### Perspectives of People Living with HIV on Access to Healthcare in Canada:

A Systematic Review and Framework Analysis.

by © Dr. Lydia Hesselbarth, Thesis submitted to the School of Graduate Studies in partial fulfillment of the requirements for the degree of

**Master of Science in Medicine (Clinical Epidemiology)** 

Faculty of Medicine

Memorial University

May 2020

St. John's, Newfoundland and Labrador

#### **Abstract**

The infection with HIV requires continuous healthcare. Some people living with HIV / AIDS (PLHA) in Canada enter the healthcare system only sporadically which has a negative effect on health outcomes for this population. To analyse patients' perspectives on access to healthcare, a systematic review with data synthesis and framework analysis was chosen to review Canadian literature. The "5 A's" on access to healthcare were used for synthesis and modified to fit our research question. Domains and Concepts on access to healthcare were developed, analyzed, and categorized into enablers, barriers, and suggestions from PLHA. From 26,190 articles, 334 met the inclusion criteria, leaving 11 relevant articles. The modified framework contained of 91 concepts in 7 domains: Acceptability, Availability, Accessibility, Affordability, Accommodation,

Communication, and Others. Our findings highlight research opportunities and can be used by decision makers and healthcare providers to improve access to healthcare for PLHA in the future.

#### Acknowledgements

I would first like to thank my supervisor Dr. Shabnam Asghari, who made this work possible. Her support and guidance gave me invaluable expertise throughout my thesis and masters program in clinical epidemiology.

I would also wish to express my appreciation to my supervisory committee Dr. Marshall Godwin and Dr. Kris Aubrey-Bassler for valuable suggestions, which helped greatly with improvement of the thesis.

Furthermore, I like to thank Alison Farrell who helped with literature search and citation management.

Finally, I would like the express my profound gratitude to my husband and my parents for providing me with support and continuous encouragement throughout my years of study and the process of this thesis. This achievement would not have been possible without them. Thank you.

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### List of Abbreviations and Symbols

HIV Human Immunodeficiency Virus

AIDS Acquired Immune Deficiency Syndrome

PLHA People Living with HIV / AIDS

HAART Highly Active Antiretroviral Therapy

ART Antiretroviral Therapy

MeSH Medical Subject Heading

Tiab Title and Abstract

EmBase Excerpta Medica database

MEDLINE Medical Literature Analysis and Retrieval System Online

PubMed Public/Publisher MEDLINE

CINAHL Cumulative Index to Nursing and Allied Health Literature

Cochrane Collection of databases, named after Archie Cochrane

PsycINFO Database of abstracts of literature in the field of psychology

RefWorks A web-based reference management software

HCP Healthcare provider

LBTQ / LGBTQ Lesbian, Bisexual, Transgender, Queer / Lesbian, Gay,

Bisexual, Transgender, Queer

e.g. Latin: exempli gratia; English: for example

NGO Non-governmental organization

IQR Interquartile range

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### **Chapter 1: Introduction**

#### 1.1 Background

1.1.1 Importance of access to healthcare for PLHA. Being HIV positive is a lifelong condition which currently affects about 75,500 Canadians and 36.7 Million people worldwide (Public Health Agency of Canada, 2015; World Health Organization, 2017). Since the implementation of highly active Antiretroviral Therapy (HAART) in 1996, the survival of HIV positive people has greatly improved (Antiretroviral Therapy Cohort Collaboration, 2008). Following this, people living with HIV / AIDS (PLHA) have a continuous need for healthcare according to current Canadian guidelines (British Columbia Centre for Excellence in HIV/AIDS Primary Care, 2015). Specifically, this means the monitoring of plasma viral load every 3 to 6 months in addition to other laboratory parameters like complete blood count, renal and liver function, fasting lipids, and glucose. Depending on each specific case, patients require the monitoring of CD4 cell counts to assess the status of the immune system and the treatment with antiretroviral therapy. In addition, PLHA have a need for continuous healthcare maintenance and education specific to HIV. This is the basis for disease control with decreased mortality, prolonged survival, and prevention of HIV transmission (Helleberg et al., 2012).

While most PLHA engage with healthcare shortly after diagnosis, there are some who do not enter the healthcare system and some access healthcare only sporadically. This sporadic care is common in marginalized populations (Rapid Response Service, 2012). Limited access of healthcare for HIV positive people can have disastrous health consequences for individuals and the general population and therefore needs to be addressed.

1.1.2 HIV care in Canada. In a universal healthcare system like Canada, we often assume easy access to all aspects of healthcare, including medication for ART (Antiretroviral Therapy). The truth is there are differences between provinces and every province makes its own decisions which drugs and treatments are covered. There are also different sources for funding like federal government drug coverage programs and private insurances. HIV positive people need to contact HIV service organizations to assess their qualification for these programs (Binder, retrieved 06/24/2018). With this complex healthcare system and difficulties reported by PLHA on drug coverage and access to healthcare services, assessing the factors contributing to these issues is essential (Rapid Response Service, 2012). This would help improve access to healthcare for HIV positive people.

Access to healthcare remains variable in Canada and it is shown that there is a disparity in access to healthcare within and between gender (Socias, Koehoorn, & Shoveller, 2016). This systematic review assessed patient perspectives but no influencing factors. Future research could evaluate if gender, race, and socioeconomic status could influence patient perspectives.

1.1.3 Healthcare and marginalized populations. Infection with HIV affects people from diverse backgrounds, and with varied resources and capabilities. People living with HIV often face stigma which results in marginalization (Uphold & Mkanta, 2005). In the Canadian Oxford Dictionary, stigma is defined as an unfavourable reputation or a mark or sign of disgrace or discredit (Barber, 2004). Ablon (2002) describes stigma as a negative attitude from society towards a disease. In relation to HIV, Rao, Andrasik, & Lipira (2018) describes how other stigmatizing factors like race,

gender, and socioeconomic factors can have a negative additive effect on healthcare outcomes. As a result, some people who do not fit in a certain category might be left out or further stigmatized regarding HIV healthcare. Therefore, it is important to assess the needs of different populations with HIV.

1.1.4 Patient perspectives on access to healthcare. Limited entry into the healthcare system is known to be caused by different factors and different perspectives need to be considered to optimize access for patients (Levesque, Harris, & Russell, 2013). The patient perspective views healthcare services from patients' eyes. While policy makers and healthcare providers work hard to improve access to healthcare, different factors might be more important for patients (Grondahl et al., 2018; Wilde, Starrin, Larsson, & Larsson, 1993). Because patients' values may be different from HCP's, it is important to understand their perspectives. This is supported in the literature where the engagement of patients into research and patient-centered healthcare showed good results (Cayton, 2004; Cleary & Edgman-Levitan, 1997; Kairy et al., 2013; Van Berckelaer et al., 2012).

Kairy et al. (2013) assessed patient perspectives during tele-rehabilitation after total knee arthroplasty. Previous studies on potential tele-rehabilitation services had found concerns from patients regarding emotional support, but Kairy et al. (2013) found that patients who experienced tele-rehabilitation during their study reported good communication and emotional support despite some technical problems. However, patients wished for some hands-on therapy for physical assessment. This shows how patients' perspectives on healthcare services can effectively be used to make improvements in healthcare. Similarly, PLHA who constantly interact with different

healthcare provider should be integrated in health research to optimize and improve their access to healthcare.

**1.1.5 Concept of access.** Researchers have seen the access to healthcare as a major concern in healthcare utilization and different dimensions on access to healthcare have been reviewed in the past. (Gulliford et al., 2002; Levesque et al., 2013) One basic theory is potential versus gained access to healthcare. (Aday, 1975) Following this, access to healthcare is defined as a combination of available services, utilization of services and barriers to access. These dimensions were further developed by several researchers with similar findings. However, the different frameworks were constantly reviewed, optimized and revised. McLaughlin & Wyszewianski (2002) emphasized the five dimensions developed by Penchansky & Thomas (1981). Their theory on access to healthcare is frequently cited and reflects both, available health services and the expectation of patients. The theory describes five different dimensions of access to healthcare, named the "5 A's": Acceptability, Accessibility, Accommodation, Affordability, and Availability. McLaughlin & Wyszewianski (2002) highlighted that these "5A's" of access "form a chain that is no stronger than its weakest link" (p. 1441). Previous studies suggest that every one of the domains is important. As an example, if the location of a healthcare facility is convenient, there could be other factors which form an unbearable boarder like Acceptability or Affordability which prevent patients from pursuing and receiving appropriate healthcare. Therefore, we must consider all aspects when access to healthcare is discussed.

Regarding access to healthcare for PLHA, a scoping review by Asghari et al.

(2018) assessed patients' perspectives on access to HIV care worldwide. However, our

focus was improvement of HIV care in Canada and consequently, a review specific to Canadian literature was required. This provides both healthcare provider and policy maker with detailed information on the perspectives of PLHA on healthcare in Canada. Asghari et al. (2018) also suggested further research regarding rural healthcare, which is an essential aspect in the Canadian healthcare system.

With a strong emphasis on primary healthcare in Canada we evaluated patients' viewpoint on specialist and primary care providers because research has shown that specialists and primary care providers are both needed to provide sufficient healthcare to PLHA (Kendall et al., 2015).

This systematic review adds more detail to the findings from Asghari et al. (2018) which evaluated the perspectives of PLHA worldwide. In contrast, this thesis provides a detailed review of Canadian literature which is needed to improve healthcare for PLHA in Canada. The research question and objectives stated below aim to provide information for healthcare providers and policy makers on how to improve healthcare for HIV positive people in Canada in the future.

#### 1.2 Research Question

To assess the current state of knowledge regarding patient perspectives which is important to improve healthcare in the future we chose the following research question for this systematic review: What are the perspectives of PLHA on the access to healthcare in Canada?

#### 1.3 Objectives

To answer our research question, four main objectives were developed:

- To describe the knowledge on access to healthcare in Canada for people living with HIV.
- 2. To identify gaps in evidence on the patient perspectives on access to healthcare of people living with HIV in Canada.
- 3. To highlight research priorities regarding patient perspectives on access to healthcare for people living with HIV in Canada.
- 4. To summarize the patient perspectives on the access to healthcare of people living with HIV in Canada.

### **Chapter 2: Methodology**

A systematic review of Canadian literature was chosen to answer the research question. It targeted any literature on the perspectives of PLHA on access to health care in Canada. There were no exclusion criteria based on age, gender, ethnicity or geographic setting. The assessed outcome includes the perspectives of PLHA on access to healthcare; there were no restrictions made on the type of healthcare or the healthcare provider. For identification of relevant studies, a literature search was performed according to the protocol by Asghari et al. (2016) and the description of the search strategy can be found below. For analysing the data, a framework analysis was used which is based on Carroll, Booth, Leaviss, & Rick (2013) and is specified in section 2.3.

A reference guide from Godfrey & Harrison (2015) from the Joanna Briggs Institute method for systematic review was used. Accordingly, 7 stages for the planning of a systematic review were used for this study, which are based on the suggestions from Godfrey & Harrison (2015). Figure 2.1 gives an overview of the 7 stages of the methodology and analysis approach.

#### 2.1 The 7 Stages of Methodology and Analysis

**2.1.1 Stage 1: Review Protocol.** Asghari et al. (2016) published a research protocol for a scoping review with the title: "Perspectives of people living with HIV on access to health care: Protocol for a scoping review." This systematic review used the literature search described in this protocol but focused only on studies conducted in Canada and summarized the studies in greater detail than what was provided in the scoping review.

• A review protocol was published by Asghari et al. (2016) and was used for literature search. Review protocol • The research question was developed by a team of content experts, researchers and PLHA: What are the perspectives of PLHA on the access to healthcare in Canada? Research question • Any literature on the perspectives of PLHA on access to health care in Canada • No exclusion based on age, gender, ethnicity or geographic setting Inclusion/ exclusion criteria • Contained of 6 steps and was guided by a librarian. Peer reviewed and grey literature was searched with combination of Mesh terms and defined keywords. Search •The identified articles were screened and assessed by one trained reviewer (5% were re-examined for verification by second reviewer) strategy • Was done by two trained reviewers and disagreement was solved in weekly discussions. Quality • A review tool for mixed method research was used. (Pluye, Gagnon, Griffiths, & Johnson-Lafleur, 2009) appraisal • Two trained reviewers identified and agreed on the patterns in the data. Disagreement resolved in weekly discussions. Data extraction •Two trained reviewers agreed on data synthesis and analysis and patterns were mapped into domains and concepts. Data

Figure 2.1 The 7 stages of methodology and data analysis approach

synthesis

**2.1.2 Stage 2: Developing a Research Question.** The research question was developed by a team of content experts, researchers and PLHA with the intention to improve primary healthcare for PLHA in Canada. After a scoping review by Asghari et al. (2018) on worldwide literature, it was decided to focus on Canadian literature and

• A framework analysis was done and a modified framework was developed.

conduct a systematic review. Because of the increasing number of publications in recent years and a unique combination of geography and healthcare setting, it is important to be aware about the current knowledge on needs of PLHA in Canada. The research question is: What are the perspectives of PLHA on the access to healthcare in Canada?

2.1.3 Stage 3: Inclusion and Exclusion Criteria. To ensure a good standard of evidence and clinical relevance, the following eligibility criteria were used for the study selection process: Inclusion criteria were (1) literature from peer-reviewed journals, (2) grey literature, such as unpublished PhD theses and reports from relevant websites, and (3) the use of only French and English articles for full-text review. Exclusion criteria were (1) audits or anecdotal information, (2) research at the planning stage (although this will be included in the research directory), (3) pilot studies, (4) undergraduate and MSc dissertations, (5) book reviews, and (6) policy analyses.

This systematic review included qualitative, quantitative and mixed method studies. There was no exclusion based on study design.

**2.1.4 Stage 4: Search strategy**. The search strategy included the following 6 steps suggested by Godfrey & Harrison (2015).

2.1.4.1 Step 1: Finding keywords. For the selection of the appropriate search terms, the following steps were used: First, the significant terms were identified from the research and a list with possible synonyms and alternate terms was created. Second, terms from Medical Subject Heading (MeSH) were searched as well as the MeSH tree. Furthermore, related words which were found in the keywords and references were also added to the list of search terms.

After creating a list of search terms, different combinations of words were tested across databases. An iterative process was used to refine the search terms through testing of different terms and combining new terms as new relevant citations were identified.

Moreover, content experts, a librarian, patients and a methodologist were contacted to find appropriate keywords. Finally, the search included a combination of MeSH and keywords, which were searched in the title and abstract (tiab) fields. This search strategy was modified for other databases as required. The list of search terms can be found in Appendix 1.

2.1.4.2 Step 2: Initial search. The validation and calibration of the search protocol was done through testing gold standard journals and studies. The gold standard literature was suggested by content experts.

2.1.4.3 Step 3: Second search. The first search was done according to Asghari et al (Asghari et al., 2016) and extracted papers published prior to May 5<sup>th</sup>, 2014. For this thesis, the search was updated with papers published prior to October 14<sup>th</sup>, 2016. Since the search strategy was already validated, the same search was used, and studies related to Canada were extracted later during screening.

Sources of relevant studies were peer-reviewed publications and grey literature. The search in electronic databases for peer-reviewed publications was guided by a librarian and the following databases were searched: Embase (1947 to October 14<sup>th</sup>, 2016), MEDLINE via PubMed (1946 to October 14<sup>th</sup>, 2016), CINAHL (1937 to October 14<sup>th</sup>, 2016), Cochrane (1993 to October 14<sup>th</sup>, 2016), and PsycINFO (1880s to October 14<sup>th</sup>, 2016). Table 2.1 shows the detailed search strategy in PubMed. The search strategy for other databases can be found in Appendix 4.

For grey literature, the following sources were used: ProQuest was searched to find PhD theses, experts were contacted about any known studies, and conferences and symposia were searched for relevant studies. All identified sources for grey literature are shown in Appendix 2.

Table 2.1 Search strategy in PubMed

#	Searches	Results
1	"HIV"[Mesh] OR "HIV Infections"[Mesh] OR HIV[tiab] OR AIDS[tiab] OR "Acquired Immunodeficiency Syndrome"[tiab] OR "Human Immunodeficiency Virus"[tiab] OR "Human Immunodeficiency Viruses"[tiab] OR "Acquired Immune Deficiency Syndrome"[tiab]	
2	Satisfaction[tiab] OR satisfy[tiab] OR perspective[tiab] OR perspectives[tiab] OR attitude[tiab] OR attitudes[tiab] OR opinion[tiab] OR opinions[tiab] OR view[tiab] OR views[tiab] OR preferences[tiab] OR preferences[tiab] OR experiences[tiab] OR "Attitude to Health" [Mesh:NoExp] OR "Patient Satisfaction" [Mesh]	
3	(access[tiab] OR accessibility[tiab] OR accessible[tiab] OR barrier[tiab] OR barriers[tiab] OR facilitators[tiab] OR utilize[tiab] OR utilize[tiab] OR utilize[tiab] OR utilization[tiab] OR use[tiab] OR utilization[tiab] OR provision[tiab] OR provide[tiab]) AND ("health services"[tiab] OR "health service" [tiab] OR "health care"[tiab] OR healthcare[tiab] OR care[tiab] OR treatment[tiab] OR therapy[tiab] OR therapies[tiab] OR service*[tiab] OR clinic*[tiab] OR "medical care"[tiab] OR "medical services"[tiab] OR program*[tiab])	
4	"Health Services Accessibility"[Mesh] OR "Health Services/utilization"[Mesh]	
5	#3 OR #4	
6	#1 AND #2 AND #5	7,367

2.1.4.4 Step 4: Reference list search. This search included the reference list of all included studies.

2.1.4.5 Step 5: Selecting studies. The study selection process was iterative. After removing duplicates, for every article, the eligibility criteria were assessed. If the article was relevant, the search strategy was reviewed and refined. The identified articles were screened and assessed by one trained reviewer. The articles were excluded if title and abstract did not meet the eligibility criteria. To verify this process, a random sample of 5% of the excluded articles were re-examined for verification by a second reviewer. If

more than 5% would have been relevant, all excluded articles would have been reexamined. The verification for the screening met these criteria and therefore, no reexamination had to be done.

For full text review, two independent trained reviewers (Dr. Shabnam Asghari and Dr. Lydia Hesselbarth) identified and agreed on the included articles. Any disagreements were resolved in weekly discussion.

2.1.4.6 Step 6: Maintaining a record. The directory for the identified studies was created in RefWorks and all studies from the final search were included. Afterwards, a directory with all included studies was created in RefWorks.

2.1.5 Stage 5: Quality appraisal. During full text review, the two reviewers appraised the articles to evaluate the quality of the studies. Any disagreement between the two reviewers was resolved in weekly discussions. The intention of the quality appraisal was not to exclude poorer quality studies, but to identify the overall quality of the included studies. Because of a variety of different study designs, a scoring system for mixed method research was used (Pluye, Gagnon, Griffiths, & Johnson-Lafleur, 2009).

First, the studies were categorized into qualitative, quantitative, and mixed method studies. Second, an Excel tool, which is based on Pluye, Gagnon, Griffiths, & Johnson-Lafleur (2009) was created and points were given according to the result of the quality appraisal (yes=2 points; partial=1 point; no=0 points). Finally, the quality score was calculated. The tool for the quality appraisal is presented together with the results in Table 2.2.

Table 2.2	Quality	annraisal	tool for	included	articles

1 able 2.2 Quality appraisal too				a 1		-	n:		n 11 1	** • • • • • •	
Article	Logie et al.	Laschinger et al.	. McCall et al.	Sanchez	Ion et al.	Gagnon	Blais et al.	Brondanı et al	Donnelly et al.	Kakkar et al.	Jackson & Reimer
Quality Appraisal - Qualitati											
Qualitative objective or	Yes ✓	Yes ✓	Yes ✓	Yes ✓	Yes ✓	Yes √		Yes ✓	Yes ✓		
question	Partial	Partial	Partial	Partial	Partial	Partial		Partial	Partial		
	No	No	No	No	No	No		No	No		
Appropriate qualitative	Yes ✓	Yes ✓	Yes ✓	Yes ✓	Yes ✓	Yes ✓		Yes ✓	Yes ✓		
approach or design or method	Partial	Partial	Partial	Partial	Partial	Partial		Partial	Partial		
	No	No	No	No	No	No		No	No		
Description of the context	Yes ✓	Yes ✓	Yes √	Yes ✓	Yes ✓	Yes ✓		Yes ✓	Yes √		
	Partial	Partial	Partial	Partial	Partial	Partial		Partial	Partial		
	No	No	No	No	No	No		No	No		
Description of participants	Yes ✓	Yes	Yes ✓	Yes ✓	Yes ✓	Yes ✓		Yes ✓	Yes ✓		
and justification of sampling	Partial	Partial ✓	Partial	Partial	Partial	Partial		Partial	Partial		
	No	No	No	No	No	No		No	No		
Description of qualitative data	Yes √	Yes	Yes ✓	Yes ✓	Yes	Yes ✓		Yes √	Yes √		
collection and analysis	Partial	Partial ✓	Partial	Partial	Partial ✓	Partial		Partial	Partial		
,	No	No	No	No	No	No		No	No		
Discussion of researcher's	Yes	Yes	Yes	Yes	Yes	Yes		Yes	Yes		
reflexivity	Partial	Partial	Partial	Partial ✓	Partial	Partial		Partial	Partial		
	No√	No√	No ✓	No	No√	No√		No√	No√		
Score	10/12=83%	8/12=66.6%		11/12=91.6%				10/12=83%	10/12=83%		
Quality Appraisal - Quantita			20,22	22,22 32,070	,,,,,	30,12		33,32 30,7	20,72		
Appropriate sampling and							Yes ✓				
sample							Partial				
							No				
Justification of measurements							Yes				
(validity and standards)							Partial ✓				
(various) and standards)							No				
Control of confounding							Yes ✓				
variables							Partial				
variables							No				
Score							5/6=83%				
Quality Appraisal - Mixed M	[ethods						3/0-03/0				
Justification of the mixed	curous									Yes	Yes
methods design										Partial ✓	Partial ✓
methods design										No	No
Combination of qualitative										Yes ✓	Yes
and quantitative data										Partial	Partial ✓
collection analysis techniques										No	No
Integration of qualitative and										Yes ✓	Yes ✓
quantitative data or results										Partial	Partial
quantitative data of festilts										No	No
Score										5/6=83%	4/6=66.6%
SCOLE										J/U-0J70	<del>4</del> /U=00.070

yes  $\sqrt{=2}$ , partial  $\sqrt{=1}$ , no  $\sqrt{=0}$ 

**2.1.6 Stage 6: Data extraction.** To ensure a systematic and consistent data abstraction, a data extraction tool was prepared in Excel, which is shown in Appendix 3. The data abstraction tool was designed to collect information on the citation type, place of study, date of study, methodology, design, characteristics of participants and healthcare provider.

The following study designs were included in the data abstraction tool:

Randomized control trial, Non-randomized control trial, Case report, Case series, Casecontrol, Cross-sectional, Cohort study, Correlation study, Ethnography, Grounded theory,
Narrative research, Phenomenological research, Observational, Community based
research design, Systematic reviews, Meta-analysis, Scoping reviews, and Field trials. If
none of those study designs fitted the study, the reviewer could choose "Others" and add
the right study design into the data abstraction tool.

The patient perspectives on access to healthcare were not categorized during the data abstraction phase and were entered under "Findings". The article quotes were directly abstracted, and every detail was entered into the Excel sheet and kept for data synthesis. The data extraction was conducted independently by two trained reviewers (Dr. Shabnam Asghari and Dr. Lydia Hesselbarth) and disagreement was solved in weekly meetings.

**2.1.7 Stage 7: Data synthesis.** The synthesis and analysis were part of frequent meetings between two researchers and were optimized until consensus was reached.

#### 2.2 Descriptive analysis

An overview on all included studies is presented in a table where first author, year of publication, location of study, type of publication, methods, type of assessed

healthcare, the study population, the age of participants, sample size and tool are shown. In addition, charts on the year of publication, the location of studies and frequency of domains helped to identify gaps in literature. Microsoft Excel was used for tables and charts.

#### 2.3 Framework analysis

To synthesize the data, a framework analysis was developed according to the literature (Carroll, Booth, & Cooper, 2011; Carroll et al., 2013; Dixon-Woods, 2011; Oliver et al., 2008). This means that an existing framework is used to categorize the data. If the data did not map into the existing categories, the framework was expanded. The method is known as "best fit" framework synthesis and Carroll et al. (2013) gave a detailed description how to use an existing framework and modify it. This way new factors, which have not been considered in the old framework can be included into the new framework.

2.3.1 Existing framework. To identify the analytical framework for this study, the identified concepts were compared to the existing models and the model which covered most of the concepts identified was used in this review. For this thesis an existing framework was used which was developed by Penchansky & Thomas (1981). It is called the "5 A's" on access to healthcare and describes different factors which have an influence on patients' access to healthcare. Following this theory, it is possible to categorize patients' perspectives on access to healthcare into Acceptability, Accessibility, Accommodation, Affordability, and Availability. This framework was discussed by McLaughlin & Wyszewianski (2002) who found it to be still up-to-date and it was used to

develop the domains in this thesis. To have a consistent definition during data synthesis the following definition for the domains of the existing framework were used:

Availability reflects the type and number of healthcare and related services and how they meet patients' needs (McLaughlin & Wyszewianski, 2002).

Accessibility represents the location of healthcare services and the ability of patients to reach it. This depends for example on travel time, travel cost, distance, and patients' mobility (McLaughlin & Wyszewianski, 2002).

Accommodation reflects the organisation of a healthcare facilities and how it meets patients' expectations and needs. For example, appointment or walk in system, opening hours, waiting time, time during doctors visit and telephone service are aspects that need to be considered. Furthermore, it includes the ability and perception of patients to accept these factors (McLaughlin & Wyszewianski, 2002).

Affordability reflects the cost of healthcare services and medication, as well as health insurance in relation to patients' ability to pay for these services. In addition, it covers patient knowledge on healthcare cost and financial resources (McLaughlin & Wyszewianski, 2002).

Acceptability represents the satisfaction of patients with providers and facilities. The focus is especially on the service of HCP in relation to marginalized patient population (e.g. ethnicity, sex, insurance) and the comfort of patients with this. Furthermore, the satisfaction of patients with healthcare facilities is influenced by factors like appearance, neighborhood, and religious affiliation (McLaughlin & Wyszewianski, 2002).

2.3.2 Modified framework. During framework synthesis, it was found that not all information could be categorized into the existing framework. Therefore, two new domains were developed: Communication and Others. Communication included the skills of healthcare providers to give and receive information to and from patients, as well as the collaboration with external agencies and the ability the overcome language barriers. If none of the six identified domains suited the topic, others were chosen to categorize the information. Overall, the modified framework contains 7 domains.

**2.3.3 Domains, concepts and article quotes.** For synthesis, the article quotes were mapped into concepts and further categorized into domains. In this thesis, an article quote represents direct information from one of the 11 studies. Concepts on the other hand represent ideas from one or several articles which have been simplified during data synthesis. The domains capture a variety of different concepts and build the skeleton for our framework synthesis and analysis. During data synthesis it was found that the concepts *Stigma* and *Confidentiality* emerged frequently and were therefore analyzed separately to avoid the loss of information.

To highlight the different terms in the text, the following styles were chosen: article quotes are shown in quotation marks ("..."), concepts are presented in *Italic* e.g., *Confidentiality* and *Stigma*, and the domains are written capitalized e.g., Acceptability.

**2.3.4 Mapping the data into concepts and domains.** During data extraction, the information from the articles was directly extracted as quotes and entered into the Excel sheet which can be found in Table A3 in Appendix 3. This information was mapped into concepts and domains and is visualized in Figure 2.2.

For example, McCall, Browne, & Reimer-Kirkham (2009) presented quotes of PLHA: ..." if I have it [HIV/AIDS], ... sometimes they... ask me in front of a whole bunch of people." (p. 1773) This information was converted into the concept *no trust that confidentiality/privacy is respected*. It also belongs to the concept of *Confidentiality* and can be found under the domain Acceptability. To summarize these findings, the most frequent concepts under each domain are presented in a table.

**2.3.5 Barriers, enablers and suggestions from PLHA.** To represent positive and negative experiences on access to health care, as well as suggestions from PLHA found in the studies, the concepts were divided into 3 categories: barriers, enablers and suggestions from PLHA.

In this thesis the term barrier shall reflect problems with access to healthcare, while enablers reflect positive experiences and attitudes of PLHA. For instance, the concept originated from Donnelley et al. (2016) seeking healthcare in HIV-specific clinics was easiest because healthcare provider (HCP) appeared to understand the impact of disclosure and confidentiality reflects a positive attitude towards specialized HIV clinics. Therefore it is an enabler towards the access of healthcare. An example for a barrier on access to healthcare is the concept denied access because of HIV.

The third category was named suggestions from PLHA and includes recommendations from PLHA how the access to healthcare could be improved. One example for a suggestion from PLHA is *one site baby sitting/day care facilities* (Laschinger, Van Manen, Stevenson, & Fothergill-Bourbonnais, 2005).

**2.3.6 Equity on access to healthcare.** During data analysis, equity on access to healthcare was also considered as a category under each domain. A detailed definition on

health equity can be found from Solomon & Orridge (2014). However, if a concept was found to relate highly to equity on access, it was marked and was part of further discussion.

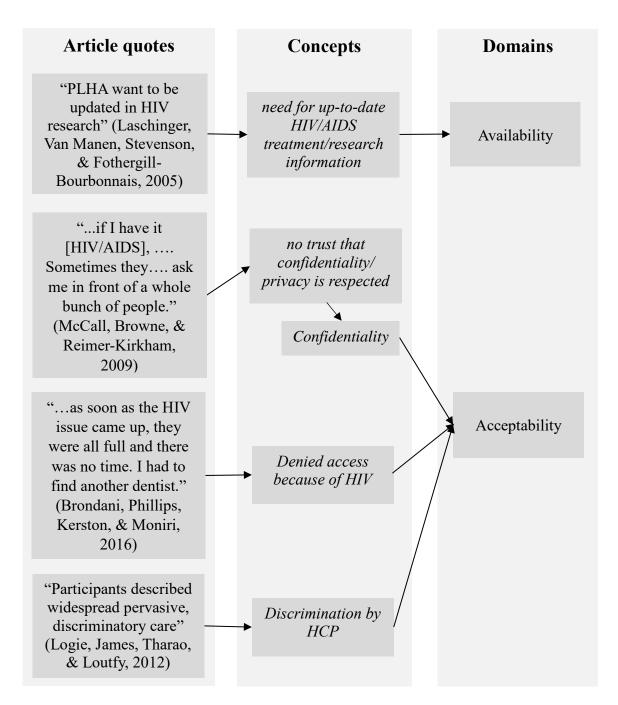


Figure 2.2 Mapping the patterns to the concepts and domains

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#### **Chapter 3: Results**

The literature search identified 26,190 articles and 9,452 duplicates were removed. As a result, 16,738 articles were screened in title and abstract, leaving 334 for full text review. Following this, 322 articles were excluded because they were not conducted in Canada. One article was found irrelevant during data extraction, because the HIV status of study participants was not reported. Finally, 11 articles were included in this review and synthesis. Table 2.1 and Appendix 4 show the detailed search strategy and results for all databases and a PRISMA diagram describes the stepwise exclusion of articles in Figure 3.1.

Of the 11 articles for inclusion in the systematic review, 8 (72%) were qualitative, 1 (9%) was quantitative, and 2 (18%) were mixed-method studies. The quality appraisal was done according to Pluye et al. and 8 studies showed a quality score of 83% and above, while only 2 studies had a score of 66% and 1 study scored 75%. The quality appraisal score of all included studies can be seen in Table 3.1.

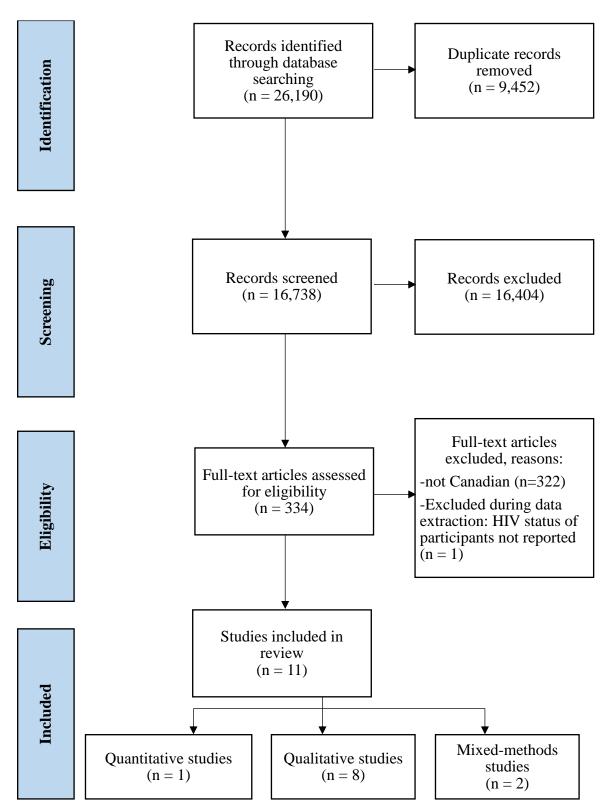


Figure 3.1 PRISMA diagram

#### 3.1 Descriptive Analysis

Table 3.1 gives an overview of the included studies, which covers information on the following: year and place of publication, type of publication, methodology, quality appraisal score, type of healthcare assessed, study population, age, sample size, and tool.

Two articles were found from grey literature (1 PhD dissertation, 1 NGO report), whereas the other 9 articles were peer reviewed. The year of publication ranged from 2005 to 2016 with more publications in recent years. Figure 3.2 visualizes the year of publication in a bar chart.

During data extraction we found that 2 articles did not specify the location but for the study by McCall et al. it was assumed to be from BC because the author and the study site is located there. Sanchez stated in his acknowledgements that most of the participants came from Toronto. Therefore, the assumption on the locations of these 2 studies were made during data analysis. Most of the studies where located in Ontario with 4 (37%) studies, which was followed by Quebec 3 (27%) and BC/Vancouver 3 (27%) studies. Only 1 study (9%) was done all over Canada. A pie chart describes the distribution of the location in Figure 3.3.

Although there was no restriction on age, we did not find any studies on people younger then 15. While 1 study focused on young people aged 19-25 who acquired HIV perinatal, other studies included a variety of different age groups and the oldest age included was 74.

Table 3.1 Overview of included studies

Author	Year	Place	Type of publication	Methods	Sample size	Quality appraisal score
Blais et al.	2015	Quebec City, Montreal	primary research / Peer reviewed	Quantitative Cross-sectional	100	83%
Brondani et al.	2016	Vancouver	primary research / Peer reviewed	Qualitative Phenomenological research	25	83%
Donnelly et al.	2016	Greater Vancouver area	primary research / Peer reviewed	Qualitative Community based research design	33	83%
Gagnon	2015	Bas-Saint-Laurent, Centre du Quebec, Mauricie, Outaouais, and Quebec, Quebec	primary research / Peer reviewed	"generic qualitative research design"	21	83%
Ion et al.	2016	Ontario	primary research / Peer reviewed	Qualitative Narrative research	77	75%
Jackson & Reimer	2005	all Canada	Report (NGO), participatory action research (PAR) design	Mixed methods Qualitative research and Cross-sectional	195	66.6%
Kakkar et al.			primary research / Peer reviewed	Mixed-methods Qualitative research and serial Cross-sectional	25	83%
Laschinger et al.	2005	Ontario	primary research / Peer reviewed	Qualitative Phenomenological research	15 focus groups from eight clinics, each 6-8 participants	66.6%
Logie et al.	2012	Toronto, Ontario	primary research / Peer reviewed	Qualitative Phenomenological research	23	83%
Mc Call et al.	2009	British Columbia *	primary research / Peer reviewed	Qualitative Phenomenological research	8	83%
Sanchez	2013	Toronto, Ontario **	Dissertation	Qualitative Community based research design	30	91.6%

<sup>\*</sup> not specified in article but Autor from BC, therefore assumption made during data abstraction \*\*mainly Toronto in acknowledgement, therefore assumption made during data abstraction

Table 3.1 (continued) Overview of included studies

Author	type of healthcare assessed	Study population	Age	Tool
Blais et al.	not specified (HIV care provider)	women with dependent children age at least 5		questionnaire administered face-to-face by the interviewer (average length of administration = 45 minutes)
Brondani et al.	dental service (dental care provider)	English speaking had sought oral care at least once in their lifetime	23-67	semi-structured individual interviews
Donnelly et al.	dental and general healthcare (doctor, nurse, dentist, social worker)	Aboriginal peoples, refugees (Latino, Asian, and African participants)	18-74	peer-trained facilitators followed a semi- structured interview guide; lasted from 44 to 121 minutes. (in focus group)
Gagnon	not specified (health professionals)	being able to speak French or English, having had at least one stigmatizing experience in a health care setting	18 and older	Individual semi structured interview
Ion et al.	maternal perinatal and postnatal care (health professionals)	Pregnant women	Median=33 IQR=29-37	face to face interview, duration 30min to 1,5h, audio recorded and transcribed
Jackson & Reimer	pharmaceutical, primary care, dental, preventative, social, mental health care, traditional medicine	Aboriginal peoples	15 and older	self-administered questionnaire composed of both closed and open-ended questions
Kakkar et al.	adult and pediatric general healthcare (doctor)	1) Perinatal HIV infection 2) Engaged in care prior to transfer (attendance at least 3 appointments per year in the 2 years prior to transfer) 3) Capacity to communicate (verbally or written), and 4) Elapsed time of at least 1 year since transfer.	19-25	semi-structured standardized questionnaire was administered by telephone (60%) or in-person (40%) interview by the CMIS research nurse, and permission obtained to contact their current treating physicians for their medical records
Laschinger et al.	not specified	adult	not specified	Focus group members were presented with ten individual themes that comprise basic care practices such as patient involvement in care and multidisciplinary team access.
Logie et al.	preventative, social and general healthcare (health professionals)	LBTQ	25-57	semi-structured focus group interview guide
Mc Call et al.	not specified	Aboriginal Cisgender Female	31-47	semi structured individual interview 60-90min
Sanchez	not specified	Latinos born outside Canada	18-69	interview not further specified

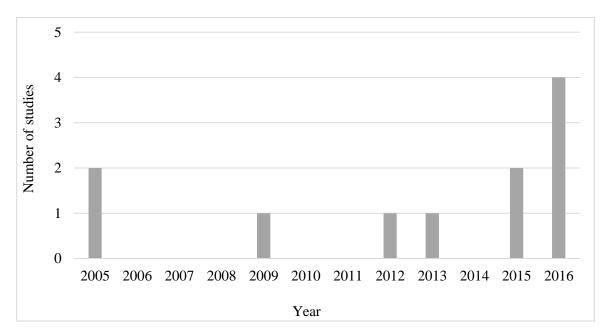


Figure 3.2 Year of publication

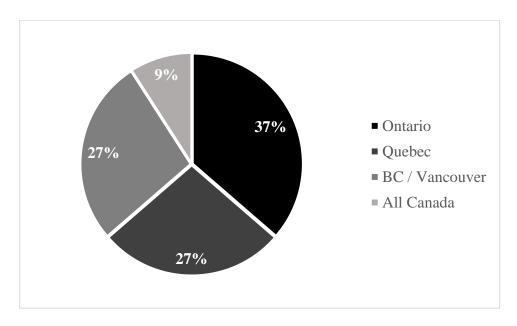


Figure 3.3 Location of study

The sample sizes were generally small and ranged from a minimum of 8 to a maximum of 195. While 6 studies used individual interviews with semi-structured or standardized questionnaires, 3 studies used focus groups, 1 study used a self-administered questionnaire, and 1 study did not specify the type of data collection approach.

The type of healthcare provider showed a wide spread through different professions (e.g. doctor, dentist, nurse...) and showed no specific pattern regarding patients' perspective on access to healthcare. Similarly, we found a focus in a variety of patient populations and while some articles reflected a broad spectrum (adult, women with children), others showed an insight on the perspectives of marginalized populations (Aboriginals and refugees, LBTQ).

### 3.2 Framework Analysis

In summary 91 concepts on the perspectives of people living with HIV on access to healthcare were identified. They were mapped into the 7 domains of the modified framework (Acceptability, Availability, Accessibility, Affordability, Accommodation, Communication, and Others) and can be found in Appendix 5, Table A5.

**3.2.1 Domains.** The articles showed a different focus on the 7 domains. Following this, the domain Acceptability was discussed by all studies and Availability emerged in 9. Accessibility was discussed by 7 articles, Affordability and Communication by 6, and Accommodation by 5.

Three articles discussed concepts, which could not be matched into these domains and were therefore categorized into the domain Others. The concept *shared decision making* (enabler) (Laschinger et al., 2005) and the concept *unknown or cultural barriers* (R. Jackson & Reimer, 2008; Serrano Sanchez, 2013) can be found in this category. It

was found that cultural barriers could influence several domains and for this reason it was kept separate. Figure 3.4 gives an overview on the frequency of each domain.

Among the 11 studies, some were more comprehensive than others. The studies from Sanchez and Laschinger et al. covered all domains, and Blais et al., Ion et al., Jackson & Reimer, and Kakkar et al. discussed 5 or more domains. In contrast, Gagnon focussed only on Acceptability. Table 3.2 shows the distribution of the domains in all included studies.

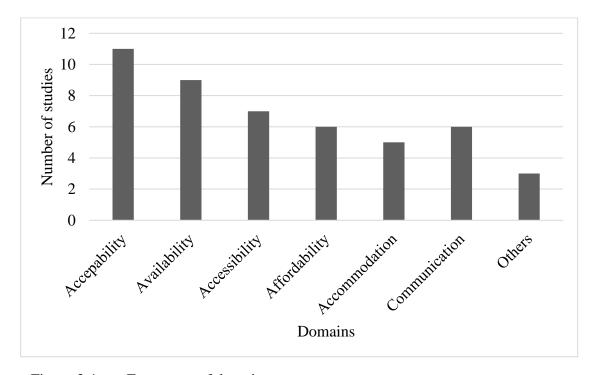


Figure 3.4 Frequency of domains

Table 3.2 Distribution of domains in included studies

Article	Acceptability	Stigma	Zonfüdentiality	Accessibility	Accommodation	ffordability	Availability	Communication	Others
Blais et al. (2015)	<b>▼</b>	S		<b>▼</b>	A	W /	4		C
Brondani et al. (2016)	✓ ✓		/	<b>√</b>		<b>√</b>			
Donnelly et al. (2016)	✓ ✓						$\checkmark$	<u>√</u>	
Gagnon (2015)	✓ ✓		<b>√</b>					<b>√</b>	
Ion et al. (2016)	•		/	/		/	/	/	
` '	<b>√</b>	<u>√</u>		<u>√</u>	,	<u>√</u>		<b>√</b>	
Jackson & Reimer (2005)	✓	<b>√</b>	<b>√</b>	<b>√</b>	<u>√</u>	<u>√</u>			<b>√</b>
<b>Kakkar et al. (2016)</b>	✓			✓	✓	✓	✓		
Laschinger et al. (2005)	✓	$\checkmark$		✓	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$
<b>Logie et al. (2012)</b>	<b>√</b>	<b>√</b>					<b>√</b>		
Mc Call et al. (2009)	<b>√</b>	<b>√</b>	<b>√</b>	<b>√</b>	<b>√</b>		<b>√</b>		
<b>Sanchez</b> (2013)	<b>√</b>	✓	✓	✓	✓	<b>√</b>	<b>√</b>	<b>√</b>	<b>√</b>
Total	11	10	6	7	5	6	9	6	3

<sup>✓</sup> domain or concept emerged

**3.2.2 Concepts.** Some concepts emerged several times in one article. Likewise, the concepts *Stigma* and *Confidentiality* emerged often in the articles with 21 and 12 citations, respectively. Therefore, a detailed analysis was done on these 2 concepts. The results with all concepts can be found in Appendix 5, Table A5. The most commonly discussed stigma was *stigma* in *public / certain communities (e.g. rural, Latino)* [n(citations)=4]. However, it was closely followed by *self stigma* [n(citations)=3] (*guilt* 

Stigma and Confidentiality are concepts under Acceptability

and shame about HIV status), stigma and tension related to disclosure [n(citations)=3], and stigmatizing behaviour/rejection by HCP [n(citations)=3].

Among the concept *Confidentiality*, the most frequently discussed topic was *no trust that confidentiality/privacy is respected by HCP* [n(citations)=4]. On the other hand, we found an enabler on access which was discussed by Donnelly et al.: *seeking healthcare in HIV-specific clinics was easiest because HCP appeared to understand the impact of disclosure*. Moreover, a suggestion from PLHA in the article from Ion et al. on how to improve confidentiality issues was found that *health care providers should have a confidential conversation in advance to create a plan to ensure privacy is maintained and respected*.

Among all other concepts the most frequently discussed barriers were discrimination by HCP [n(citations)=6] and transportation/ distance/ geography problems [n(citations)=6]. Among satisfactory aspects improved/ effective communication [n(citations)=3] and non-judgemental, patient, respectful and compassionated care [n(citations)=3] were the most commonly discussed enablers. Within the suggestions from PLHA, two concepts emerged most frequently: extra training for HCP in HIV care [n(citations)=2] and patients' need for up-to-date HIV/AIDS treatment and research information [n(citations)=2]. The most frequently discussed enablers and barriers on access to healthcare and suggestion from PLHA within the modified framework can be found in Table 3.3.

**3.2.3 Equity.** Eight concepts were found to be related to Equity on access to healthcare and can be seen in Appendix 5, Table A5. Concepts related to Equity were

discussed by 5 studies and most commonly PLHA felt inequity related to sexual orientation (3 concepts).

Table 3.3. Most frequent barriers, enablers and suggestions from PLHA on access to healthcare in the modified framework

Domains	Barrier	Enabler	Suggestions from PLHA
Acceptability	discrimination by HCP n(citations)=6	non-judgmental, patient, respectful and compassionate care n(citations)=3	extra training for HCP in HIV care n(citations)=2
Stigma n(citations)=21)	stigma in public / certain communities n(citations)=4	/	/
Confidentiality n(citations=12)	no trust that confidentiality/privacy is respected by HCP n(citations)=4	seeking health care in HIV-specific clinics easiest because HCP appeared to understand the impact of disclosure and confidentiality n(citations)=1	health care providers should have a confidential conversation in advance to create a plan to ensure privacy is maintained and respected.  n(citations)=1
Availability	lack of services n(citations)=2	receiving help from community health centre / HIV clinic helped n(citations)=2	patients need for up-to-date HIV/AIDS treatment/research information n(citations)=2
Affordability	financial barriers / resources n(citations)=3		- supply of taxi vouchers and bus tokens for patients traveling to and from the clinic n(citations)=1 - established and accessible fund for necessities that a patient urgently needs n(citations)=1
Accessibility	transportation / distance /geography problems n(citations)=6	electronic knowledge exchange n(citations)=1	"one stop shopping" n(citations)=1
Accommodation	long waiting time n(citations)=2	return phone calls within reasonable timeframe and live person to answer n(citations)=1	one site baby sitting/ day care facilities n(citations)=1
Communication	lack of communication n(citations)=2	improved/effective communication n(citations)=3	HCPs should notify patients if scheduled appointments are delayed, because especially burdensome when young children accompany patients n(citations)=1
Others	unknown or cultural barriers n(citations)=2	shared decision making n(citations)=1	

### **Chapter 4: Discussion**

Overall, we found 91 concepts which reflect the patient perspectives on access to healthcare for people living with HIV in Canada. Among all concepts we found topics around *Stigma* and *Confidentiality* arose most frequently. This was followed by concerns related to *discrimination by healthcare providers* and *transportation/distance and geography problems*. Despite these and many other challenges faced by PLHA, we also found enablers on access to healthcare. We found an appreciation for *non-judgmental*, *patient, respectful and compassionate care* as well as *improved/effective communication* as the most frequently cited enablers to healthcare. Furthermore, PLHA suggested areas for improvement like *patients need for up-to-date HIV/AIDS treatment/research information* or *extra training for HCP in HIV care*. These commonly cited concepts among Canadian literature can help to implement patient perspectives in future policy development.

One goal was to establish gaps in literature to guide further research opportunities. While we found only one Canada wide study in the form of an NGO report, all the peer-reviewed articles were conducted in British Columbia, Ontario, and Quebec. This suggests research opportunities on patients' perspectives on access to healthcare in other provinces, but especially in Saskatchewan and Manitoba which showed the highest diagnosis rate in 2015 (Public Health Agency of Canada, 2016).

Most of the 11 relevant Canadian articles were qualitative studies, and the calculated quality score was reasonable. Our analysis showed more publications in recent years. The patient population varied in the analyzed studies from marginalized populations to all people living with HIV in Canada or a certain region.

To answer the research question, a framework analysis was used to map the data from the included articles into concepts and domains. A framework from Penchansky & Thomas (1981) which is known as the "5 A's" on access to healthcare was modified to fit our needs.

4.1.1 Domains in the modified framework. We found two new domains (Communication and Others) in addition to the existing framework (Acceptability, Availability, Affordability, Accessibility, and Accommodation). The new domains were developed as an agreement between the reviewers, because it was found that some concepts can influence several domains. It was found that Communication was especially important to highlight as a separate domain, because it is one of the roles defined by the Royal College of Physicians and Surgeons of Canada in the CanMEDS framework (Royal College of Physicians and Surgeons of Canada, 2019). Therefore, communication is a skill every healthcare provider should have.

Two concepts were categorized into Others and 10 concepts were categorized into Communication which means that our framework was almost consistent with the findings from Penchansky & Thomas (1981). This is similar to the findings from Levesque et al. (2013) and the scoping review on perspectives of PLHA by Asghari at al. (2018), which found that Communication among others should be considered as an additional theme to the 5 A's from Penchansky and Thomas (1981). However, because of our categories within the domains we needed less additional domains than Asghari at al. (2018). The categories barriers and enabler on access to healthcare and the category suggestion from PLHA allowed us to clearly reflect positive and negative experiences on healthcare as well as ideas for improvement from HIV positive people.

**4.1.2 Common concepts.** The most commonly cited concepts were related to Acceptability. The concept *Stigma* emerged 21 times in the included articles and most commonly cited was stigma in public / certain communities. This means that stigma has a huge impact in this population on the access to healthcare and therefore needs special consideration. This is also reflected in the literature where stigma was found to be a big problem for different patient population in relation to HIV diagnosis (Eaton et al., 2018; Pantelic, Boyes, Cluver, & Thabeng, 2018; Rao et al., 2018).

Rao et al. (2018) found that black women with HIV diagnosis had worse health outcomes than white women. This was attributed to several stigmatizing factors like race, socioeconomic status and gender. The reason is that people who experience stigma were found to delay their access to healthcare or failed to access it completely (Kinsler, Wong, Sayles, Davis, & Cunningham, 2007). Likewise, we found the concept *stigma other than HIV*. This means that PLHA have other factors like ethnicity, gender, sexual orientation, or socioeconomic status that place a risk of stigma. This causes further marginalization and is consistent with Rao et al. (2018) who described the additive effect of multiple stigmatising factors with the result of poor long-term health outcomes.

The concept *Confidentiality* emerged often with 12 citations in the included articles. Most commonly discussed was no trust that confidentiality / privacy is respected by HCP. Likewise, this barrier for PLHA needs extra respect when providing healthcare to this population. However, the literature review resulted not only in barriers on access, it also shows enablers and suggestions from PLHA on access to healthcare. Relating to the concept *Confidentiality*, PLHA reported that seeking health care in HIV-specific clinics was easiest because the HCPs working there appeared to understand the impact of

disclosure and confidentiality. This shows patient satisfaction with current healthcare access and policy changes need to consider these patient needs to prevent a negative impact. A suggestion from PLHA on how to address confidentiality issues is that health care provider should have a confidential conversation in advance to create a plan to ensure privacy is maintained and respected. This is one example for a suggestion from patients on how to improve healthcare.

4.1.3 Equity on Access. Another aspect we found was equity on access to healthcare. During data analysis it was occasionally found that concepts related to equity. On example is equity on Acceptability. Two articles found that PLHA felt unwelcome because of gender/ sexual orientation in support group/ HIV organisation. This shows that the access to healthcare could be altered by gender and sexuality. It is important to bring this information to support groups and HIV organisation because research has shown that privileged groups are less likely to perceive their own advantages (Mindrup, Spray, & Lamberghini-West, 2011). For HIV support groups this could mean that the privileged group are homosexual men, because this might be a majority in a group of HIV positive people. Accordingly, we found that heterosexuals or homosexual women felt unwelcome in HIV organizations, because of their gender or sexual orientation. Therefore, every effort should be made to reduce disparities on access to healthcare because of problems related to equity.

**4.1.4 Importance of all aspects on access to healthcare.** Even through some concepts emerged more frequently like discrimination by HCP with 6 citations, it is important to consider all aspects on access to healthcare, especially, if policy makers and HCP want to improve the access to healthcare for PLHA. According to McLaughlin &

Wyszewianski (2002), who wrote on the different aspects on access to healthcare and advocated the 5 A's on access, it is important to consider different ways access to healthcare can be influenced. This means for example if affordability is improved through universal healthcare insurance this does not mean that patients certainly would access healthcare. The reason is that other aspects than Affordability influence patient decisions. Therefore, it is crucial to implement all factors which are known to be relevant to patients when providing healthcare (Kinsler et al., 2007; Penchansky & Thomas, 1981). In this systematic review, we found 92 concepts which reflect patients' perspectives on access to healthcare in Canada and can be used by policy makers and HCP to improve access to healthcare for PLHA.

4.1.5 Rural healthcare. Some aspects of access like rural versus urban healthcare need special consideration (Asghari et al., 2018). In this review, the following concepts could be identified as barriers on access to healthcare in rural areas. PLHA raised the concern that being denied access to healthcare services because of HIV which arose in many regions but especially in rural areas. This is an alarming issue for PLHA in rural areas, because of the continuous need for healthcare. Other barriers were stigma in public / certain communities (e.g. rural), lack of services (e.g. hospice program in rural area) transportation / distance /geography problem (e.g. to traditional aboriginal service, secondary health services, alternative and complimentary service, substance use program, and educational events for rural PLHA). We also found the suggestion of extra training for HCPs (e.g. rural family physician in HIV care/ for pharmacist in HIV medication). This implies that PLHA feel a lack of information from their HCP which is not specific to Canada and it has been stated in studies from other countries (Asghari et al., 2018). To

address this need, a holistic approach including clinical training as well as improving communication skills is required (Leonard, Graham, & Bonacum, 2004). Some studies suggest role-playing as a strategy for communication skills training (V. A. Jackson & Back, 2011).

4.1.6 Primary healthcare and HIV specialist care. Currently research shows that PLHA might have a better outcome when treated in primary care (Chu & Selwyn, 2011; Ding et al., 2008). If policy makers have the intention to shift HIV and AIDS care to the primary healthcare setting, it is important to consider current problems in access to care for PLHA. Some concepts in this systematic review reflect barriers which are related specifically to primary or general healthcare. One concept is that HCP outside the HIV network were seen more judgmental and less knowledgeable, competent, and experienced than those inside. We found that patients experienced rejection when seeking dental services and when seeking general healthcare in rural areas. Similar thoughts are reflected when PLHA report a fear of rejection when seeking services, and therefore go to specialized HIV clinics. These concepts and the suggestion of extra training for HCP show the negative experience and attitude towards general and primary healthcare and a preference towards HIV specialist care. Furthermore, this negative experience could lead to avoidance of certain types of healthcare.

People living with HIV/AIDS stated several positive experiences with relation to specialised HIV services. These are: health education in HIV clinic, feeling a sense of belonging in HIV/AIDS service organisation, seeking health care in HIV-specific clinics was easiest because HCP appeared to understand the impact of disclosure and confidentiality, and receiving support from community health centre / HIV clinic helped.

This shows that the shift from one healthcare to another is not simple because of patient provider relationships, trust or negative experiences. However, it can be possible if patients are involved in the discussion and our current knowledge on patient perspectives is used to improve healthcare. Interestingly, this means not only the improvement of current problems on access but also the continuity of good work and successful patient-provider relationships. According to current literature, HIV would be best managed through inter-professional care which ensures for example health promotion and disease prevention in primary healthcare and HIV specific treatment in specialist care (Kendall et al., 2015).

**4.1.7 Gaps in literature.** The descriptive analysis was performed to identify gaps in evidence and provide recommendations for research opportunities. This systematic review found a focus on PLHA in Ontario, Vancouver/ BC, and Quebec and according to the Public Health Agency of Canada (2016), the number of new HIV/AIDS cases was highest in these three provinces in 2015.

Only one NGO report was conducted all over Canada and was found during a grey literature search. This stands in contrast to a higher diagnosis rate (per 100,000 population) than the national average (5.8 per 100,000) in Saskatchewan (14.4 per 100,000), Manitoba (8.1 per 100,000), and Ontario (6.1 per 100,000) in 2015 (Public Health Agency of Canada, 2016). The high diagnosis rate in these three provinces implement a need for more HIV research specially in Saskatchewan and Manitoba. Furthermore, PLHA in Atlantic provinces, Alberta, Yukon, Northwest Territories and Nunavut are not represented in current research.

Our systematic review showed more publications in recent years which could be a positive effect of the increased funding for patient oriented research since 2012 and following the launch of Canadian Institute for health research strategy to increase patient oriented research (Canadian Institutes of Health Research, 2011).

### 4.2 Limitations

Even though every effort was made to reduce limitations in this systematic review, some points need to be considered. The level of evidence of this review could be not as rigorous as other systematic reviews as most of included studies are qualitative studies. However, because of the research question on perspectives of PLHA it was expected to have more qualitative studies because it can be sufficiently described with this study design.

During the screening of title and abstract, the risk of bias needed extra consideration because only one reviewer was assigned for this task. Consequently, 5% of the articles were re-examined and the screening process was found to be valid.

One may question the comprehensiveness of electronic search. Further to electronic search, we contacted the Canadian researchers with focus on HIV and reviewed reference lists of all included articles. This strategy resulted in a comprehensive search result.

There are a variety of models that could have been used for the framework analysis and one may argue that the social ecological model makes for a more suitable conceptual framework. However, we used the 5 A's on access to healthcare because it looks at healthcare from the lens of patients which is suitable for our research question.

Future research could use the social ecological model which assesses the whole picture in the health system.

This review developed an evidence on the PLHIV perspective on access to healthcare in Canada. Future research could provide more insight into how to use the findings of this review to make required changes to practice and to identify mechanisms to institute such a shift to, for example, reduce stigma.

This systematic review summarized Canadian published papers on patient perspectives but no influencing factors. Future research could examine if other factors like gender, race, and socioeconomic status could influence PLHIV perspectives and their access to healthcare.

### 4.3 Conclusion

This systematic review highlights the importance of access to healthcare for PLHA by describing patients' perspectives on access to healthcare and identifying some areas that need improvement in the future. Our framework on access to healthcare for PLHA in Canada was consistent with the findings of the "5 A's" on access to healthcare from Penchansky & Thomas (1981). However, we found that Communication, shared decision making, and cultural barriers were also important for PLHA when accessing the healthcare system. Nevertheless, future research on access to healthcare can be based on the existing framework from Penchansky & Thomas (1981) which highlights the importance of different aspects regarding access to healthcare (McLaughlin & Wyszewianski, 2002). Small modifications are required to fit a certain research question.

Stigma related to HIV is an important barrier on access to healthcare, especially stigma in public / certain communities. Some studies suggest community intervention as a

successful approach in reducing HIV related stigma (Apinundecha, Laohasiriwong, Cameron, & Lim, 2007; Bos, Schaalma, & Pryor, 2008; French, Greeff, & Watson, 2014). These studies show that a combination of education, skill building, and contact with PLHA could result in changes in knowledge, attitudes and preventive practices (Bos et al., 2008). In our research we found the suggestion from PLHA to continue and enhance public education as well as awareness initiatives. This could help gaining acceptability towards HIV.

Some studies suggest HIV related stigma among health professionals could be reduced if a certain number of popular opinion leaders adopt the new behavior (Li, Guan, Liang, Lin, & Wu, 2013; Li et al., 2013). These leaders could be trained to reduce stigmatizing attitudes and behaviour towards people with HIV and to educate other healthcare professionals. Moreover, the techniques learned could be used to reduce stigma towards other factors and improve patient provider relationship in general (Li et al., 2013).

Another common concern among PLHA was confidentiality. Although it is essential that HCP respect patients' rights and follow the law (Canadian Medical Association, 2011), a recommendation from PLHA in our study was that health care provider should have a confidential conversation in advance to create a plan to ensure privacy is maintained and respected.

Despite the Canadian health system's commitment to reduce inequity and gender discrimination, our review reports concerns regarding access to healthcare due to sexual orientation and gender. This is an important issue that needs to involve policy makers,

healthcare planners, researchers and healthcare providers to fulfill optimum commitment from decision makers in all levels of healthcare.

Another important aspect is access to healthcare in rural and remote areas.

According to PLHA, the use of telehealth with videoconferencing could be helpful to make specialist services and education more available to these individuals; however, it is vital to have access to quality healthcare locally. Training for primary healthcare providers in HIV care and communication skills could help to improve patient satisfaction with healthcare in rural areas.

Many studies suggest that an interdisciplinary team with primary healthcare and specialist results in better outcome for HIV positive people. Our review shows PLHA felt generally more comfortable in HIV specialized services, than in general healthcare. Although it is very important to respect patients' choices to ensure continuous access to HIV care; training for healthcare providers in general care services to improve communication skills and reduce stigmas would help to enhance knowledge transfer which ultimately results in patient satisfaction.

Finally, our research found gaps in literature. The studies were mainly conducted in Ontario, Quebec and BC or by researchers form these provinces. We did not find studies from Atlantic Provinces or Prairie Provinces. More research on the perspectives of PLHA on access to healthcare in these provinces is required, particularly in provinces with a higher diagnosis rate of HIV e.g. Saskatchewan and Manitoba.

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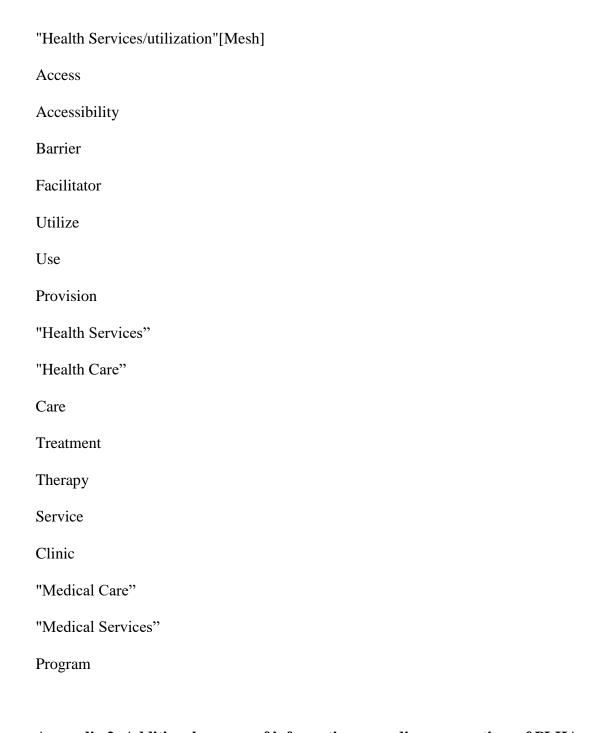
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## **Appendices**

# **Appendix 1: Search terms** Search Terms for HIV. "HIV"[Mesh] "HIV Infections" [Mesh] HIV **AIDS** "Acquired Immunodeficiency Syndrome" "Human Immunodeficiency Virus" "Human Immunodeficiency Viruses" "Acquired Immune Deficiency Syndrome" Search Terms for Perspective (variations of terms were also searched). "Attitude to Health"[Mesh:NoExp] "Patient Satisfaction"[Mesh] Satisfaction Perspective Attitude Opinion View Preference Experience Search Terms for Access to Healthcare (variations of terms were also searched).

"Health Services Accessibility"[Mesh]



# Appendix 2: Additional sources of information regarding perspectives of PLHA on access to healthcare

Conferences and workshops.

Annual Advanced Management Issues in HIV Medicine

Conference on Peer Education, Sexuality, HIV & AIDS

International AIDS Conference (AIDS 2014)

Southern African HIV Clinicians Society Conference 2014

International Conference on HIV/AIDS, STDs & STIs – 2014

Annual National Conference on Social Work and HIV/AIDS

U.S. Conference on AIDS

Association of Nurses in AIDS Care 2014

IAS Conference on HIV Pathogenesis, Treatment and Prevention

Annual Canadian Conference on HIV/AIDS Research

American Conference for the Treatment of HIV

Conference on Retroviruses and Opportunistic Infections

Infectious Diseases Society of America (IDSA) Conference

National HIV Prevention Conference

International Workshop on HIV Treatment, Pathogenesis and Prevention Research in

**Resource-poor Settings** 

International Workshop on HIV & Hepatitis Coinfection

International workshop on HIV Pediatrics

International Workshop on HIV & Aging

International Workshop on HIV Transmission – Principles of Intervention

### Organizations Relevant to HIV.

World Health Organization

**UNAIDS** 

**CDC** 

AIDS.gov

AIDS Committee of Newfoundland and Labrador

AIDS.org

AIDS Vancouver

World AIDS Day

Ontario HIV Treatment Network

**HIV Edmonton** 

Regional HIV/AIDS Connection

Stop HIV/AIDS

## **Grey Literature on HIV.**

Clinical Trials.gov

U.K. Department of Health

Thomson Center watch

TRIP (published literature would be retrieved as well)

## **Appendix 3: Data abstraction table**

Table A3 Data abstraction table

A. Review Details		Notes
Reference:		
First Author		
Year of Publication		
Place of Publication		
Peer or Grey	Peer reviewed	
	Grey literature	
Type of Publication	Primary research	
	Review or meta-analysis	
	Commentary	

	Protocol
	Conference proceeding
	Working paper
	Dissertation/thesis
	Report (NGO)
	Report (government)
	Fact sheet
	Policy/position statement
	News article/ Op-ed
	Other
B. Project Details	
Program/Project Name	
Country	
Location	
<b>Geographical Setting</b>	Urban
	Rural
	Rural-remote
	Not specified/Not reported
Site of Study	Aboriginal health/ friendship
•	centres
	Community health centre
	Dental Clinic
	General Healthcare
	Home Care
	Hospital
	Outpatient
	Government ART Center
	Primary care clinic/ Family health
	clinic
	Prisons/Correctional Facilities
	Sexual health/HIV Clinic
	Other
	Not specified/Not reported
<b>Duration of study</b>	less than one month
	1-3 months
	4-6 months
	7-11 months
	1-2 years
	3-5 years
	6 years +
	Not specified/Not reported
	not specifica/not reported

C. Sample Characteri	stics
Age	
Gender	Cisgender Male
	Cisgender Female
	Transgender male
	Transgender female
	Two-spirited
	Other
	Not specified/Not reported
Sub-community	MSM
·	LGBTQ
	PWID or people who smoke crack
	People who smoke crack
	Aboriginal peoples
	Racialized groups
	Transgender individuals
	Commercial sex workers
	Inmates
	People born outside of Canada
	Pregnant women
	People receiving ART
	Other
	Not specified/Not reported
Participant health	Excellent
status	Very good
	Good
	Fair
	Poor
	Other
	Not specified/Not reported
D. Methodology	
Aim of study	Access to Care
•	Satisfaction with Care
	Barriers to Care
	Barriers to ART
	Other
	Not specified/Not reported
Study approach	Quantitative
	Qualitative
	Mixed-methods
Study design	RCT

	Non-randomized control trial
	Case report
	Case series
	Case-control
	Cross-sectional
	Cohort study
	Correlation study
	Ethnography
	Grounded theory
	Narrative research
	Phenomenological research
	Observational
	Community based research design
	Systematic reviews
	Meta-analysis
	Scoping reviews
	Field trials
	Other
<b>Data collection method</b>	Interview
	Survey
	Focus group
	Observation
	Case study
	Document review/analysis
	Other
Sampling	Non-probability
	Probability
Sample Size	
Participation Rate	
Tool	
E. Findings	
Perspectives of PLHA	
on access to healthcare	
Type of Service	Pharmaceutical
	Primary care
	Clinical/curative
	Dental

	Preventative
	Outpatient
	Inpatient
	Social
	Promotive
	Rehabilitative
	General Health Care
	Mental Health Care
	Not reported
	Other
Compensation	Yes
	No
	Not applicable/ not reported
Service Provider	Doctor
	Nurse
	Dentist
	Dental Assistant
	Pharmacist
	Outreach Worker
	Social Worker
	Psychologist
	Other
	Not specified/Not reported
Patient Demographics	
	Other
	Not reported
Conclusions	
Limitations	
Additions	

# **Appendix 4: Search strategies and results**

Table A4.1 Search strategy for Embase

#	Searches	Results
1	'human immunodeficiency virus'/exp OR 'human immunodeficiency virus	
2	infection'/exp hiv:ti OR hiv:ab OR aids:ti OR aids:ab OR 'acquired immunodeficiency syndrome':ti	
	OR 'acquired immunodeficiency syndrome':ab OR 'human immunodeficiency virus':ti	
	OR'human immunodeficiency virus':ab OR 'human immunodeficiency viruses':ti OR	
	'human immunodeficiency viruses':ab OR 'acquired immune deficiency syndrome':ti OR 'acquired immune deficiency syndrome':ab	
	ort acquired immune derivine, syndrome tac	

3	#1 OR #2	
4	'attitude to health'/exp OR 'patient attitude'/de OR 'patient preference'/exp OR 'patient satisfaction'/exp	
5	satisfaction:ti OR satisfy:ti OR perspective*:ti OR attitude*:ti OR opinion*:ti OR view*:ti OR preference*:ti OR experience*:ti OR satisfaction:ab OR satisfy:ab OR perspective*:ab ORattitude*:ab OR opinion*:ab OR view*:ab OR preference*:ab OR experience*:ab	
6	#4 OR #5	
7	(access*:ti OR barrier*:ti OR facilitator*:ti OR utiliz*:ti OR utilis*:ti OR provision:ti OR provide:ti OR access*:ab OR barrier*:ab OR facilitator*:ab OR utiliz*:ab OR utilis*:ab OR provision:ab OR provide:ab) AND ('health service':ti OR 'health services':ti OR 'health care':ti OR healthcare:ti OR care:ti OR treatment:ti OR therapy:ti OR therapies:ti OR service*:ti OR clinic*:ti OR 'medical care':ti OR 'medical services':ab OR health services':ab OR 'health services':ab OR therapy:ab OR therapies:ab OR service*:ab OR care:ab OR treatment:ab OR therapy:ab OR therapies:ab OR service*:ab OR clinic*:ab OR 'medical care':ab OR 'medical services':ab OR program*:ab)	
8	'health care utilization'/exp	
9	#7 OR #8	
10	#3 AND #6 AND #9	10,836

Table A4.2 Search strategy for CINAHL

#	Searches	Results
1	(MH "HIV Infections+") OR (MH "Human Immunodeficiency Virus+") OR (MH "HIV- Infected Patients+")	
2	TI (HIV OR AIDS OR "acquired immunodeficiency syndrome" OR "human immunodeficiency virus" OR "human immunodeficiency viruses" OR "acquired immune deficiency syndrome") OR AB (HIV OR AIDS OR "acquired immunodeficiency syndrome" OR "human immunodeficiency virus" OR "human immunodeficiency viruses" OR "acquired immune deficiency syndrome")	
3	#1 OR #2	
4	(MH "Attitude to Health") OR (MH "Health Beliefs") OR (MH "Patient Satisfaction")	
5	TI (satisfaction OR satisfy OR perspective* OR attitude* OR opinion* OR view* OR preference* OR experience*) OR AB (satisfaction OR satisfy OR perspective* OR attitude* OR opinion* OR view* OR preference* OR experience*)	
6	#4 OR #5	
7	(MH "Health Services Accessibility+") OR (MH	
	"Health Resource Utilization") OR (MH "Health Services+/UT")	
8	TI (access* OR barrier* OR facilitator* OR utiliz* OR utilis* OR provision OR provide) OR AB (access* OR barrier* OR facilitator* OR utiliz* OR utilis* OR provision OR provide)	
9	TI ("health services" OR "health service" OR "health care" OR healthcare OR care OR treatment OR therapy OR therapies OR service* OR clinic* OR "medical care" OR "medical services" OR program*) OR AB ("health services" OR "health service" OR "health care" OR healthcare OR care OR treatment OR therapy OR therapies OR service* OR clinic* OR "medical care" OR "medical services" OR program*)	

10	#8 AND #9	
11	#7 OR #10	
12	#3 AND #6 AND #11	3,391

Table A4.3 Search strategy for PsychInfo

#	Searches	Results
1	DE "HIV" OR DE "AIDS"	
2	TI (HIV OR AIDS OR "acquired immunodeficiency syndrome" OR "human immunodeficiency virus" OR "human immunodeficiency viruses" OR "acquired immune deficiency syndrome") OR AB (HIV OR AIDS OR "acquired immunodeficiency syndrome" OR "human immunodeficiency virus" OR "human immunodeficiency viruses" OR "acquired immune deficiency syndrome")	
3	#1 OR #2	
4	DE "Client Satisfaction"	
5	TI (satisfaction OR satisfy OR perspective* OR attitude* OR opinion* OR view* OR preference* OR experience*) OR AB (satisfaction OR satisfy OR perspective* OR attitude* OR opinion* OR view* OR preference* OR experience*)	
6	#4 OR #5	
7	DE "Health Care Utilization"	
8	DE "Health Care Services" OR DE "Continuum of Care" OR DE "Long Term Care" OR DE "Mental Health Services" OR DE "Palliative Care" OR DE "Primary Health Care"	
9	TI (access* OR barrier* OR facilitator* OR utiliz* OR utilis* OR provision OR provide) OR AB (access* OR barrier* OR facilitator* OR utiliz* OR utilis* OR provision OR provide)	
10	TI ("health services" OR "health service" OR "health care" OR healthcare OR care OR treatment OR therapy OR therapies OR service* OR clinic* OR "medical care" OR "medical services" OR program*) OR AB ("health services" OR "health service" OR "health care" OR healthcare OR care OR treatment OR therapy OR therapies OR service* OR clinic* OR "medical care" OR "medical services" OR program*)	
11	#8 OR #10	
12	#9 AND #11	
13	#7 OR #12	
14	#3 AND #6 AND #13	3,424

# Table A4.4 Search strategy for Cochrane

#	Searches	Results
1	MeSH descriptor: [Health Services Accessibility] explode all trees	
	MeSH descriptor: [Health Services] explode all trees and with qualifier(s): [Utilization	
	MeSH descriptor: [Health Services] explode all trees and with qualifier(s): [Utilization   - UT]	

3	(access* or barrier* or facilitator* or utiliz* or utilis* or provision or provide) and ("health services" or "health service" or "health care" or healthcare or care or treatment or therapy or therapies or service* or clinic* or "medical care" or "medical services" or program*):ti,ab,kw (Word variations have been searched)			
4	MeSH descriptor: [Attitude to Health] this term only			
5	MeSH descriptor: [Patient Satisfaction] explode all trees			
6	satisfaction or satisfy or perspective* or attitude* or opinion* or view or views or preference* or experience*:ti,ab,kw (Word variations have been searched)			
7	MeSH descriptor: [HIV] explode all trees			
8	MeSH descriptor: [HIV Infections] explode all trees			
9	HIV or AIDS or "acquired immunodeficiency syndrome" or "human immunodeficiency virus" or "human immunodeficiency viruses" or "acquired immune deficiency syndrome":ti,ab,kw (Word variations have been searched)			
10	#1 or #2 or #3			
11	#4 or #5 or #6			
12	#7 or #8 or #9			
13	#10 AND #11 AND #12	1,172		

# Appendix 5: All concepts and domains, categorized into enablers, barriers and suggestions from PLHA

Table A5 All concepts and domains categorized into enablers, barriers and suggestions from PLHA

Domain	Enablers to healthcare	Barriers to healthcare	Suggestions from PLHA
Acceptability	- PLHA satisfied with medical care	- patient dentist relationship changed when HIV status was	- nonjudgmental HCP
n(concepts)=31	(Blais) (Brondani)	enclosed (Brondani)	(Donnelly)
	- dentist with previous HIV experience	- denied access because of HIV especially in rural areas	- improving the transition
	(Brondani)	(Brondani) (Donnelly)	process from pediatric to
	- Disclosing of HIV status resulted in	- 9.8% personal issues to access traditional aboriginal	adult care (Kakkar)
	more attention (Donnelly)	services (Jackson)	- extra training for HCP (e.g.
	- health education in HIV clinic	- poor care performance at Traditional Aboriginal Services	rural family physician in HIV
	(Donnelly)	(18%) (Jackson & Reimer)	care/for pharmacist in HIV
	- feeling sense of belonging HIV/AIDS	- young PLHA feel that nobody cares in adult care	meds (Laschinger) (Brondani)
	service organisation (Ion) (McCall)	compared to pediatric care (Kakkar)	- education for whole
	- non-judgmental, patient, respectful	- young PLHA were not ready to transition at age 18	population about HIV to gain
	and compassionate care (Jackson)	(Kakkar)	tolerance (Laschinger)
	(Ion) (Laschinger)	- PLHA felt unwelcome because of gender/ sexual	- youth prefer staying longer
	- decreased health resulted in increased	orientation in support group/HIV organisation (Logie)	under pediatric care (Kakkar)
	use of substance use program and	(Donnelly) *	
	social and family service (Jackson)	- Fear of Rejection when Seeking Services, therefore go to	
	- sensitivity to specific cultures	specialized HIV clinic (McCall)	
	(Laschinger)	- HCP outside the HIV network were seen as more	
	- aesthetically welcoming and	judgmental and less knowledgeable, competent, and	
	comfortable atmosphere (Laschinger)	experienced as those inside (Gagnon)	
	- cared for by someone they knew	- lack of understanding on HIV progression and symptoms,	
	(Laschinger)	no believe in therapy (McCall)	
	- recognized as an individual and cared	- no acceptance of disease by PLHA (McCall)	
	for individually (Laschinger)	- discriminatory attitudes and policies towards Aboriginal	
		women, gender, ethnic identity (McCall) (Sanchez) *	
		- power imbalance creates lack of accountability from	
		physicians to patients (Sanchez)	
		- lost confidence in physicians due to difficult patient-doctor	
		relationship (Sanchez)	
		- discrimination by HCP (Brondani) (Donnelly) (Gagnon)	
		(Ion) (Jackson) (Logie)	

Concept: Stigma n(concepts)=11		- self-stigma (guilt and shame about HIV status) (Brondani) (McCall) (Bird) - stigma and tension related to disclosure (Brondani) (Donnelly) (Bird) - stigmatic attribute / labeling (e.g. as infections, as drug user) (Brondani) (Gagnon) (Bird) - stigmatizing behaviour / rejection by HCP (Brondani) (Donnelly) (McCall) - episodic stigma ("generally well treated" with the exception of the "isolated cases") (Gagnon) - symbolic stigma (Gagnon) - structural stigma (Gagnon) - avoidance of sigma-intensive health care settings by few PLHA (Gagnon) - HIV related stigma (Ion) (Jackson) - stigma in public / certain communities (e.g. rural, Latino) (Laschinger) (Logie) (Sanchez) (Bird) - stigma other than HIV (PLHA who were further marginalized by their ethnicity, socioeconomic status, and sexual orientation experienced stigma that ultimately placed unique barriers to the use of health services and resources)	
Comment	1. 1 1.1 . 1111	unique barriers to the use of health services and resources.) (Donnelly) *	
Concept: Confidentiality n(concepts)=6	- seeking health care in HIV-specific clinics easiest because HCP appeared to understand the impact of disclosure and confidentiality (Donnelly)	<ul> <li>tension related to disclosure (Brondani) (Donnelly)</li> <li>disregard of privacy and confidentiality by HCP (e.g. Nurses talked in restaurant about HIV status) (Donnelly) (Ion)</li> <li>inadvertent disclosure (e.g. speaking loud) (Ion) (Sanchez)</li> <li>no trust that confidentiality/ privacy is respected by HCP (Jackson)(Sanchez) (Brondani) (McCall)</li> </ul>	- Suggestion that health care providers should have a confidential conversation in advance to co-create a plan to ensure privacy is maintained and respected. (Ion)

Availability n(concepts)=14	- receiving support from community health centre / HIV clinic helped (Brondani) (Laschinger) - access to a multidisciplinary team (Ion) - Varity of treatments to chose from (Laschinger)	- service specific barrier (8.2% for Traditional Aboriginal Services) (Jackson) - inadequate care or objections to an abstinence-based approach for use of addiction treatment, harm reduction and/or needle exchange programs (Jackson) - lack of services (e.g. hospice program, in rural area) (Jackson) (McCall) - Mental Health and Counselling Services: Aboriginal PLHA indicate they do not know if or where such services exist (26.3%), they feel the care or service they receive is inadequate (18.4%) (Jackson) - inability to find family physician (Laschinger) - incompetent healthcare (unprepared/uneducated) (Logie) (McCall) - lack of primary and secondary HIV prevention programs for lesbian, bisexual and queer participants (Logie) * - lack of mental health and counseling in Spanish (Sanchez)	- need for up-to-date HIV/AIDS treatment/research information (Jackson) (Laschinger) - continuation and enhancement of public education and awareness initiatives (Jackson) - need for temporary housing (Laschinger) (Kakkar)
Accessibility n(concepts)=6	- electronic knowledge exchange (Laschinger)	- transportation / distance /geography problem (Ion) (McCall) (e.g. to traditional aboriginal service, secondary health services, alternative and complimentary service, substance use program (Jackson) (e.g. educational events for rural PLHA (Laschinger) (Blais) (McCall) - housing instability and homelessness (Ion) (Kakkar) - immigration status (Ion) (Sanchez) * - HIV one of many problems (McCall)	- one stop shopping (all facilities in one location) (Laschinger)
Affordability n(concepts)=5		- drug coverage problem (Ion) (Sanchez) - financial barriers/ resources (Jackson) (Sanchez) (Blais) - income security concerns (Kakkar)	- supply of taxi vouchers and bus tokens for patients traveling to and from the clinic (Laschinger) - recommendation of an established and accessible fund for necessities that a patient urgently needs (Laschinger)

Accommodation n(concepts)=6	- return phone calls within reasonable timeframe and live person to answer (Laschinger)	<ul> <li>long waiting time (Jackson) (McCall)</li> <li>not enough time during appointment (Kakkar)</li> <li>long waitlist to see specialist/specialized services</li> <li>(Laschinger) (McCall)</li> <li>limited clinic hours (McCall)</li> </ul>	- one site baby sitting/ day care facilities (Laschinger)	
Communication n(concepts)=10	- improved/ effective communication (Brondani) (Ion) (Blais) - improved information seeking (Brondani) - HCP took time to listen (Ion) - collaboration between health care providers and external agencies (Laschinger) - small gestures like a smile (Laschinger)	- willingness of communication and disclosure depending on experience of PLHA (Donnelly) - lack of communication (Ion) (Sanchez) - silencing (Ion) - language difficulties (Sanchez) *	- HCPs should notify patients if scheduled appointments are delayed, because especially burdensome when young children accompany patients (Laschinger)	
Others n(concepts)=2	- shared decision making (Laschinger)	- unknown and cultural barriers (Sanchez) (Jackson & Reimer) *		
n (all concepts) =91				

<sup>\*</sup> Equity on access to healthcare