This is an original scoping review protocol of concepts related to and assisting with understanding adaptation to living with HIV as a chronic illness by adult individuals living with the illness.
- The proposed review will explore literature on constructs of living with HIV as a chronic illness but also consider integration of HIV into identity and self-management. It also attempts to map and document what may be beneficial to achieve sustained outcomes in HIV chronic illness care and management.
- Material identification and synthesis will include specialised databases and grey literature data, thus improving the comprehensiveness of the search.
- Exclusion of studies with certain key populations from the scope is necessary as these groups' characteristics may be potentially confounding factors in the adaptation process. This and the exclusion of studies documented in languages other than English may limit the review's richness.

countries (LMICs) effected a fundamental shift in the clinical management of HIV. A once fatal acute illness transformed into a manageable chronic illness and people living with HIV (PLHIV) on long-term therapy can reach a life expectancy comparable with that in the general population.<sup>1 2</sup>

To consider HIV as a chronic illness and to realise the best possible clinical outcomes, PLHIV on ART must achieve near perfect, lifelong adherence rates of 95% or more.<sup>3 4</sup> Although challenges and barriers to good ART adherence have been elaborated on<sup>5 6</sup> and effective strategies aimed at improving self-management for PLHIV have been identified,<sup>7</sup> poor adherence to ART persists and is recognised as of critical global public health concern.<sup>8–10</sup> Studies in all settings have reported ART adherence rates below the 95% rate required for optimal viral suppression.<sup>11 12</sup> Additional evidence also suggests that adherence rates decline the longer PLHIV have been on treatment.<sup>9 11</sup>

Adherence to treatment and clinical outcomes are typically regarded as the most important indicators for evaluating the success or failure in the management of many chronic illnesses.<sup>13 14</sup> HIV is no exception. The importance of adherence to ART and viral suppression are often first pieces of information or education patients are provided with once diagnosed.<sup>15</sup> While this knowledge is crucial, this framing of adherence to treatment becomes problematic because it assumes the individual to be submissive and non-questioning subjects in their own care.<sup>16 17</sup> This biomedical approach to chronic illness management and adherence, can undermine the individual's personal experience, psychosocial evolution and growth related to living with a chronic illness.<sup>13 16</sup>

Learning to live with a chronic illness, referred to in this paper as adaptation, has been widely explored in previous research and there is extensive literature about the theory of living with a chronic illness.<sup>18–22</sup> This concept is embedded in the definition of chronic illness itself, defined as the lived experience of long-term ill health.<sup>23 24</sup> Chronic illnesses may be non-communicable (eg, diabetes) or communicable, as is the case for HIV, and encompass how people live and cope with the interference they bring.<sup>23 24</sup> The adaptation process is conceptualised in a range of different ways within the literature; biographical work, legitimisation, adjustment and transition, among others.<sup>25–29</sup> Despite descriptive differences, these conceptualisations commonly argue that the chronically ill individual must appraise and acknowledge their changed situation as a result of the illness, incorporate or integrate the chronic illness into their identity, lives and lifestyles and take action to change their personal circumstance.<sup>21 25 28</sup> Fundamentally, the ideal outcome of adaptation is for individuals to take control of their health and therefore live as well or positively as far as their chronic illness and context allow.<sup>30 31</sup> Pertinent to this review are the notions of and the inextricable link between integration of the chronic illness into identity and self-management or taking action to manage the illness by chronically ill individuals.

A number of studies have theorised about, reviewed and empirically tested the concept of integration of chronic illness into identity.<sup>17 32–36</sup> Integration of chronic illness into identity is defined as an ongoing process of reconciling the duality of self; merging the past non-ill self with the present chronically ill self and creating a new identity that is positively adapted to living with chronic illness.<sup>33 37–39</sup> Integration has been shown to be the very premise of healing and ultimately living well with a chronic illness.<sup>34 40 41</sup> Moreover, it is because of integration of chronic illness into identity that chronically ill individuals are able to cultivate novel and constructive health patterns, successfully engage in health promoting behaviours and actively assume responsibility for their illness self-management.<sup>28 39–42</sup>

Self-management on the other hand is embedded in and could be perceived as both a characteristic of and an outcome of the process of integrating chronic illness

into identity.<sup>21 28 29 43</sup> Studies have demonstrated self-management as a descendent of integration, that integration precedes self-management and that without integration, the self-management processes and or outcomes may be suboptimal or not completed.<sup>32 35</sup> Others have shown how the undertaking of self-management related tasks of a chronic illness could be used to manage chronic illness identity issues.<sup>28 44</sup> Self-management theory considers the chronically ill individuals and their families as critical role players in their own care and treatment.<sup>45</sup> With self-management, the assimilation of healthful behaviours into daily function and their continuous and consistent performance throughout the illness trajectory are deliberate, this with the aim of preventing or mitigating the potential negative impact of chronic illness.<sup>28 45–48</sup>

Be that as it may, research into the broader construct of adaptation and the concepts of integration of chronic illness into identity and self-management, has tended to focus on common chronic illnesses such as rheumatoid arthritis<sup>28 49</sup> and diabetes.<sup>17 34 50</sup> With ubiquitous availability of and access to ART rendering HIV, a once fatal infectious illness, to become a manageable chronic illness<sup>1 2 51</sup> research interest has also progressed, although gradually, towards highlighting the importance of recognising the critical role of integration of HIV as a chronic illness into identity in its self-management.<sup>36 52–54</sup> For instance, Wouters<sup>36</sup> elevates the notion of integration (of HIV) into identity and proposes a theory of hybrid identity, that is, incorporation of HIV and ART into one hybrid identity that is susceptible to, yet resilient against changes caused by external and internal conditions. The hybrid identity may be used by PLHIV as a resilience resource and may in fact, potentially contribute towards sustained adherence to ART.<sup>36</sup> On the other hand, Ho and Goh<sup>53</sup> highlight gaps in the available literature, pointing to issues related to conceptual clarity, that the studies are not sufficiently underpinned by theory and that instances where there is rejection of an HIV identity should also be appreciated in the literature.<sup>53</sup>

However, the extent of applicability of the existing theoretical work on chronic illness adaptation, to HIV, has not been comprehensively explored. There is therefore a need to identify and map the extent to which HIV-related adaptation research has been conducted. To this end, the proposed review will take stock of the existing studies and will contribute a review of the scope of research on adaptation, including the concepts of integration into identity and self-management, in relation to HIV. Our primary objective is to identify, synthesise and summarise empirical research relating to adaptation to living with HIV as a chronic illness. Within the identified HIV adaptation literature, we explore and distill concepts, frameworks or theories that have been used or proposed, deliberately scrutinising the literature for integrating HIV into identity. We further categorise key characteristics related to integrating HIV into identity, including self-management aspects. We do this to achieve two undertakings: we

first intend commenting on applicability, relevance and usefulness of these concepts to HIV as a chronic illness and second, we aim to locate and clarify the concept of HIV illness identity.

Studies with HIV positive adults 18 years and older, addressing the concept of adaptation as described, will be included in the review. We will consider HIV research conducted between the years 2000 and 2020, the period within which access to ART became widespread and rendered HIV a manageable chronic illness,<sup>1</sup> particularly for LMICs. Although contexts may vary, studies conducted in both HICs and LMICs will be reviewed. Only studies published in English will be considered for inclusion.

## METHODS AND ANALYSIS

### Study design and protocol

The aim of this study is to understand the extent of knowledge in the area of adaptation, integration and self-management in relation to HIV. A scoping review is the most appropriate approach as it maps concepts underpinning a research area and the main sources and types of evidence available.<sup>55</sup> This study protocol is informed by the scoping review methods proposed by the Johanna Briggs Institute (JBI).<sup>56 57</sup>

The Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews format and checklist was employed for the drafting of this scoping review protocol.<sup>55</sup> This protocol title was registered with the Open Science Framework on 2 August 2020 with registration number [osf.io/3zv4f](https://osf.io/3zv4f). Any significant changes made to the protocol will be documented.

### Eligibility criteria

The inclusion criteria are based on the Population, Concept and Context framework as proposed by the JBI for scoping reviews as a less restricted alternative to the Population, Intervention, Comparator, Outcome framework.<sup>56 57</sup>

### Population/types of participants

The current scoping review will include review and empirical studies with either qualitative or quantitative content relevant to adaptation to living with HIV as a chronic illness and with reference to HIV positive adults 18 years and older, male or female. Studies including infants, children, adolescents and key populations, such as gay men, other men who have sex with men, sex workers, transgender people, people who inject drugs and prisoners<sup>58</sup> as participants and those that report gender as a non-binary concept will be excluded. This exclusion is based on the understanding that these personal demographic, social or sexual behavioural characteristics may influence how living with HIV illness is or is not experienced, and that these characteristics may therefore constitute confounding population factors.

### Concept

The core and primary concept of interest for the proposed scoping review is adaptation to living with HIV as a

chronic illness. We understand adaptation to be a broad concept that encompasses the notions of integration and self-management. We, therefore, will not limit our search to the two concepts. In addition, given our interest in the impact of the process of adaptation on the patient, a critical concern for our scoping review is to consider only those studies that document the lived experience of HIV, as told by or from the perspective of the patient. To this end, studies detailing living with HIV from the family and or a professional's perspective will be excluded. The scoping review will additionally purposively seek and extract from those selected HIV adaptation studies, any emerging aspects of integration and patient self-management, as a result of the adaptation process. Lack of reference to either integration or self-management will however not constitute an exclusion criterion.

### Context

The primary focus of the scoping study is HIV as a chronic illness. To this end, adaptation studies of other chronic illness will not be included in the scoping review. In addition, searches for the review will be contained to studies conducted between the years 2000 and 2020; a period during which HIV had largely been classified as a manageable chronic illness simultaneously in both HICs and LMICs.

### Information sources and search strategy

The literature will be sourced through searches of: (1) electronic bibliographic databases; (2) grey literature and (3) screening of reference lists of included documents. First, the databases, MEDLINE, SCOPUS and Cochrane Library, will be searched as they have been recommended to be the ideal database combination for expansive coverage.<sup>59 60</sup> Additionally, because the topic under review, adaptation to living with HIV as a chronic illness, straddles disciplines, we will also search the CINAHL and SocINDEX (via EbscoHost) databases. Second, a grey literature search of Social Science Research Network (SSRN) eLibrary and Open Access Theses and Dissertations will also be conducted. Finally, screening of reference lists of included documents for relevant articles will be undertaken. This comprehensive search approach was selected to exhaust all possible information on the subject. Types of published peer-review articles eligible for inclusion will include original research, review articles, short reports and case studies.

### Electronic bibliographic databases

An experienced research librarian provided expert input into the development of the search strategy. An analysis of the Medical Subject Headings terms and the words in the title, abstract, and keyword sections of a subsample of relevant literature, about adaptation to living with HIV and or chronic illness,<sup>21 25 29 54 61–63</sup> informed the search strategy design. In addition, the search will include all identified synonyms for adaptation, to optimise sensitivity. Using an iterative approach, the research team

will review preliminary search results for relevance and will suggest modifications and improvements before the search strategy is finalised. The search strategy will be validated using the same subsample of papers. A sample search strategy developed for PubMed (detailed in online supplemental appendix I), will be refined for use in the other selected electronic databases, with assistance from the librarian. The lead reviewer will perform the final searches from inception to date of search, export the search results into Mendeley Desktop and remove all duplicates.

### Grey literature Search

To preclude publication bias and to further explore the breadth of information on the topic, a grey literature search will also be conducted. A systematic search of the SSRN will collect any available preprints on the subject and via the Open Access Theses and dissertations platform, we will gather dissertations and theses with relevant content.

### Reference list screening

Reference lists of all included sources will be screened for potential additional sources.

### Source selection

For the purposes of this proposed scoping review, we have adopted and customised the JBI template for source of evidence details, characteristics and results extraction instrument (online supplemental appendix II). The adapted extraction tool will be used in both the initial stages of study screening (to confirm study relevance) and selection and the later phase of data extraction from the selected studies. To ensure systematic and reproducible study selection and data charting processes and to foster high inter-rater reliability, a calibration exercise will be undertaken. For this pilot, first the review lead will use a seminal article to ascertain if the extraction instrument is appropriate for its intended use. Once confidence with the tool has been internally established, all members of the review team be involved in the pilot of the extraction tool, using a minimum of twenty abstracts to review titles and abstracts against the above-mentioned inclusion criteria. We will review the results of the calibration, discuss any discrepancies among reviewers and make refinements to the extraction tool as identified and required. We will then share the balance of the search results among the reviewers in the team for duplicate independent screening. Reviewers will at the same time document reasons for exclusion on the extraction form and progress those articles considered relevant and eligible, to the second phase of full-text screening. Confirmed sources for inclusion in the scoping review will then be moved to the final stages of data extraction, charting and synthesis.

### Data extraction, charting and synthesis and presentation of results

The customised data extraction tool (online supplemental appendix II) will be used to collect relevant

information on: (1) key study characteristics (eg, publication year, publication type, study design, country, patient population characteristics); (2) detailed information on the definition and words and terms used to describe adaptation or living with HIV anywhere in the article and (3) information on words and terms used to describe any aspect of HIV self-management anywhere in the article. The lead reviewers have formulated a matrix of variables that will form the basis for data extraction (table 1).

Following identification and selection of relevant HIV adaptation literature, we will explore and isolate within those studies, the theories, constructs and models and frameworks that have been applied or proposed. Subsequently, we will scrutinise and extricate from those theories, constructs and models any aspects related and relevant to integration into identity and self-management of HIV. We aim to provide a descriptive summary of what has been foregrounded in the area of living with HIV as a chronic illness, and offer commentary on applicability, relevance and usefulness of discovered concepts within the literature. Where relevant, we intend suggesting how these concepts may be adapted specifically for HIV as a chronic illness.

The reviewers will independently chart data in duplicate from each eligible article. Should there be any disagreements among the reviewers, these will be resolved through discussion or in case of an impasse, the supervising researcher will provide final adjudication. Data charting will be implemented using Microsoft Excel. Throughout these processes of screening, data extraction and charting, the supervising researcher will provide oversight and perform frequent and random checks. A narrative description and summary of the search decision process, study identification and inclusion decision flow chart; aims of the reviewed sources, concepts adopted and results that relate to the review objective will precede the presentation of the results. Importantly, the relevance of isolated data, together with supporting evidence for the implications to the review objectives will be presented, for included sources. A final meeting will be held between the lead reviewer, senior supervising researcher and members of the review team to review study results, discuss any refinements proposed and finally approve the final outcome of the study.

### Risk of bias assessment or quality appraisal

Consistent with the JBI scoping review methodology and as this is a scoping review that aims to map all available knowledge regarding adaptation and self-management in relation to HIV, we will not perform a risk of bias assessment. Although not routine for scoping reviews, we will however appraise the quality of the selected articles, reviews, reports and case studies. The JBI provides a number of critical appraisal tools, in the form of checklists, to evaluate the relevance, reliability and results of the selected published papers. A number of these checklists will be referred to and deployed in evaluating the quality of the potential studies for inclusion in the review.<sup>64</sup> Documents retrieved through the grey literature searches will not be appraised.

**Table 1** Matrix of sample variables related to the antecedent concept (integration of HIV) and descendent concept (self-management of HIV), adapted from Schulman-Green *et al*<sup>48</sup> and organised according to the dimensions within the individual and family self-management theory<sup>45</sup>

Adaptation/ living with HIV	Adjustment, transitioning, acceptance, integration, incorporation, coping, making meaning, enrichment/growing as a person as a result of HIV, Identity		
Self-mManagement	Context dimension	Presence of family, friends healthcare providers and community	<ul style="list-style-type: none"> <li>▶ Social support (ability and capacity to enlist illness related help, for example, family member assists with collecting chronic medication from healthcare facility on behalf of patient)</li> <li>▶ Communication, relationship and service provision coordination</li> <li>▶ Spiritual support, capacity to address social and environmental challenges (eg, stigma)</li> </ul>
	Process dimension	Education about HIV and taking Ownership	<ul style="list-style-type: none"> <li>▶ Acquiring information about HIV</li> <li>▶ Learning about individual regimen</li> <li>▶ Learning about body's responses (side effects from treatment)</li> <li>▶ Becoming an 'expert' about HIV</li> </ul>
	Outcome dimension (proximal and distal)	actual engagement in self-management behaviours/ health promoting activities specific to HIV	<ul style="list-style-type: none"> <li>▶ Management of daily illness needs</li> <li>▶ Completing health tasks (keeping to care provision appointments)</li> <li>▶ Maintaining good health behaviours (consistent adherence to ART)</li> <li>▶ Changing health behaviours (consistent use of condoms)</li> <li>▶ Any other issues related to health status (viral load suppression), quality of life or</li> <li>▶ perceived well-being (living well with HIV)</li> </ul>

### Patient and public involvement

Given the methodological focus of this study, patients or the public were not involved in the design or drafting of our protocol or conduct, or reporting, or dissemination plans of our research.

### DISCUSSION

The review will allow for the identification, synthesis and summary of existing knowledge on adaptation to living with HIV as a chronic illness and specifically explore the concepts of integration and self-management for adult PLHIV. This review will enable the elaboration of a comprehensive repository of constructs used to describe the HIV chronic illness experience. In addition, because we also explore the usefulness and relevance of integration and self-management to HIV as a chronic illness, an adapted framework for managing HIV as a chronic illness, premised on these two concepts and informed by the scoping review will be developed.

### Application of results

At a broader theoretical level, the review work will build on a growing body of literature that examines the concept of adaptation to living with a chronic illness, specifically in our case, what may be applicable to HIV as a chronic illness. A unique aspect of the current scoping review is

that it not only explores literature on constructs of living with HIV as a chronic illness but by framing the scope against the concepts of integration and self-management, it also attempts to map and document what may be beneficial for sustained outcomes in HIV chronic illness management. Evaluating whether chronically ill individuals successfully adapt to living with chronic illness and their attempts at attaining the ideal of positive living in their illness trajectory, particularly for HIV, is an area within chronic illness care that is relatively unexplored. Exploring and expanding knowledge on these concepts therefore may strengthen and improve HIV chronic care and management.

At a practical level, this work may inform an approach to HIV chronic care by healthcare professionals that recognises the critical role of HIV illness adaptation and integration and its relation to self-management and eventual impact on patient outcomes. Furthermore, knowledge gathered from the study may contribute towards a framework that could guide healthcare professionals and significant others in facilitating and assisting PLHIV to successfully adapt to living with HIV, with the aim of assuring better outcomes for the patient.

### Potential implications and next steps

This scoping review work will form part of and be the initial stage of a multiphase research study aimed at

investigating the relationship between the construct of HIV illness identity; the extent to which the ill individual has integrated their HIV chronic illness diagnosis into their identity or sense of self, and patient outcomes such as sustained ART adherence. To this end, the scoping review will situate the HIV illness identity construct within the broader adaptation to living with a chronic illness body of literature.

### Ethics and dissemination

This scoping review forms an initial stage of a multi-phase doctoral research study and is also part of the Sinako cluster randomised control study, for which ethics approval has been obtained.<sup>65</sup> Results of the proposed review will be published in a peer-reviewed journal and presented at related scientific events.

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**Contributors** NPS conceived and developed the study objectives. NPS, LK, CM and EW contributed meaningfully to the drafting and editing of the protocol, reviewed and revised the final version of the protocol. All authors, NPS, LK, CM and EW approved the final manuscript.

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