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# Canadian Policymaker Experiences on Reducing Syndemic Stigma for HIV and Substance Use Disorder

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Abstract

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# Abstract

People living with HIV (PLWH) and substance use disorder (SUD) experience highly stigmatized lives fraught by influences such as criminal law and stigmatizing public policies. Despite free access to antiretroviral therapy (ART) and mental health services for all Canadian citizens, suboptimal adherence to ART and administratively cumbersome mental health interventions still exist. Many researchers have found the health services for both HIV and SUD to be dynamic, costly, and difficult to maintain; as such, the purpose of this study was to explore the knowledge gap related to the policy implications of syndemic stigma experienced by PLWH and SUD in Canada. Using the advocacy coalition framework and a snowball sampling strategy, semistructured in-depth interviews with six policymakers were conducted to explore how members of a policy coalition in the Canadian public health care system described the problem of syndemic stigma as it pertains to PLWH and SUD. The data sets were gathered and analyzed within a nine-step coding and analysis instrument created for this study, which enabled the emergence of triangulated themes and was used for future policy recommendations. It was demonstrated in the findings that while all policymakers were passionate about the work of helping PLWH and SUD, none were specifically trained in public administration; therefore, they were less equipped at solving any of the public policy problems and the structurally reinforced stigma that the PLWH and SUD continue to face. To effect positive social change, when attempting to solve complex policy problems such as syndemic stigma, organizations and other researchers should view it as a public policy problem that is solvable when practicing evidence-based public administration.

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# Dedication

I dedicate this work to those living with, and experiencing, syndemic stigma.

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# Chapter 1: Introduction to the Study

## Introduction

The stigma associated with the human immunodeficiency virus (HIV) has been researched for over 3 decades. The stigma experienced by people living with HIV (PLWH) has been described as something that occurs both internally and externally (DiStefano, 2016; Ferlatte et al, 2015; Kamen et al., 2015). These stigma experiences are known to be linked to increased rates of mental health issues among this population, including substance use disorder (SUD). Added to the problem of HIV stigma are the many daily life mental health concerns associated with SUD for which seeking help can also be accompanied by further stigmatizing experiences (Ferlatte et al., 2015; Kamen et al., 2015). In this study, I explored the policy implications of the dual stigma epidemic as a syndemic problem in the context of the Canadian health care system. Syndemic stigma is created by the synergistic interrelationship of two co-occurring stigma epidemics, causing a new and typically more egregious type of stigma (Ferlatte et al., 2015).

## Background

On the topics of problematic substance use and HIV stigma, several researchers stated that many people experience multiple types of stigma at different times throughout their lives (Beuthin et al., 2015; Brent, 2016; Genberg et al, 2009; Logie et al., 2012; Pretorius et al., 2016). PLWH and those with SUD feel ostracized as a result of these stigmatized experiences, and because many do not seek treatment for their chronic health issues, large numbers of this population die, either from suicide or complications due to AIDS (Salway et al., 2018).

Because this policy problem was explored in the context of the Canadian health care system, it is important to understand that antiretroviral therapy (ART) and mental health services are free for all Canadian citizens, yet suboptimal adherence to ART and administratively cumbersome mental health interventions still exist (Government of Canada [GC], 2018; Starace et al., 2002). For this syndemic stigma problem, there are several policy implications. In the Canadian national *90-90-90* strategy, there are three national public health targets worth mentioning. These are: 90% of PLWH will know their HIV status, 90% of PLWH will be on ART, and 90% of those on ART will have achieved an undetectable viral load (GC, 2018; World Health Organization [WHO], 2015).

The policy implications in support of systemic change have been explored by several national organizations, such as the Canadian AIDS Treatment Information Exchange, which created guidelines on the structural changes in organizations that may be used to augment effectiveness of their health services (Canadian AIDS Treatment Information Exchange, 2018). Several researchers have stated there is a need for specialized approaches to health service provision and seamless navigation between services for PLWH (Brown et al., 2016; Chollier et al., 2016; Chong, et al. 2017; Furlotte & Schwartz, 2017). Each of these researchers investigated HIV stigma and articulated that the debilitating effects of a negative self-concept were linked to suboptimal ART adherence, but for individuals concurrently living with mental health concerns such as SUD, the effects of stigma related to that experience were prevalent as well. Therefore, PLWH who are also involved with substances may have determinants of health that are contextually specific to their population (Ferlatte et al., 2015). In order to achieve the 90-90-90 targets for the Canadian national strategy, it could therefore be argued that these specialized approaches to health services might be structurally enabled by new policies specifically related to syndemic stigma for HIV and SUD (GC, 2018).

## Problem Statement

There is a problem when PLWH who also experience mental health concerns such as SUD not only face high-risk determinants of health that may be contextually specific to their population (Ferlatte et al., 2015), but also contend with a double stigma related to both HIV and their SUD. This is the concept of syndemic stigma. To eventually achieve the 90-90-90 targets for the Canadian national strategy, specialized approaches to health services are needed that are structurally enabled by new policies specifically related to syndemic stigma (GC, 2018; WHO, 2015). This problem, and the numerous policy considerations surrounding it, are thoroughly explored in Chapter 2.

## Purpose of the Study

The purpose of this study was to qualitatively explore the public policy implications of syndemic stigma among people living with both HIV and SUD in Canada. Via semistructured in-depth interviews, I investigated the perspectives of policymakers, to better understand the policy implications of individuals living with these illnesses. The literature gap I addressed was policy-driven research aimed at understanding the unique determinants of health for this population, along with how to reduce stigma through new policy.

## Research Question

RQ: How do members of a policy coalition in the Canadian public health care system describe the problem of syndemic stigma as it pertains to living with HIV and SUD?

## Theoretical Framework for the Study

The semistructured in-depth interviews were grounded in the advocacy coalition framework (ACF) to enable the identification of the inner world of individuals within a larger system of beliefs and social constructs (Weible & Sabatier, 2018). Exploring the inner world of my research participants was how I intended to understand the policy implications surrounding the syndemic stigma of living with HIV and SUD.

In describing the ACF, Weible and Sabatier (2018) stated that when the common beliefs of multiple individual actors form a coalition, their purpose shifts toward having the beliefs of the group actualized in policy. By conducting this study, I intended to uncover the beliefs of the policymakers as a step in the process toward new public policy actualization. The participants for this study were people who identified as policymakers or people who contributed to the creation of public policy affecting PLWH and SUD. While the ACF accounts for the inner world of individuals, the application of it requires that organizational, legislative, and systemic influences be considered as well. The ACF is aligned with the philosophical tenets of general qualitative methodologies and was used to better understand the experiences of people interacting with this policy problem. More discussion on the ACF is found in Chapter 2.

## Nature of the Study

I used a general qualitative methodology to conduct this research. In consideration of the problem and purpose of this study, one justification for the use of a general qualitative approach was that a constructivist epistemology and ontology are relevant when giving voice to phenomena consisting of multiple complex personal narratives (Bacchi, 2016; Miller, 2015). Using a general qualitative approach aligned best with my problem and purpose because qualitative methodologies require researchers to explore the meaning and sense-making processes of individuals via the tenets of social constructionism (Beuthin et al., 2015). The data were analyzed using a qualitative coding and analysis instrument that was created for this study. The nine-step instrument supported a standard audit trail, summary transcription, and the emergence of triangulated themes.

This methodology was also aligned with my choice of theoretical framework (i.e.: the ACF) because both have an emphasis on exploring the essence, structure, and meaning of the issues (Weible & Sabatier, 2018). Understanding the essence and structure of this problem was important because it was where I gained a better understanding of the policy implications the population might experience, especially with respect to structurally reinforced syndemic stigma. Ultimately, this study informed the policy recommendations in Chapter 5.

## Definitions

For this study, the following terms and definitions were used:

*Advocacy coalition framework (ACF)*: A complex policy theory involving the systematic identification of the inner world of individuals within a larger system of beliefs and social constructs (Weible & Sabatier, 2018).

*Health care*: In the Canadian context, universal health care that is provided to all individuals and is supported by the Canada Health Act, which provides for Canadians to gain access to health care services (GC, 2019a).

*Human immunodeficiency syndrome (HIV)*: A medially diagnosed viral condition whereby the immune system of the infected individual is denigrated to the point that they are far more susceptible to opportunistic infections. If HIV is not treated, it can lead to acquired immunodeficiency syndrome (AIDS; British Columbia Centre for Disease Control [BCCDC], 2019).

*Intersectional stigma*: In consideration of the various unmet social determinants of health that a PLWH and SUD might be experiencing, the confluence point where these determinants might provide insight into the type of stigma most prominently occurring at an individual level. (GC, 2018; Logie et al., 2011).

*Policymakers*: Individuals who work collaboratively to write policy. For the context of this research, these are the Canadian health policies affecting PLWH and SUD (Luxon, 2019). These people may either be professional policy decision makers (Greer et al., 2017), like public or not-for-profit sector employees, or they may also be peer volunteers with lived or living experience. The inclusion of volunteers as policymakers is common in the Canadian public health sector. When creating public policy, both employees and people with lived and living experience surrounding a phenomenon are invited to participate at the policymaking table and are treated as equals, each with specialized knowledge from their professional and personal experiences (Greer et al., 2017).

*Substance use disorder (SUD)*: A medically diagnosed condition for individuals living with problematic use of one or more licit or illicit psychoactive substances resulting in a clinically significant impairment or distress (Brenner et al., 2019).

*Syndemic stigma*: Created by the synergistic interrelationship of two co-occurring stigma epidemics, causing a new and typically more egregious type of stigma (Ferlatte et al., 2015)

*90-90-90 strategy*: The World Health Organization targets that have been adopted as part of the Canadian national health strategy. They are: 90% of PLWH will know their HIV status, 90% of PLWH will be on ART, and 90% of those on ART will have achieved an undetectable viral load (GC, 2018; WHO, 2015).

## Assumptions

To describe the national context for this study, a short explanation of the Canadian health care system is warranted. The Canadian publicly funded health care system is allocated via federal tax revenue. This structure was predominantly adopted throughout several Canadian Provinces by the mid-20th century, and in 1984 the Canada Health Act was passed, which provides for Canadians to gain access to health care services based on five principles: public administration, comprehensiveness, universality, accessibility, and portability (GC, 2019a). The Canadian federal government acknowledges the need for ongoing reform, and as such it continually hones and provides assurances, some legislated and some via funding commitments, to ensure that Canadians receive the services they need.

One topic to highlight is the structural inequalities that might exist in the delivery of universal health care. For PLWH and SUD, there are several gaps in a universal system that is meant to equitably distribute resources to those who are in need. PLWH and SUD live at the intersection between stigmatized life experiences for each of their conditions. This structural gap with regards to health care exists for both conditions separately, but based on the acknowledgement for ongoing reform mentioned above, an important assumption that I am making is that when PLWH also live with SUD, the gap widens and may need specialized policies to change this experience of the Canadian health care system.

Another set of assumptions was related to the honesty of my participants, in that throughout the process I assumed they were telling the truth about their experiences to the best of their ability. This assumption of relying on the honesty of participants is common in qualitative research (Simon & Goes, 2013). Another assumption concerning honesty was related to the inclusion criteria: I assumed that when participants stated that they identified as policymakers, they have participated and do participate in policy work.

## Scope and Delimitations

The participants met the following requirements:

- people residing in Canada,
- legally an adult in their province,
- English speaking, and

- working or volunteering as a policymaker (or participating in the creation of policy) for people living with SUDs and HIV.

Because I used a snowball sampling strategy, policy decision maker participants emerged via word of mouth and electronically from a variety of peer, social, and professional networks. Further scope information is provided in the inclusion criteria that are laid out in the procedures for recruitment found in Chapter 3.

For this study, the approximate number of participants to reach saturation was estimated to be 10 policymakers. The reason this number was likely to be sufficient is aligned with the Guest et al. (2020) formula for determining saturation, which is inductive thematic analysis. Further discussion on saturation is found in Chapter 3. The participant population were people who self-identify as policymakers who are involved in the creation of policy for PLWH and SUD.

There were four central policy concepts surrounding the phenomenon that I asked policymakers about:

1. intersectional stigma and syndemic stigma,
2. health services for HIV and SUD,
3. public policy and other legal implications, and
4. previous stigma reduction interventions.

Several decisions that I made to arrive at this scope have also resulted in some delimitations that may affect the trustworthiness of the study. For example, when writing policy, it is typical to engage with multiple stakeholders around the given policy topic (Bacchi, 2016). This was a delimitation because it is related to the trustworthiness component of transferability, which was positively affected by specifically interviewing policymakers. Another decision that I made was to create a specialized coding and analysis tool for the study that was methodologically aligned within one document to augment the credibility and transferability of the study.

The rationale for exploring the policymaker perspective was also based on the inclusion of the various experiences found in the stigma process articulated by Pretorius et al. (2016). Pretorius et al. argued that the stigma process included several perspectives that were interrelated. To overtly link group data set triangulation to policy writing, conducting analyses such as these could be likened to policy stakeholder engagement, which is a key component to creating good social policy (Bacchi, 2016). Triangulating the data sets was another delimitation because it was meant add to the validity and usefulness of the data for local health services and policymakers.

## Limitations

One limitation of this study was the possibility that while participants may write policy for the population, they may not have lived experience with HIV and SUD. Another possible limitation was that some of the policymakers lack experience around the topic of syndemic stigma. With regards to ethics, and to ensure my study was not likely to put my participants at any risk beyond everyday life, I did an early ethics consultation and shared my premise with Walden’s Institutional Review Board (IRB). They did not identify any red flags in terms of the vulnerability of my participants (Personal email communication, July 12, 2019).

## Significance

The syndemic stigma experiences had not yet been qualitatively researched using social and behavioral sciences, specifically, public policy theory. Therefore, I intended to begin filling this gap by conducting a general qualitative study specific to the policy implications surrounding the phenomenon of syndemic stigma. I explored this via the intersections of the various experiences of policymakers. I chose to explore this perspective so the data from each interview were able to be triangulated for common themes. The potential for social change was enhanced because recommendations coming from this study have been specifically designed to enable better public policy. Further discussion on these items will follow in the next two chapters.

## Summary

In this introductory chapter, I provided insight as to the background, problem, and purpose of my phenomenon of interest, the syndemic stigma experienced by PLWH and SUD. I also described how this phenomenon was explored as a policy problem via the experiences of Canadian policymakers using the ACF. I briefly presented the gap in literature in this chapter, but extensive discussion on how the literature gap was uncovered exists in Chapter 2. I then report the details of the research methods in Chapter 3. This is followed by results and recommendations in Chapter 4 and Chapter 5 respectively.

# Chapter 2: Literature Review

## Introduction

I explored the policy problem of syndemic stigma in the context of the Canadian health care system, where ART and mental health services are free for all Canadian citizens. Despite free services, suboptimal adherence to ART and lengthy wait times to access mental health services still exist (GC, 2018; Starace et al., 2002). To better understand the role that public policy might play in reducing stigma, the purpose of this qualitative study was to explore the public policy implications of syndemic stigma for PLWH and SUD in Canada.

In their meta-analysis of the effectiveness of stigma reduction programs, Mak et al. (2017) found that stigma continues to be a major barrier for PLWH in choosing to access health services. Several researchers have stated there is a need for specialized approaches to health service provision for PLWH and SUD (Brown et al., 2016; Chollier et al., 2016; Chong et al., 2017; Furlotte & Schwartz, 2017). Each of these researchers investigated stigma and articulated that the debilitating effects of a negative self-concept were linked to suboptimal ART adherence.

For individuals living with mental health concerns such as a SUD, the effects of stigma are compounded. This is to say, PLWH who also experience mental health concerns such as a SUD, not only face high-risk determinants of health that may be contextually specific to their population (Ferlatte et al., 2015), but they also contend with a double stigma related to both their HIV and their substance use. The following major sections in this chapter include:

1. The literature search strategy.
2. The theoretical foundation.
3. The literature review related to the key policy concepts of this study.
4. A summary of key themes and a conclusion.

## Literature Search Strategy

In this section, I state the library databases that were accessed during the literature search along with the key search terms. I provide discussion as to the iterative search process that took place over the last 2 years. Finally, I describe the additional measures that were taken to ensure search saturation was achieved.

### Accessed Library Databases and Search Engines Used

The following Walden Library databases yielded the results that were used in this literature review: SAGE Journals, Thoreau, Academic Search Complete, ProQuest Health & Medical Collection, LGBT Life with Full Text, PsycARTICLES, ScienceDirect, SocINDEX with Full Text.

### Key Search Terms and Combinations of Search Terms

The search terms that rendered useful results included: *stigma, HIV, policy and stigma, mental health and HIV, AIDS, suicide, depression, lived experience, chronic illness stigma, health care and HIV, health care and substance use, problematic substance use, substance use disorder, service provider perceptions and Substance use, service provider perceptions and HIV, HIV medication adherence, addiction and HIV,* and *public policy and HIV*.

### Iterative Search Process

The iterative nature of searching databases went beyond the above-mentioned keywords. For example, I typically found further articles cited within the articles that were downloaded and used in this dissertation. Across the available literature, it became evident that there existed a gap in policy-specific research aimed at reducing syndemic stigma through engaging in new policy process interventions. Much of the existing literature on HIV and substance use stigma have been investigations where a singular stigma had been studied, despite the knowledge that a person commonly experiences multiple types of stigma simultaneously throughout their lives (Bekele et al., 2013; Beuthin et al., 2015).

To align this awareness of the literature gap to my problem statement in Chapter 1, in Canada, treatment options are available for both HIV and for SUD, yet suboptimal medication adherence still exists. In the clinical interaction between PLWH and their health care providers, PLWH are often offered mental health interventions upon first diagnosis of their positive HIV status. This is the reason that I searched for a variety of major themes associated with that clinical interaction and the overall care continuum for PLWH and SUD. I present the major policy concepts and some discussion in the upcoming section on literature related to key concepts.

### Additional Measures to Arrive at Saturation

One additional strategy that I used to arrive at saturation was to find several recent Walden dissertations that were related to some of my key concepts. A Walden University doctoral student, Herring (2019), investigated a related topic, which was  to understand how to improve HIV health services for African American men who have sex with men. Herring did so by exploring the cultural competency of health workers. This Walden doctoral researcher used a theoretical framework called the PEN-3 cultural model (Herring, 2019). Herring found that health care workers with cultural competency training had better relationships with their clients, which increased client retention. Stemming from Herring’s research, one policy implication for ART adherence might be that by requiring employees of a health services organization to have this training, the organization might see higher client retention.

Another example of a Walden doctoral student investigating a related topic was Moore (2018), who studied the effects of social supports on health seeking behaviors among the same population that Herring had explored (i.e., African American men who have sex with men). Moore interviewed 14 African American men who have sex with men and found these participants indicated that the likelihood of regular testing and more in-depth discussions with health providers was increased when they had peer support outside the therapeutic relationship. The implications for ART adherence are evident, and the policy implications for this could range from increased public funding for peer support groups and other social mixers to requiring organizations to offer peer support as part of their regular services.

Neither of these examples of other doctoral researchers were exploring syndemic stigma specifically related to HIV and substance use, nor did they use the ACF as their theoretical framework. However, the topic and methods my Walden colleagues used has provided some insight into the types of policy-related interview questions I might explore in my study. For example, I asked my participants about the types of services they provide within their policies and the previous stigma interventions their organizations may have participated in. Also, I asked about anything related to syndemic stigma that might prevent program success, such as client retention and relationship or community building. I also asked my participants about the types of policy changes that might be needed to reduce the syndemic stigma and improve outcomes that are aligned with the 90-90-90 strategy.

## Theoretical Foundation

In this section, I provide a description of the ACF, the major theoretical propositions of ACF, and how ACF has been applied to this study. Additionally, I offer the rationale for choosing the ACF along with why this framework relates to this study.

### The Advocacy Coalition Framework

The researchers investigating stigma have predominantly relied on psychometric tools from a variety of disciplines such as epidemiology, social work, psychology, medicine, and nursing (Windsor et al., 2013). For this study, I used Sabatier and Jenkins-Smith’s ACF as my theoretical framework (Cisneros, 2016). Pierce et al. (2017) described the ACF as a policy process that ensures four broad sets of criteria that most policy processes attempt to achieve. According to Pierce et al. (2017), these policy process criteria are:

- internal validity of policy concepts that include causal mechanisms, falsifiable hypotheses, and be broad in scope;

- being subject to empirical testing that may lead to conceptual and theoretical development;
- seeking to explain much of the policy process and have normative elements; and
- addressing both actors and institutions. (p. 2).

Knowing the main goals of the ACF is important because these items have to some extent guided the themes of my interview questions. I discuss this further in Chapter 3 as it pertains to methodological alignment.

### Major Theoretical Propositions and Assumptions

To describe the major theoretical propositions and major hypotheses of the ACF, I provide a brief summary of its inception and purpose, and I include a delineation of any assumptions appropriate to the application of the theory in the context of this study. Sabatier and Jenkins-Smith introduced the ACF in 1988 as a method through which complex policy processes and longitudinal policy change could be analyzed and better understood (Cisneros, 2016). They did so by describing the interactions between various coalitions and articulated how policy changes and policy demands were met across a longitudinal and complex continuum. Weible et al. (2011) expanded on this and stated that by using the ACF, the impacts a given policy might have on individual citizens and social groups could also be reviewed and analyzed.

Some of the major assumptions of the ACF is that policy processes and policy change ought to account for the multiple groups of actors within all levels of government and the private sector concerning a policy topic. Weible et al. (2011) stated that actors can become a coalition through shared beliefs and shared patterns of coordination; also, one of the purposes of the ACF is to root an understanding of how coalitions naturally form using psychological rather than microeconomic factors (Weible et al., 2011, p. 1). These coalitions make policy demands ranging from being in total agreement with other coalitions to being in direct opposition to one another (Weible et al., 2011). These policy demands from coalitions are also viewed as what matters most to the given coalition and are born of a variety of internal and external influences across time.

Another major assumption of the ACF is that coalitions are considered boundedly rational groups capable of making strategic and logical policy demands worth implementing for the betterment of their coalition (Pierce et al., 2017). These policy demands are also referred to as strategic actions made by coalitions seeking influence, but to be considered strategic actions, they must also contain normative elements that are testable, measurable, and replicable (Luxon, 2019).

One important role that coalitions play is in the building and maintaining of relationships to support the implementation of their respective strategic actions (or policy demands). The additional nuance within this assumption is that relationships do change over time and are vulnerable to changes in governmental priorities. Weible et al. (2011) argued that it is therefore important for coalitions to continuously monitor the strategic actions of other pertinent coalitions while weighing the benefits of taking any strategic action. One controversy about the use of the ACF is there is a lack of understanding as to the complexities of its employ, including which strategic actions are to be used and when (Weible et al., 2011).

To summarize these assumptions, Weible et al. (2011) established that (a) policy subsystems were the main unit of analysis; (b) that the analysis would account for a longer-term perspective; (c) the similar behaviors of actors within subsystems would be considered coalition behaviors; and (d), the policy designs, strategic actions, or demands on policy could be interpreted as coalition beliefs. It is worth noting that within these assumptions, there exist many ways of interpreting each assumption. I explore this further in the next subsection.

## How Advocacy Coalition Framework Has Been Applied

Previous applications of the ACF have included complex super-systems such as federal governments and other large institutions, on topics like national and global environmental reform and foreign policy (Weible et al., 2011). As stated, coalitions appear to form naturally within complex human activity systems, but there are many ways of codifying how these human behaviours take place. Each ACF assumption mentioned in the last subsection can be interpreted differently; for example, several researchers seeking to better understand how coalitions are formed used a variety of metrics like “quadratic alignment procedure”, “egocentric network correlation”, and “block models” (Weible et al., 2011, p. 3).

Codifying how my coalition of interest might form is less needed because my participants have self-identified as policymakers for the provision of health care; and the focus of this study was to better understand how they interact with any policy related to the syndemic stigma experiences of PLWH and SUD. To remain aligned with the purpose of this study, it is more important to understand the needs of the coalition rather than how they formed. The exploration for this study is most related to the fourth ACF assumption listed in the previous subsection, a way to understand the needs of the coalition based on their interactions with the policies related to syndemic stigma.

## Ways Other Researchers Have Approached the Topic of Stigma

It is important to consider that with any chronic illness care continuum, there exist individualized combinations of external and internal influences affecting the patients' health status. In Canada, it is common to view these influences as determinants of health (Bekele et al., 2013; Canadian AIDS Treatment Information Exchange, 2018). Examples of HIV literature on determinants of health have been well researched, and include: food security, intimate partner relationships, employment, disclosure of HIV status, quality of life, and living with SUD (Adam et al., 2015; Aibibula et al., 2017; Bazzi, 2019; Bekele et al., 2013; Brown et al., 2016; Steward et al., 2011).

Within the existing mental health literature related to stigma, determinants of health are considered foremost in the intersectional intervention assessments for mental health supports (GC, 2019b). This is relevant because both HIV stigma and substance use stigma are measured in a variety of different ways. For example, there exists a global HIV stigma index that is being generated on an ongoing basis by PLWH; whereby, intersectional approaches to the questionnaire have been used to understand the prevalence of multiple stigma experiences (Global Network of People Living with HIV, n.d.; Friedland et al., 2018).

Another example of measurements found within HIV literature, is the quality of life assessment. In their quantitative research, Bekele et al. (2013) asked participants using a standardized quality of life tool and found that increased social supports, specifically the nonclinical support provided by family and friends of the PLWH, were linked to higher adherence to HIV medication. This is important to my research because the quality of life assessment is one metric tool that influenced my interview questions, which is also aligned with the WHO (2015) recommended data analysis indicators.

As an alternative way to understand the lived experiences of PLWH who are involved with substances, and to supplement these different stigma measurements, the ACF was applied as the theoretical framework while exploring the problem of syndemic stigma. The ACF was used to capture the essence and intent of the policies that are related to the provision of healthcare for those living with the syndemic stigma of these two illnesses. Explanations for such, along with previous uses of the ACF, are in the following three subsections.

### Rationale of the Choice to Use the Advocacy Coalition Framework

The rationale of the choice to use the ACF was based on the WHO (2015) recommendation insofar as it is related to monitoring the effectiveness of the contextually specific approaches to public policy and related guidelines for PLWH. WHO (2015) recommended that while collating available data and comparing them against the 90-90-90 targets, countries ought to longitudinally consider retention rates after providing linkages to ART and other services for those newly diagnosed with HIV. The longitudinal approach is aligned with one of the assumptions of the ACF. And in taking a longitudinal approach to policy change, recommendations could be tailored to the needs of those HIV+ population subgroups whose ART adherence is further from achieving the 90-90-90 targets than others.

The choice to use the ACF for this study also stemmed from the applicability of boundedly rational coalitions making strategic actions toward policy change. Once the data was gathered and analyzed, some of the interview responses from individual participants were found to be similar. Since those policymakers, whose policy demands were found to be similar could be considered part of a coalition, I discerned that new coalition relationships were possible. As articulated in the previous section, coalitions meet the criteria of being boundedly rational because they can take strategic actions and make policy demands while seeking to have influence over policy change.

## Literature Review Related to Key Concepts

In this section, an exploration of the literature related to the phenomenon of PLWH and SUD will take place. There is a total of four subsections in this section which are aligned with the key policy-related concepts discussed throughout the proposal.

### Intersectional Stigma and Syndemic Stigma

It is worth delineating the terms intersectional stigma and syndemic stigma; though in defining these terms, it is also important to discuss the term stigma as well. Starting with stigma, many researchers described the main elements of stigma as something related to labeling, stereotyping, separation, status loss, and discrimination, where power imbalances are exercised (Baral et al., 2012; Friedland et al., 2018; Logie et al., 2016). However, this definition of stigma is not exhaustive, since it refers primarily to the invoked stigma placed upon people by external individuals.

According to Pretorius et al. (2016) the stigma process has four dimensions: “triggers of stigma,” “stigmatizing behaviours,” “types of stigma,” and “the outcomes of stigma” (p. 2). The piece of the stigma process that I was most interested in was the outcomes of mental health stigma, and whether participants believed that mental health issues such as SUD was causing any barriers to ART adherence among PLWH. In HIV research, several other types of stigma have been investigated. Common among these various stigma types found in the HIV literature are internal, external, hidden, structural, legal, and public (Mak et al., 2017; Pachankis, 2007).

### ***Intersectional Stigma***

Intersectional stigma is an approach to determining exactly which stigmas might be experienced by an individual (Logie et al., 2011). When thinking of intersectional stigma, one would begin by considering the various unmet social determinants of health that a PLWH and SUD might be experiencing. It is at the confluence point where these determinants meet, that some insight into the type of stigma most prominently occurring at an individual level might be gleaned (Quinn, 2019).

For example, a PLWH and SUD might have intersecting determinant health needs for food and hosing security, along with health services. So, a health services provider might aim to link this person with supports based on these needs. The health service provider might also be cognizant that the individual could also be living with some internalized stigma associated with these intersecting unmet determinants of health. Thus, while intersectional stigma may be an assessment that pertains to individuals, syndemic stigma is an identification or labeling of a chronic and potentially less solvable structural problem experienced by larger groups or populations (Quinn, 2019). To address many forms of stigma simultaneously, both ways of naming the experience of multiple stigmas are useful because each provide different types of information and causal insights to inform public policy change.

### ***Syndemic Stigma***

According to Ferlatte et al. (2015), the term syndemic refers to the synergistic interrelationship between two co-occurring epidemics. Syndemic stigma applies to groups and relates to two or more concurrent and interrelated epidemics that are experienced by entire populations of individuals (Ferlatte et al., 2015). This term is commonly used by epidemiologists, even though its roots are considered by many to be a departure from the historical biomedical approach to disease treatment and shifting over to that of a critical biocultural perspective of exploring determinants of health rather than disease (Singer & Clair, 2003). Knowing this is important because it situates the historical timing of the term syndemic as one that has emerged in the health system evidence over last 20 years.

The terms syndemic and substance use were used together by DiStefano (2016) who studied the syndemic links between substance use, trauma, and HIV. Also, there are many examples of studies on the separate experience of HIV stigma, and substance use stigma. Several HIV researchers have defined stigma experiences for PLWH as occurring both internally and externally (Ferlatte et al., 2015; DiStefano, 2016; Kamen et al., 2015). Stigma experiences are known to be linked to increased rates of mental health issues among this population including SUD. As mentioned, PLWH experience multiple and differing types of stigma about having HIV at different times throughout their lives (Beuthin et al., 2015; Brent, 2016; Genberg et al, 2009; Logie et al., 2012; Pretorius et al., 2016).

The term syndemic has also been used to support the exploration of similar types of experiences, such as the population living with, or at risk of, seroconversion (HIV transmission). In their qualitative study, Pollard et al. (2018) interviewed participants to better understand the syndemic relationship between high-risk sexual behaviours such as chemsex (i.e. having sex while using substances) and the co-occurring high rates of childhood trauma of this group. Researchers such as Chidrawi et al. (2016) investigated community stigma interventions that either had been or were in the process of being implemented. The identification of the multiple stigmas experienced by PLWH and SUD had not been specifically called a syndemic problem before Ferlatte et al. (2015) coupled the epidemiological term syndemic with the widespread social phenomenon of HIV and SUD stigma. That said, Logie et al. (2011) had referred to the multiple stigmas experienced by PLWH as intersectional stigma.

To offer an opposing opinion on the use of syndemics, Tsai (2018) argued that using syndemic to support the explanation of the experience of individuals may not be as effective as some had hoped. The reason for this critique is one that cannot be ignored. Tsai purported that using statistical scores alone could not be used to empirically articulate the internal subjective experiences of individuals and recommended that mixed methods research be conducted when using syndemics. However, Tsai and Venkataramani (2016) offered a definition of syndemics that was aligned with those mentioned by other researchers earlier in this section. In the case of my study, only qualitative data were gathered; so, this may be considered by some as one limitation to my resultant data, especially from a positivistic perspective.

## Health Services for HIV and Substance Use Disorder

When thinking about the key concepts of SUD, it is useful once again to consider the types of stigma and some of the possible motivations for accessing health services that might be at play for people living with this illness. Logie et al. (2012) used the minority stress model to study gender non-conformity issues among PLWH who are also living with depression. To further knowledge on the topic of stigma, Opollo and Gray (2015) even studied the effects of stigma for health care providers who were also living with HIV.

For PLWH who also lived with a substance use comorbidity, the World Health Organization (WHO) (2014) reported that stigma and discrimination were commonly experienced by this population. This experience played a role in their choice to access health services (WHO, 2014). Sin and DiMatteo (2013) found that treating PLWH who were experiencing depression showed higher adherence to ART. The global 90-90-90 strategy adopted by the GC (2018) is meant to support the creation of better policies aimed at addressing testing, treatment, and prevention, though policy driven research is lacking.

The key mental health related concepts found in the lives of PLWH who experience stigma were described by Palmer et al. (2011) and Salway et al. (2019) as a widespread sense of helplessness, high-risk behaviors related to sex and drug use, depression, anxiety, negative self-image, negative in-group bias, and suicidal ideation. These mental health related experiences among PLWH are such that they are not always consistently addressed throughout the care continuum, which contributes to the significance of a study on the policy implications of syndemic stigma, rather than exploring one stigma at a time using other methodologies.

While it is known that mental health interventions are linked to higher adherence to antiretroviral drugs, not all services are accepted by PLWH. When PLWH also live with substance use issues, they are at a higher risk of not adhering to their ART, and therefore will eventually develop AIDS, as well as augment the likelihood of seroconverting with others (Sin & DiMatteo, 2013). Many PLWH are aware of this, and when HIV stigma is compounded with living with a SUD, PLWH sometimes become less able to consistently change their behaviors during periods of instability throughout their lives (Palmer et al., 2011; Salway et al., 2019). This supports the need for policy solutions to address the need for health service organizations to have appropriate mental health supports available to their patients and clients.

There exists but one study that is the most closely related to the key concepts under investigation in my study. Salway et al., (2019) explored the needs of PLWH who also were living with a SUD. A key finding of their study was that the individuals who were the likeliest to experience syndemic stigma, would prefer to access both HIV and mental health services in one location over having to seek help at multiple locations (Salway et al., 2019). While providing services for HIV may be possible, specialized mental health services specifically for people living with addiction in Canada, is such that referrals for addiction treatment is a lengthy process. While wait times are widespread across multiple types of health services, this key gap could be considered a structural one in relation to the allocation of specialized resources aimed at streamlining simultaneous access to multiple health services.

In the specific case of accessing mental health services, the WHO (2015) articulated that included as part of a robust national strategy to achieving the 90-90-90 targets, countries need to account for the determinants of health for this population. For example, in British Columbia Canada, individuals who are newly diagnosed with HIV are linked with medical and mental health support services (BC Centre for Excellence in HIV/AIDS [BCCE], 2009; BCCE, 2018). Though, it is left to the individual citizen to adhere to their medication and to access other supports they deem important. When individuals are experiencing an acute need for substance use services and their mental health is deteriorating, they are also met with long wait times for accessing these services, thus remaining at risk of transmitting HIV due to these unmet determinants of health that might otherwise help them to make safer sexual health choices (Bazzi et al., 2019).

## Public Policy and Other Legal Implications

In British Columbia Canada, the trusted and publicly available clinical guidelines for individuals newly diagnosed with HIV comes from the British Columbia Center for Disease Control (BCCDC) and the British Columbia Centre for Excellence in HIV / AIDS (BCCE). Both organizations have stated in their respective guidelines to immediately offer and link PLWH with medical, medication, and mental health support services (BCCDC, 2017; BCCDC, 2019; BCCE, 2009; BCCE, 2018). Apart from ensuring that PLWH become linked to these services, the BCCDC guideline also specifies that PLWH would benefit from being linked to other community services such as peer support groups (BCCDC, 2017; BCCDC, 2019). Individuals are provided information on these resources and many PLWH use them. However, it is not well known the length of time that people continue to use the services, or the extent to which they are comfortable seeking support when they are experiencing acute mental health concerns related to problematic substance use.

As mentioned, Canada has adopted the 90-90-90 WHO (2015) strategy. In British Columbia, 30.5% of PLWH do not have a suppressed viral load (GC, 2017). Thus, the current service guidelines set forth by the BCCDC have yet to be totally effective at meeting the 90-90-90 targets. When creating public policy to reduce syndemic stigma, various types of stigma each have different contributing factors that need to be considered when applying the ACF. To draw alignment and relevance as to the utility of the ACF, one type of external influence found in the ACF is called a system shock.

An example of a current system shock would be the recent public policies affecting the BCCDC with the declaration of the COVID-19 public health emergency. The BC Centre for Excellence HIV / AIDS (BCCE) has discontinued for the current time, the precision viral load plasma detection services for PLWH who have a suppressed viral load on a variety of antiretroviral medications. They have done so to reallocate lab resources for COVID-19 testing (BCCE, 2020). This is detrimental to public safety because several researchers have stated that after an individual has been diagnosed with

HIV, an unknown viral load status is considered a high-risk scenario for PLWH (Bryan & O'Byrne, 2012; Barré-Sinoussi et al., 2018).

### *Legal Implications of HIV Nondisclosure*

Adam et al. (2015) explored the effects of making HIV status disclosures in new relationships. The study took place in a Canadian context where disclosure laws are changing, meaning, new antistigma policy will need to be created. Key legal implications playing a direct role in the stigma experiences of PLWH is related to the criminalization of HIV non-disclosure. According to Section 273 of the Criminal Code (R.S.C., 1985, c. C-46), PLWH who do not disclose their HIV status to potential sexual partners can be charged with aggravated assault regardless of whether seroconversion (HIV transmission) took place during the sexual act.

In British Columbia, the relevant policy related to disclosure of HIV status is entitled: Sexual Transmission, or Realistic Possibility of Transmission, of HIV, coded as SEX2, and is found in the Crown Counsel Policy Manual (British Columbia Prosecution Service, 2019). Here, the policy as to whether charges are laid is related to the probability of transmission at the time of the sexual act. The effect that criminalization of sexual acts has had for PLWH in being required to disclose their HIV status has increased the likelihood of PLWH being subject to stigmatizing behaviours from sexual partners, and ostracization from their families as well as from the LGBT2SQ+ community (Canadian HIV / AIDS Legal Network [AIDSLAW], 2019; Beuthin et al., 2015; Genberg et al, 2009; Logie et al., 2012; Pretorius et al., 2016).

The recent important change to the statutory framework associated with HIV disclosure is found in the nuance of the realistic probability of transmission. According to the Crown Counsel Policy Manual (2019), individuals with a suppressed viral load can no longer be charged with aggravated assault if they do not disclose their HIV status to their sexual partners. This is because the likelihood of HIV transmission when a PLWH has an undetectable viral load is nil. This is known as the Undetectable = Untransmittable (U=U) movement, and it has far reaching organizational policy implications that are causally related to this legislative policy directive (Department of Justice Canada, 2017). Widespread education about this legal nuance could serve to reduce the stigma associated with HIV disclosure.

### ***COVID-19 Implications***

As mentioned regarding system shocks, the world faces another potentially life-threatening virus in COVID-19; and there is arguably much to be learned from the pandemic response to the HIV / AIDS crisis of the 1980s and 1990s. While the COVID-19 pandemic response is outside the scope of this dissertation, the Canadian HIV / AIDS Legal Network recently commented on four policy issues related to the COVID-19 pandemic response which they described as being relevant lessons learned during the AIDS crisis. The four policy issues are: “criminalization and public health monitoring”; “prisons and other places of detention”; “universal access to shelter and housing, income and other supports, and health care”; “travel and border restrictions” (AIDSLAW, 2020). Any of the public policy measures taken during COVID-19 that have implications for ongoing monitoring of viral load indicators for PLWH and other determinants of health, are likely to have impacts for PLWH and SUD which will need to be explored in future research after the COVID-19 crisis.

## Previous Stigma Reduction Interventions

In Vietnam, Hammett et al. (2014) reviewed the role and impact of expanding pharmacy services aimed at reducing HIV rates in local communities. Later, Hammett et al. (2018) conducted a case study of a local community plan to end HIV among people who inject drugs, including the policy implications of the community plan. They found two policies that needed to be present for a program such as this to be successful: that nongovernmental organization (NGO) clinics needed to be publicly funded, and that substance use treatment had to be part of the services provided by the expanded public health clinic.

Another example was Dass-Brailsford (2019) who studied the relationship between HIV stigma, substance use, and trauma, and found that integrated health service interventions needed to also be aimed at reducing HIV status disclosure stigma. Salway et al. (2019) researched the local needs of PLWH and substance use comorbidities in British Columbia Canada. They used a waiting room survey in local sexually transmitted infection (STI) clinics in Metro Vancouver, Canada and discovered that most of the survey participants would access substance use services if the clinic offered them within the same edifice.

Chidrawi et al., (2016) researched levels of pre- and post-intervention stigma in communities. The purpose was to understand the levels of impact that stigma education might have when groups were immersed in learning about the effects of stigma. Genberg et al. (2009) studied the stigma experiences of PLWH in four countries to better understand how these experiences might be different in these countries. They attempted to uncover whether stigma played a role in PLWH getting tested, and whether the external stigma attitudes could be a factor in the spread of the disease. They highlighted stigma as being a major contributory factor for whether PLWH will seek ART for their HIV.

Mak et al. (2017) conducted a meta-analysis of stigma reduction programs, and the inclusion criteria used for selecting the stigma reduction interventions that they reviewed are important to this study. This is because they reviewed a broad catchment of outcome metrics which may be considered when policy is being written. In particular, the two metrics most common to have had a positive impact toward reducing HIV stigma were knowledge and attitudes (Mak et al., 2017). Mak et al. further reported that the number and frequency of the stigma reduction sessions also had an effect. Specifically, larger positive changes in knowledge and attitudes were reported when an intervention offered more than one session, which has implications for organizational policy aimed at reducing syndemic stigma.

To relate the Mak et al. (2017) meta-analysis to my selection of concepts, and to provide justification for the rationale of my selection, the reduction of any type of stigma is arguably done when there is an augmentation of human dignity, which typically occurs through the provision of education and awareness building activities. The complexities of syndemic stigma are such that even with the reduction of one type of stigma there are several others affecting the experiences of this population.

Since all the above examples are stigma related research on the topics HIV and SUD, it may be useful to provide some examples of the availability of policies aimed at reducing other types of stigma. A database search for the terms policy and stigma was conducted, which resulted in an endless number of peer reviewed articles on anti-stigma policy research. Topics such as obesity, race, poverty, physical disabilities, people with prior criminal convictions, blood donation, and ageism. Of note, is that the anti-stigma policy research related to HIV and SUD were not at the forefront of the search results.

## Summary and Conclusions

The major themes in the literature related to the lived experience of PLWH and SUD describe a highly stigmatized life fraught with many influences ranging from criminal law, internal beliefs and self-perceptions, external interactions, and stigmatizing public policies. Before my proposed study, policy recommendations have been made by researchers who have not explored the problem of syndemic stigma with the complex public administration policy change theory provided for by the ACF. The main justification for the use of the ACF in this study, is that doing so may uncover new insight into policy recommendations for future consideration by policymakers. In the next chapter on research methods, an exploration of the study design and methodological alignment, along with the specific steps that were taken to conduct the interviews, are provided.

# Chapter 3: Research Method

## Introduction

In this chapter, I present the research design and rationale and include the role of the researcher, methodology, issues of trustworthiness, and ethical considerations. The purpose of this general qualitative study was to better understand the policy implications of the syndemic stigma experienced by PLWH and SUD, and the main research question was:

RQ: How do members of a policy coalition within the Canadian public health care system describe the problem of syndemic stigma as it pertains to living with HIV and a SUD?

## Research Design and Rationale

To enable a qualitative exploration of this phenomenon, and to answer the research question, I designed a study to explore the experiences of policymakers working in the Canadian health care system. Several standardized steps are outlined in the complete interview protocol found in the Appendix. To explore the design rationale, it is worth reiterating the policy-related structural inequalities that might exist in the delivery of universal health care. For PLWH and SUD, there are several gaps in a universal system that is meant to equitably distribute resources to those who are in need. PLWH and SUD live at the intersection between stigmatized life experiences for each of their conditions. As mentioned in Chapter 2, this structural gap with regard to health care exists for both conditions separately, but when a PLWH also lives with SUD, the gap widens.

Canadian health care policymakers are charged with the task of maneuvering a variety of political environments along with the need to ensure ongoing public value for the overall health services of all Canadians. The health services for PLWH and SUD are known to be dynamic, emergent, costly, and difficult to maintain; as a result, the task of policymakers who are charged with creating equitable access to these services, especially in the face of the federally adopted 90-90-90 strategy, are challenging (GC, 2018; WHO, 2015). I chose to use this framework because it accounts for complex policy environments such as this. Further discussion as to the central policy concepts and philosophical orientation follow in the next two sections.

Given the various health services with which this population might interact, I want to better understand the complex experiences and perspectives of coalition members surrounding the policy problem of syndemic stigma. To define the central concepts related to the phenomenon of this study, and to answer my research question, there are four central policy concepts that I asked policymakers about:

1. Intersectional stigma and syndemic stigma.
2. Health services for HIV and SUD.
3. Public policy and other legal implications.
4. Previous stigma reduction interventions.

## Research Tradition and Rationale

In consideration of the problem and purpose of this study, one justification for the use of a general qualitative approach is that a constructivist epistemology and ontology are relevant when giving voice to phenomena consisting of complex personal narratives of a population (Bacchi, 2016; Miller, 2015). I used a general qualitative approach to the interviews to investigate this phenomenon. One reason this approach aligned best with my problem and purpose was because in using the theoretical framework of the ACF, I was required to explore both the individual experiences through a lens of social constructivism as well as the experience of a coalition via social constructionism.

A general qualitative study was also aligned with my problem and purpose because in using the ACF, emphasis was placed on exploring the essence, structure, and meaning of the issues (Weible & Sabatier, 2018). Understanding these elements of this problem was important because they offered clues as to some of the policy related issues the HIV+ and SUD population might experience, particularly with respect to structurally reinforced stigma. This enabled the recommendations provided in Chapter 5.

## Role of the Researcher

This section contains some of my preinterview reflections. I intended to interview policymakers with whom I have no personal or professional relationships. Part of the reason for this preinterview reflection was to enable an exploration of some of my learned biases and to understand how I might react with more awareness during my interviews. Throughout the following subsections, I provide detail on personal and professional relationships and researcher bias mitigation strategies.

### Personal and Professional Relationships

Academically, I have a public policy specialization and work professionally as a policymaker in the Canadian health care system. In consideration of the two organizations with whom I initiated a snowball sampling strategy, the likelihood of having participants who are colleagues was possible but not probable because both organizations were external to my professional workplace organization. Participants identified via word of mouth or the poster were not likely to have any power relationship issues worth noting. If one had emerged, I would have addressed this with the potential participant and consulted with my dissertation chair as to whether it would be appropriate for their participation.

### Researcher Bias

Apart from any potential professional experiential biases related to my work as a public administrator, my I noted my original intrinsic motivation in my reflexive notes throughout my dissertation process. One pertinent item worth sharing is that while I work professionally as a policymaker and health care administrator, I do not live with HIV or an active SUD. It was my intention to use the process of reflexive journaling to examine my emergent personal constructions as they may be related to the research. Further discussion on this, including steps that were built into the research process, are in the coding and data analysis subsections.

## Methodology

This section includes the participant selection logic, instrumentation, significance, procedures for recruitment and data collection, the summary interview guide, and the data coding and analysis plan.

### Participant Selection Logic

Participants are also referred to as policymakers throughout this study. The purpose of this study was to better understand the experiences and perspectives of policymakers surrounding the policy problem of syndemic stigma. The study began with a request to the two organizations to distribute an electronic flyer via internal email to colleagues who may know one another within and outside of their organizations. This allowed for interested parties to emerge of their own choice. The inclusion criteria to invite potential participants were advertised in an electronic flyer that stated how this was a qualitative study seeking individuals for telephone or Zoom interviews who have lived experience surrounding the creation and implementation of public policies related to PLWH and SUD, specifically as they pertain to stigma. The inclusion criteria were:

1. people residing in Canada,
2. a legal adult in their province.
3. English speaking, and
4. work or peer volunteer as a policymaker (or participant in the creation of policy) for people living with SUDs and HIV.

As mentioned in the definitions section of Chapter 1, policymakers were defined as people who were policy decision makers, such as public sector employees, or were peer volunteers with direct lived experience. It is those individuals who work collaboratively to write policies affecting PLWH and SUD. The reason for the inclusion of volunteers as potential policymaker participants is related to the common occurrence in the Canadian public health sector. It is a standard that when creating public health policy, people with lived experience concerning a phenomenon to be invited to participate as peers at the policymaking table and are treated as equals with specialized knowledge based on their lived experience (Greer et al., 2017). Once participants received the flyer and contacted me to express interest, I started by responding to any initial questions they posed. After this, I asked for a statement in an email from them to confirm that they identify as an individual who met the inclusion criteria. All workplace organizations where participants might be employed were masked, and identity information were coded in an anonymous manner. More information on the topic of confidentiality is in the ethical procedures section of this chapter.

With regard to sample size and saturation, Guest et al. (2020) researched the relationship between sample size and saturation and suggested that while this number can to some extent be a number that is determined arbitrarily, it is one that is different for every study. In this study, the approximate number of participants was estimated to be 10 policymakers. The reason this number was likely to be sufficient is that it aligned with Guest et al.’s (2020) formula for determining saturation, which is inductive thematic analysis. By following the nine-step process established in the research coding and analysis instrument, and throughout the interviews, I saw the data emerge from raw precoded participant statements in the early summary transcription step to that of rich descriptions and objective themes in the latter steps. Saturation was an emergent determination that became apparent after several interviews; and this is discussed further in Chapter 4.

## Instrumentation

The complete interview protocol is in the Appendix. The process to arrive at this guide included reflection on the methodological implications, specifically the questions needed to gather this type of data, and alignment with the problem and purpose. I created questions that were aimed at uncovering the meanings behind the experiences, the possible stigmas, and how policy might help this population. The interviews took place via telephone Zoom and were recorded using the standard audio recording app within Zoom or on the cellular phone via the Call Recorder app that was accessible via the Google Play Store. Data are kept secure in a two-stage password protected electronic storage location, and a coded file naming convention was used to anonymize the data. Only I have the encryption key and file passwords.

### Researcher-Developed Instrument

A new coding and data analysis instrument was created for this study that follows the Halcomb and Davidson (2006) text and the Laureate Education (2019) field notes document. In total, there are nine steps that were taken within one document. The first three steps were from the adjusted Walden field notes document, and the last six steps came from an adjusted Halcomb and Davidson coding document. The exact steps and how they were used is discussed in detail within the coding and analysis subsection below.

One reason this instrumentation had been developed, was to enable all procedural analysis and audit trail steps for the study to take place in one document. Also, in conducting a general qualitative study, a standardized approach was needed to ensure issues of trustworthiness are accounted for. The credibility, dependability, transferability, and confirmability of this instrument were both based in learning from previous studies, as stated by Halcomb and Davidson (2006), but also in the uniqueness of the application of the ACF. That is, there needed to be a standardized manner to collate data that was reasonably repeatable by other researchers.

## Procedures for Recruitment, Participation, and Data Collection

With the various health services this population might interact, I wanted to understand the experiences and perspectives of coalition members surrounding the policy problem of syndemic stigma. My research question was: How do members of a policy coalition within the Canadian public health care system describe the problem of syndemic stigma as it pertains to living with HIV and an SUD? I planned to have English-speaking, adult, Canadian participants who identified as a policymakers, either professionally or as a peer volunteer, who worked collaboratively to write policies affecting PLWH and SUD.

### *The Electronic Flyer and Welcome Email*

Whenever potential participants received the electronic flyer, and contacted me to state their interest, they were provided with the welcome email which contained information to support their decision to participate or to not participate (see Appendices B and C). As articulated in the Walden IRB consent template, elements of consent included: provision of background information, articulation of procedures and some sample questions; a statement as to the voluntary nature of the study; a summary of risks and benefits of being in the study; a statement regarding non-payment; the information as to how privacy would be handled; the IRB contacts for questions; and procedure for obtaining consent.

The welcome email contained all the additional consent and confidentiality information, along with some sample interview questions aimed at enabling the potential participant to make an informed decision. These steps all contributed to the trustworthiness of the study because they ensured transferability and dependability. The Walden University IRB contact information was also included, a summary of participation risks and benefits, and an invitation to respond with a statement such as: "I consent to participate, and these are the times I am available for my telephone / Zoom interview".

### ***Interview Booking and Implications***

Once the participant interviews were booked based on their preference of platform and time (i.e. telephone or Zoom), privacy implications for Zoom and telephone interviews were addressed in a standardized manner by using the complete interview protocol (see Appendix). I personally conducted telephone or Zoom interviews with one participant at a time, to maximum of four participants in one day. On average, the interviews took 30-60 minutes.

### ***During the Interview***

Each interview was semi-structured in that, there were four main policy concepts that served as pre-coding guides, but the questions were open-ended and limited to approximately three questions for each conceptual section. In-the-moment follow-up questions were posed, and participants were given forewarning in the welcome email and opening interview statements that this would be the case. At the end of the interview, a standard closing statement was shared with each policymaker participant, and while member checking did not occur, a request to contact them after the interview in the event further clarification was needed on any of their data.

### ***Postinterview, Transcriptions, and Data Security***

To ensure content validity and credibility, all participants were engaged in a standardized manner using the same steps, which are provided in the complete interview protocol. The informed consent process began via email in advance of the interview. Peer debriefing for participants was suggested at the end of the interview, and all data sources created during the Zoom interview such as audio recordings, summary transcriptions within coding document, and my reflexive journals were uploaded to a secure cloud location with a two-stage security authentication to protect participants and their data. More information on security is in the ethical procedures section later in this chapter. The next two subsections provide information on the procedures and data and analysis collection.

## Interview Guide

The complete interview protocol is found in the appendices. Among the appendices, I have included the electronic flyer, the email invitation with sample interview questions, additional informed consent information, the introductory statements, the interview questions, and the concluding / closing statements (see Appendices A-C). Also included in the complete interview protocol, is the exact consent verbiage provided by the IRB’s Office of Research and Compliance.

## The Coding and Analysis Plan

To code and analyze the semistructured interviews, I created an instrument that included some aspects of the Laureate Education (2019) field notes document and amalgamated them with the Halcomb and Davidson (2006) coding document. This one hybrid document served as the instrument for the audit trail, summary transcription, as well as the location where the coding process unfolded. This instrument contained nine steps that were taken to document each interview in a standardized manner. The first three steps are from the adjusted Walden field note document, the last six occurred in the adjusted Halcomb and Davidson coding document.

1. Create a video code number, so the identifying information were not visible in this record.
2. Time / setting.
3. Other unusual / interesting characteristics.
4. Summary transcription and pre-coding based on four policy concepts aligned with Chapter 2 (Reflexivity observational: What impressions, thoughts, critiques, unanswered questions did you observe in the interview?).
5. Journal immediately after interview (Reflexivity bracketing: this interview has made me aware of some inner belief).
6. First Cycle Descriptive: Preliminary verbatim content analysis based on exactly what I heard.
7. First Cycle Concept: Secondary content analysis based on the concepts that participants spoke about.
8. Second Cycle Patterns: Thematic review of larger themes repeated and emphasized.
9. Quick Memos and Summary notes (logistical and other).

The data were organized within the same excel coding document where a summary transcription with a separate Excel tab for each participant was generated. This enabled the credibility of the study through the creation of a structured and themed dataset that are analyzed in Chapter 4. Since the four policy concepts were standardized for all interviews, these concepts served as preliminary coding categories. The four categories were used in the coding document to organize the data and to surface researcher internal analysis processes. The four pre-coded sections were aligned with the policy concepts discussed in Chapter 2. These were: intersectional stigma and syndemic stigma, health services for HIV and SUD, public policy and other legal implications, and previous stigma reduction interventions.

The pre-coding took place in Step 4; and having pre-coded the data, my analysis plan of the interview questions included responses from the various participants, which were then triangulated between each of the participant responses. This process has emerged while iterating on the analysis and coding plans, and in building the instrument for this study. To follow established policymaking processes, it was important to be able to triangulate between the datasets because the findings would consist of the individual policymaker experiences (Bacchi, 2016; Pretorius et al., 2016). Group data set triangulation is a common analysis practice for qualitative research, and it was used by other HIV stigma researchers such as Lohiniva et al. (2016). Narrative triangulation is also done during policy writing efforts, in that, one could liken this process to a formal stakeholder engagement, which is a key component to policy writing (Bacchi, 2016).

Doing so added to the validity and usefulness of the eventual policy recommendations that are made in Chapter 5.

There existed a need to understand aspects of the reflexive steps of the coding process (Steps 4 through 8). While the study was a general qualitative one, some aspects of phenomenological inquiry were important because they aligned with the theoretical framework, the ACF. The specific aspects of phenomenological inquiry that were pertinent were those related to my internal iterative processing as a human research instrument. Moustakas (1994) described four steps of phenomenological method which were considered in the creation of this coding and analysis plan; these steps are epoche, phenomenological reduction, imaginative variation, and synthesis.

This study was an exploration of how participants described stigma as it related to the policy they have written and implemented. Specific public policy statements are cocreated by public servant team members, typically, after consultation with internal and external stakeholders, and are intended to serve the public. As such, there were some descriptions that were provided in the interviews that caused new realizations for the researcher to be put forth as recommendations in Chapter 5.

It is for this reason that Steps 4 and 5 were required as coding steps. They were meant to surface any of my personal beliefs, and to ensure that my beliefs were considered as a coding step. In consideration of what Moustakas (1994) had described, Steps 3 and 4 served as a sort of phenomenological reduction step, whereby I described what was observed, so as to potentially surface and name unknown biases and to give insight into what seemed important to me as the research instrument.

Steps 4 and 5 were used to both pre-code the data in a summary transcription, but also to describe in a structured manner, any explicit realizations that occurred within the researcher, after engaging with the previous two steps. After having engaged in a process like phenomenological reduction found in Steps 3-6, Steps 7 and 8 could to some extent be compared to Moustakas' (1994) imaginative variation. This is because it is in steps 7 and 8 where the researcher is meant to process and synthesize what was heard and described in Steps 3-6; then, the data was transformed into what may be considered the essence found in the conceptual and thematic componentry of the data.

Throughout this process of differentiating the data from what might be considered researcher attributed patterns and groupings (Steps 3-6), I continually interacted with the data and intentionally engaged in a meaning and sense making process. The entire process was meant to support a social constructionist and co-created understanding of data from multiple perspectives. Ultimately, serving toward the reintegration and synthesis of all essential parts within Steps 7 and 8. All datasets (or perspectives) consisting of individual participant narratives including discrepant cases were to be triangulated to determine final codes and eventual policy recommendations.

## Issues of Trustworthiness

Since this study was an exploration of policymaker experiences within Canadian health care system, it is worth overtly stating that as the researcher, I too, am a Canadian citizen working within the health care system as a policymaker. The next four subsubsections are credibility, transferability, dependability, and confirmability, each consisting of statements on how the study as articulated in the complete interview protocol found in the Appendix and the coding and analysis section of this chapter was conducted in a manner that ensured each issue of trustworthiness was accounted for.

### Credibility

Regarding the accuracy with which the phenomenon has been represented, after being individually coded within the coding instrument, I triangulated the data sets from the participants with lived experience surrounding this phenomenon. Furthermore, the interview guide and complete interview protocol are noted in the instrumentation section where I have been transparent in my recruiting, consent, and summary transcription processes. To augment credibility, the data were organized within an adapted coding and analysis instrument that included steps from the Laureate Education (2019) field notes that was adapted and amalgamated with the Halcomb and Davidson (2006) coding document. This one hybrid document served as the instrument for the audit trail, summary transcription, as well as the location where the coding process unfolded.

### Transferability

Regarding transferability, three stages of descriptions and coding of the data collection was used in the process, each step was documented in the coding and analysis instrument. This instrument was created by adjusting and amalgamating two documents for research. One was Laureate Education’s (2019) field notes document, and the other was Halcomb and Davison’s (2016) coding document. The instrument included a total of 9 steps which are articulated in the coding and analysis plan.

Recruitment took place via a snowball sampling strategy. As a starting point, previously formed connections between myself and two external organizations were leveraged to allow for interested parties to emerge of their own choice. This request to distribute an electronic flyer via internal email to their colleagues both internal and external to their organizations. Recruitment information was also shared via a paper flyer for posting on any available local workplace bulletin boards (see Appendices B and C). Namageyo-Funa et al. (2014) stated that using word of mouth with participants as gatekeepers was one of the most effective ways to ensure an effective recruitment strategy.

## Dependability

To replicate this study, I have included the complete interview protocol in the Appendix and have engaged in reflexivity via journaling to log the ways in which my thinking on the topic has emerged over time. Reflexive journaling enables researchers to learn throughout the qualitative journey as to their process and to safely explore their leniencies (Hare, 2016, p. 13). During the interviews, Steps 4 and 5 were taken to demonstrate my initial thoughts as the data were heard from the participant for the first time. These two steps are also for pre-coding and summary transcribing, then bracketing first-pass researcher placed meanings that may emerge. Engaging in this type of reflexivity is commonly used to codify the inner world of qualitative researchers (Houghton et al., 2013). Discussion as to the coding process and the relationship to certain aspects of phenomenological inquiry are provided in the coding and analysis plan section.

### Confirmability

My role as researcher came with some intrinsic motivation toward this topic. The intention for the interviews was to explore the experiences of policymakers with lived experience surrounding two well-researched, yet synergistically interrelated, social phenomena. To confirm the data analysis and coding process, I used an instrument created for this study, which demonstrated the administrative steps that were taken leading up to, during, and after the interviews. As mentioned in the dependability section, borrowing from Moustakas (1994), Steps 4-8 enabled the data to be reduced into descriptive codes that were useful as phenomenologically reduced themes that had been uncovered through a process of seeing the data as objectively as possible.

Member checking was not used; this is because the audio recordings were used, and a summary transcription was generated that informed the latter steps of the data analysis and the emergent interaction with the raw data. Halcomb and Davidson (2016) compared verbatim transcription to summary transcription; and, with regards to the role and utility of each, they argued the choice is largely based on the theoretical framework and eventual purpose of the data. The choice to generate a summary transcript and to not member check is aligned with the theoretical framework being the ACF. Here, the purpose of the ACF was to uncover the essence, meaning, and structure of groups, or policy coalitions (Luxon, 2019; Weible et al., 2011). However, a request to contact participants after the interview was made to account for the event where I needed further clarification on any of the data. The interview recordings were repeatedly listened to until the data was recorded within the coding document for each individual participant interview.

## Ethical Procedures

The ethical considerations for this study have come directly from the Walden University Institutional Review Board (IRB) Ethics Approval Checklist. The informed consent standards that were used in the design of this study are:

1. The provision of background information.
2. Articulation of procedures and some sample questions.
3. A statement as to the voluntary nature of the study.
4. A summary of risks and benefits of being in the study.
5. A statement regarding non-payment or financial compensation for participation.
6. Reasonable information as to how privacy was handled.
7. The IRB contacts for questions.
8. Information as to the procedure for obtaining consent (see Appendices A and B).

The use of a snowball sampling strategy provided for the policymaker participants to emerge organically from anywhere; as such, formal partner organization relationships were not required. The Walden University's IRB approval number was: 11-25-20-0658292, expiring on November 24, 2021.

Publications coming from this study do not include the identities of individual participants, nor their workplaces. Details that might identify participants, such as the specific city of the study, are also not shared. Additional steps to deidentify participants, their organization, and to anonymize the data included the removal of the provincial geographic identifiers. I did not use the personal information for any purpose outside of this research study. The data are kept secure in a two-stage password protected electronic storage location, and a coded file naming convention has been used to anonymize the data, and only the researcher has the encryption key and file passwords. Data shall be kept for a period of at least 5 years, as required by Walden University, and two separate calendar reminders have been set as a reminder to delete the data 5 years after the study was completed.

Potential risk categories that were included in the Walden University ethics checklist included privacy, psychological, relationship, legal economic / professional, physical. When constructing the research protocol, each were acknowledged and mitigated to ensure that no risks beyond regular daily life were experienced by participants. With regards to addressing participant refusal to complete the interview, and the reporting of adverse events, it is relevant to reiterate the voluntary nature of this study. Since this study took place in Canada with Canadian citizens, all participants are also provided informed consent that has been aligned with the Canadian Tri-Council consent process (GC, 2020). Specifically, they were reminded that consent was given voluntarily, it was their right to stop the interview anytime, and they may withdrawal their consent anytime. As aligned with the Tri-Council ethics in Canada, I did not use coercion of any kind to force participation. On this, there were no adverse events that took place during the interview (i.e., violence, injury, conflict). Had there been however, I had plans in place to report this using the Walden University adverse event reporting template immediately following the event.

## Summary

Within this chapter, the research design and rationale were discussed, and the central concepts and research tradition were shared. The second section included an exploration of the role of the researcher and ethical safeguards to mitigate power relationships as well as plans to handle researcher bias. Detailed descriptions of the selection logic, instrumentation, the procedures for recruitment, complete interview protocol, and coding and analysis plan were provided in the third section. Issues of trustworthiness were then outlined in the fourth section to demonstrate that the methods were credible, transferable, dependable, and confirmable. In the fifth section, I outlined the ethical procedures, which considered the Canadian context and were based on the Walden University standards set forth in the IRB checklist. These research methods and ethical procedures were built into the study to ensure that by participating in this study, participants were safe and did not incur any risk beyond regular daily life. In the next chapter, a detailed presentation of the findings from the participant interviews will be presented. These will include details surrounding the data collection and analysis, to include the themes that emerged.

# Chapter 4: Results

## Introduction

In this chapter, I present the setting, trustworthiness, and results of the data collection. The purpose of this general qualitative study was to better understand the policy implications of the syndemic stigma experienced by PLWH and SUD, and the main research question was:

RQ: How do members of a policy coalition within the Canadian public health care system describe the problem of syndemic stigma as it pertains to living with HIV and a SUD?

## Setting

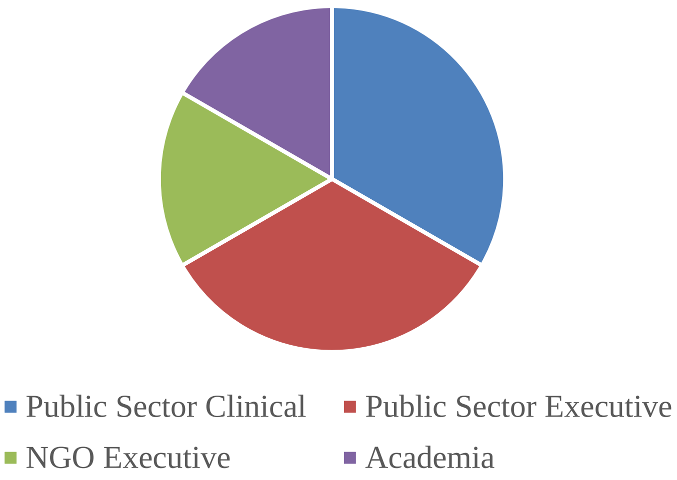
Once the study was approved by Walden University’s IRB, I began by posting the electronic flyer using social media platforms (i.e., email, Twitter, and LinkedIn) as well as on the local health services bulletin boards. A total of six participants were booked for interviews between November, 2020, and January, 2021. For their records, the participants each received the consent form and the interview questions as attachments to the electronic calendar appointment. Interviews ranged from 30-60 minutes via recoded audio Zoom or telephone call, and each participant was able to provide responses from their respective experiences. Each of the interview questions were categorized within the four policy concepts described in Chapter 2.

## Demographics

The study participants spanned varying academic and professional lived experiences in policymaking. Participants ranged from administrative executives, frontline clinical health care providers from the public health services sector, academia, to NGOs. In Figure 1 below, the participant backgrounds are quantitatively represented to show the diverse mix of experience that contributed to the data. This diversity of experience was important to both saturation and to the trustworthiness of this study; I expand on it further in the next section.

**Figure 1**

*Participant Backgrounds*



While my snowball sampling method could have brought any number of participants, this breadth of experiences aligned with what may be considered an interdisciplinary group of participants because it represented actors who occupy divergent professional experiences. This variety influenced the number of participants that were needed to reach saturation, which will be discussed in greater detail in the next sections on trustworthiness and the results.

## Data Collection

Ultimately, there were six participant interviews conducted for this study. The data were collected via semistructured virtual interviews. As was the individual participants' preference, four interviews were done via Zoom, and two via telephone. The recordings were anonymously coded and saved in a two-stage encrypted cloud file storage location that will be kept for 5 years. One variation to the methods stated in Chapter 3 was that rather than coding immediately after an interview, I journaled and then returned to relisten to the data, and I continued coding over the course of approximately 4 weeks. While doing so, I recursively used the nine steps outlined in the coding and analysis plan of Chapter 3.

This variation emerged because it gave more time for reflexivity between hearing the interview live, and then relistening to the data while coding. Van Seggelen–Damen et al. (2017) stated that the process of reflection was something that augmented the scientific rigor of any study, but that it needed time to allow for realizations to emerge within the researcher. Another reason that further reflection and interaction with the data after the interview was helpful was because it enabled me to focus only on the human interaction of conducting the live interviews and engaging with the participants. Then after the six interviews, I believed it was important relisten to the data while coding. There were no unusual circumstances, adverse events, nor discrepant cases that were encountered in data collection process.

## Data Analysis

As described in Chapter 3, to code and analyze the semistructured interviews, I created an instrument that included some aspects of the Laureate Education (2019) field notes document and amalgamated them with the Halcomb and Davidson (2006) coding document. This one hybrid document served as the instrument for the audit trail, summary transcription, and the location where the coding process unfolded. This instrument contained nine steps that I used to document each interview in a standardized manner. I organized the data within the same excel coding document where I generated a summary transcription with a separate Excel tab for each participant. This enabled the credibility of the study through the creation of a structured and themed dataset for analysis.

Because I used the four policy concepts articulated in Chapter 2 as sections of interview questions for all the interviews, they also served as preliminary coding categories. These were: intersectional stigma and syndemic stigma, health services for HIV and SUD, public policy and other legal implications, and previous stigma reduction interventions. Precoding took place in Step 4, and having precoded the data, my analysis plan of the interview questions included responses from the various participants. These codes were later inductively triangulated between each of the participant datasets to arrive at themes for recommendations, and this process is described in detail later in the results section.

To be consistent with established policymaking processes, it was important to triangulate between the different perspectives of the individual policymaker experiences

(Bacchi, 2016; Pretorius et al., 2016). Group data set triangulation is a common analysis practice for qualitative research, and it has been used by other HIV stigma researchers such as Lohiniva et al. (2016). Narrative triangulation is also done during policy writing efforts, and this process could be likened to a formal stakeholder engagement, which is a key component to policy writing (Bacchi, 2016). Doing these steps added to the validity and usefulness of the eventual policy recommendations that appear in Chapter 5.

The deductive and inductive steps in the coding and analysis process (Steps 4 through 8) were predominantly general qualitative in nature. Some aspects of phenomenological inquiry were important because they were aligned with the theoretical framework, the ACF, which I have discussed in detail in Chapter 2. Some of the descriptions in the interviews provided for the emergence of new realizations that appear in the recommendations made in Chapter 5. Each of the steps in the coding and analysis instrument were required and were found to be helpful because they served to surface and account for my personal beliefs as the human research instrument.

In consideration of what Moustakas (1994) had described as being part of phenomenological inquiry, for this study, Steps 3 and 4 served as a sort of phenomenological reduction step where I described what was observed to potentially reveal and name unknown biases and to give insight into what seemed important to me as the research instrument. Steps 4 and 5 were used to both precode the data in a summary transcription and to describe in a structured manner any explicit realizations I had after engaging with the previous two steps.

After being involved in a process like phenomenological reduction found in Steps 3-6, Steps 7 and 8 could to some extent be compared to Moustakas' (1994) imaginative variation. This is because it is in Steps 7 and 8 where the researcher is meant to process and synthesize what was heard and described in Steps 3-6; then, the data was transformed into what may be considered the essence of the conceptual and thematic components.

Throughout this process of differentiating the data from what might be considered researcher attributed patterns and groupings (Steps 3-6), I continually interacted with the data and intentionally engaged in a meaning and sense making process. The entire process was meant to support a social constructionist and cocreated understanding of data from multiple perspectives, ultimately moving toward the reintegration and synthesis of all essential parts in Steps 7 and 8. I triangulated all datasets (or perspectives) consisting of individual participant narratives to determine final codes presented later in Table 1 of the results section and the emergent themes used for the recommendations in Chapter 5. Finally, although the plan outlined in Chapter 3 was to use all data regardless, there were no discrepant cases worth noting.

## Evidence of Trustworthiness

In the next four subsubsections I discuss credibility, transferability, dependability, and confirmability, each consisting of statements on how the study, as articulated in the complete interview protocol found in the Appendix and the coding and analysis section of this chapter, was conducted in a manner that ensured each issue of trustworthiness was accounted for.

### Credibility

Regarding the accuracy with which this phenomenon has been represented, after being individually coded with the coding instrument, I triangulated the data sets from the participants located in Table 1 of the results section. Furthermore, the interview guide and complete interview protocol are noted in the instrumentation section where I have been transparent in my recruiting, consent, and summary transcription processes. The one variation to the data collection was noted in the above subsection.

To augment credibility, I organized the data in an adapted coding and analysis instrument that included steps from the Laureate Education (2019) field notes that was adapted and amalgamated with the Halcomb and Davidson (2006) coding document. This one hybrid document served as the instrument for the audit trail and summary transcription and was the location where the coding process unfolded.

### Transferability

Regarding transferability, three stages of descriptions and coding of the data collection planned for in Chapter 3 and were used in the data collection process; each step was documented in the coding and analysis instrument. This instrument was created by adjusting and amalgamating two documents for research. One was Laureate Education’s (2019) field notes document, and the other was Halcomb and Davison’s (2016) coding document. The instrument included a total of 9 steps which are articulated in the coding and analysis plan section of Chapter 3.

Recruitment took place via a snowball sampling strategy. As a starting point, previously formed connections between myself and two external organizations were leveraged to allow for interested parties to emerge of their own choice. This took place via an email request to distribute an electronic flyer via internal email to their colleagues both internal and external to their organizations. Recruitment information was also shared via a paper flyer for posting on any available local workplace bulletin boards (see Appendices B and C). Namageyo-Funa et al. (2014) stated that using word of mouth with participants as gatekeepers was one of the most effective ways to ensure an effective recruitment strategy. Another strategy that I used, was to public post my electronic flyer on my Twitter and LinkedIn accounts, which yielded most of my participants, who reached out after having viewed my profile on one of these social media platforms.

## Dependability

Since this study was an exploration of policymaker experiences within Canadian health care system, for my role as a Canadian citizen working within the health care system as a policymaker, while conducting the interviews I used the concept of bracketing described by Moustakas (1994) as epoche to overtly explore and actively conduct research. To replicate this study, I have included the complete interview protocol in the Appendix and have engaged in reflexivity via journaling to log the ways in which my thinking on the topic has emerged over time. Reflexive journaling enables researchers to learn throughout the qualitative journey as to their process and to safely explore their leniencies (Hare et al., 2016, p. 13).

During the interviews, Steps 4 and 5 were completed to demonstrate my initial thoughts as the data were heard for the first time. These two steps are also for pre-coding and summary transcribing, then bracketing first-pass researcher placed meanings that emerged. Engaging in this type of reflexivity is commonly used to codify the inner world of qualitative researchers (Houghton et al., 2013). Further discussion as to the coding process and the relationship to certain aspects of phenomenological inquiry are provided in the coding and analysis plan section of Chapter 3.

## Confirmability

My role as researcher came with some intrinsic motivation toward this topic. The intention for the interviews was to explore the experiences of policymakers with lived experience surrounding two well-researched, yet synergistically interrelated, social phenomena. To confirm the data analysis and coding process, I used an instrument that I created for this study, which demonstrated the steps that were taken leading up to, during, and after the interviews. As mentioned in the dependability section, borrowing from Moustakas (1994), Steps 4-8 enabled the data to be reduced into descriptive codes that were useful as phenomenologically reduced themes that were uncovered through a process of seeing the data as objectively as possible.

Member checking was not used; this is because the audio recordings were used, and a summary transcription was generated that informed the latter steps of the data analysis, and the emergent iterative interaction with the raw data. Halcomb and Davidson (2016) compared verbatim transcription to summary transcription; and, with regards to the role and utility of each, they argued the choice is largely based on the theoretical framework and eventual purpose of the data.

The choice to generate a summary transcription and to not member check is aligned with the theoretical framework being the ACF. Here, the purpose of the ACF was to uncover the essence, meaning, and structure of groups, or policy coalitions (Luxon, 2019; Weible et al., 2011). However, a request to contact participants after the interview was made to account for the event where the researcher needed further clarification on any of the data. This extra check in with participants after the interviews was not needed because the interview recordings were repeatedly listened to until the data was recorded within the coding and analysis instrument.

## Results

This study was open for two calendar months from the end of November 2020 to the end of January 2021, and all the data were analyzed using the coding and analysis instrument that had been developed for this study. The data presented below will include the codes and themes that emerged from the six in-depth semi-structured interviews. In keeping to the overarching research question, I have organized the data under each of the four policy concepts that have been used throughout this dissertation.

### Intersectional Stigma and Syndemic Stigma

Three open ended questions were asked of all participants for this part of the interviews. Participants were asked to describe what stigma meant to them, and they unanimously described stigma as being a negative thing that most PLWH and SUD might have, or still do experience. One participant stated that the stigma that PLWH and SUD experience “stops them from accessing health services.” Another participant shared that many of their patients “do not feel safe telling their entire story to every health care provider they meet because it could lead to stigmatized charting and being treated differently by future health care providers.” Another participant stated that despite services being needed, “PLWH and SUD are often diagnosed with other behavioral and learning disabilities, which results in program ineligibility for services available to the larger HIV community.”

Only two of the participants had a clear working definition of intersectional and syndemic stigma. While most of the participants were unable to define the differences, once they were explained, each participant had examples from their previous experience as policymakers where the definition I provided was relevant to their policymaker work. One participant shared that one of their practices when interacting with people living with SUD was to “believe their truth.” This was viewed as a trust building tool whereby patients were treated in a non-stigmatizing manner as active participants in their care. Most participants shared that building trust was one of the prominent ways to reduce the experiences of stigma for PLWH and SUD, but they added that to do this effectively, health care providers needed time to reflect on their beliefs, and in some cases be shown different ways of being.

## Health Services for HIV and Substance Use Disorder

Participants were also asked about the health services experiences of their patients and / or clients. One participant reported that their organization would only refer their clients to specific individuals within other organizations that they knew would be “safe” and “non stigmatizing”. This participant also reported that since their clientele were so often stigmatized when interacting with “health care providers and people in general, … that it takes a lot of trust building work for [their health care] colleagues to get to the bottom of the current health presentation.” One participant shared that the “problem of retelling their stories with each new provider often stops PLWH and SUD from asking for help."

This reality was underscored by another participant statement who shared that "we will not be able to solve the problem of stigma if we do not have policies that require all of us to treat people in a nonstigmatizing manner; included in these policies are the structurally enabling, or disabling, ways in which resources are allocated". Furthermore, one participant shared that "accountability at all levels in the organization built into the policies was needed for measurable change to become possible." Accountability was discussed in the responses of another participant who emphasized the need for both "organizational and regulatory infrastructures for follow-up when care is subpar". All participants stated that services for this population were inadequately funded, leaving them structurally vulnerable. Another participant shared that "some health service funding had been historically tied to specific initiatives." This participant shared that the work was "important for a time, and then suddenly went away with a change in leadership." Another participant recalled a "costly and time-consuming blood testing policy [investigating for HIV] that also went by the wayside when leadership changed." When asked about what their organizations could do better to ameliorate the services for PLWH and SUD, all participants shared that better policies were needed.

## Public Policy and Other Legal Implications

When asked about their knowledge as to the applicable anti-stigma policies within their organization, none of the participants shared that they were aware of any specific policies to reduce stigma for PLWH and SUD. One participant stated they were uncertain as to “where the anti-stigma policies were located, let alone exactly how the policy revision process took place within their organization.” It is worth noting that none of the participants reported having taken formal academic training in public administration; however, one participant did have formal academic training in policymaking. Each of the participants responded to the best of their ability given their experiences in participating in the policymaking process.

The participants self-identified as having participated in the policymaking process within their organizations, and while it was evident that the participants were passionate about making things better for PLWH and SUD, most participants were uncertain as to exactly how to write a policy or how to lead a policy writing process using policy theory and methodologies. One participant shared that many times, “the local interpretation of a given policy was left to the immediate leadership of their unit…”, and that it was “rarely a shared interpretation; rather, one person’s take on how things should be.” All participants stated they believed there was a need for more awareness as to the specific laws and regulations that might be at play for PLWH and SUD. Additionally, most participants shared that more training on the human and legal rights would reduce the structural vulnerabilities for those living with HIV and SUD.

One participant reported that “due to the use of the biomedical approach provided by many physicians and nurses, that it was possible for the less medically treatable health care needs to remain unaccounted for in the care continuum.” This participant also shared that “the level of bureaucracy within their organization as it related to policy was prohibitive to anyone actually seeing real change.” Another participant shared that policy was “a nightmare within [their organization], and that the pockets of excellence [they] had witnessed were only due to ground-up change initiatives.” This participant went on to share that “structural changes within public organizations [were therefore] next-to-impossible to effect.”

Something worth highlighting was that no mention of the Canadian 90-90-90 strategy was made by any of the participants. Instead, the participants’ responses were more focused on the SUD aspects of health services rather than HIV. It is possible that this is related to the absence of people trained in public administration within the participant pool for this study, because at the federal level, Health Canada makes overt linkages to these targets and to facilitate their inclusion in the provincial health strategies.

## Previous Stigma Reduction Interventions

One of the participants shared a grassroots initiative to reduce stigma for PLWH and SUD in which their organization had been previously involved. The initiative amounted to an informal agreement that had been struck with local police to reduce the overwhelming burden of emergency calls for opioid related overdoses. In this instance, the organization agreed to attend the emergency calls alongside police to ensure that individuals were linked with harm reduction health services immediately post-overdose. Another participant shared their organization had embarked on a process to “augment harm reduction awareness, services, and to revise their associated policies.” One participant shared that while they were not aware of many formal interventions, that “each clinician could do their individual best to learn more” and later suggested “as an accountability indicator measured within policy, that linking antistigma work to job performance might serve to reduce stigma."

## Emergence of Themes for Recommendations

To arrive at the themes, I engaged in a two-step process starting with the deductive categorization of the collated codes shown in Table 1, and then moved to an inductive analysis of the tabulated data to allow for the emergence of themes. The data presented in Table 1 below were deductively collated from Step 8 of the coding and analysis instrument. The act of placing the data into Table 1 was a deductive one because the table was constructed to align with the four main policy concepts that were used to pre-code the data, which had originated in the policy concepts that emerged in the literature review in Chapter 2. The data in Step 8 were arrived at by engaging in steps 4-8 that were influenced by the process of phenomenological reduction and imaginative variation of the raw participant data as described by Moustakas (1994).

To support inductive triangulation however, all the data from Step 8 were placed in Table 1 below, and then I engaged in a noetic process described by McGuirk (2008). The themes that emerged could be likened to the noematic core or the confluence between the raw data and the meanings I placed on my interpretation of the data (McGuirk, 2008) which I used while distilling the three themes for the recommendations made in Chapter 5.

As the human research instrument interacting with the data in Table 1, I wanted to phenomenologically reduce and observe the data for what it was on its own (Moustakas, 1994). Having been influenced by Krysztofiak's (2020) conceptualization of noematic synthesis, I spent time consciously imagining what may be missing from the perspective of public administration theory. While observing the data for what might be missing, I found themes and then later filled these perceived gaps with recommendations that were aligned with this specific theoretical lens. The themes, and further discussion as to how they emerged are provided directly below Table 1.

**Table 1**

*Data Triangulation*

| | Stigma | Services | Policy | Prevention |
|---|---|---|---|---|
| Participant 1 | Loss of worthiness | Self-determination | Harm reduction | PLWH and SUD are not a drain on the system |
| Participant 2 | Link to stereotyping | Living at risk is safer than the health services | Antistigma policy | Disempowered policymakers |
| Participant 3 | Stigmatizing diagnoses | Self-determination | Structural stigma; client directed care; collaborative transparent; trauma informed. | Accountability: Policy needs widespread buy-in |
| Participant 4 | Population health is more wholistic | Syndemics and population health theory to allocate resources; building trust | Equity seeking Populations; tools to enable the clinicians to build trust | HIV and mental health seem less Important than other illnesses. |
| Participant 5 | Humility to counteract stigma | Systemic retraumatization | Implementation is Longitudinal | Meet people where they are at and believe their truth. |
| Participant 6 | Stigma is structurally promulgated | Every aspect of care has stigma embedded | Most lack basic policy competency | Exceptionalism as the culture for change is unsustainable |

The themes that emerged from the data in Table 1 are aligned with the three recommendations in Chapter 5. By engaging in a process of moving from the deductive reasoning of the phenomenologically reduced data found in Table 1, to inductive reasoning through noematic synthesis, I found the following three themes:

1. Lack of evidence based terminological awareness (recommendation one),
2. Lack of public administration and policy training (recommendation two) and,
3. Lack of trust from stigmatizing practice and policy (recommendation three).

For the first theme, most policymaker participants reported a lack of knowledge as to the meaning of the terms syndemic stigma and intersectional stigma. As such, I believe the lack of awareness of these evidence-based terms may be contributing to the structural vulnerability experienced by PLWH and SUD. This is because policymakers who do not possess the language to describe the problem they are facing, may be less equipped at affecting outcomes through policy.

For the second theme on public administration and policy training, as seen in the policymaker data from Table 1, there was lack of specialized training in public policy and public administration theories like the ACF. I believe this may be contributing to an inability to make boundedly rational and strategic policy demands as a coalition because each policymaker is acting autonomously without an awareness of one another.

On the third theme related to practice, the policymakers repeatedly reported that “trust” and “building trust” were an important part of reducing stigma. In order to reduce stigma and build trust, I point to Bauer (2014) who described ways to do this by augmenting health equity. It is for this reason that I believe there exists a need for health equity theory to be woven into the clinical practice of health care providers, and be supported by policy statements that require accountability for the main tenets of health equity. The main tenets were described by Castillo et al. (2020) as being related to harm reduction, cultural safety, and trauma and violence informed practice.

These themes were guided by the knowledge gaps first identified by the participants; and they emerged based on my training as a social and behavioral scientist specializing in public policy and public administration. The emergence of these themes is aligned with the theoretical framework provided for in the ACF because the themes are based on my noematic synthesis or my co-constructed essence of the participant data (Krysztofiak, 2020; McGuirk, 2008; Weible et al., 2011). More discussion on these key themes as they relate to the recommendations, is found in Chapter 5.

## Summary

In this chapter, I have shared the method with which the data were analyzed, coded, and themed; the evidence of trustworthiness, as reiterated from Chapter 3, that demonstrated the ways in which the study had been conducted in a credible, transferable, dependable, and confirmable manner. While only open for two months, the participants that emerged for this study were from diverse backgrounds, which enabled the data to be as broad and as encompassing as might be needed for alignment to the theoretical tenets of the ACF.

The data that were gathered contained several examples where better policy could affect positive social change. Though, while the participants were experts in their respective areas, public administration expertise was totally absent from all participant responses. By applying the ACF to the complex policy problem of syndemic stigma in this study, it is apparent that using this advanced complex methodology was helpful at determining the essence and the structural gaps and could be used for future policy problems. In the next and final chapter, some discussion and interpretation of the data, along with some recommendations will be provided.

# Chapter 5: Discussion, Conclusions, and Recommendations

## Introduction

The purpose of this study was to qualitatively explore the public policy implications of syndemic stigma among people living with both HIV and SUD in Canada. Via semistructured in-depth interviews, I investigated the perspectives of policymakers to better understand the policy implications of individuals living with these illnesses. The research gap I addressed was regarding policy-driven research aimed at understanding the unique determinants of health for this population, along with how to reduce stigma through new policy.

I used a general qualitative methodology to conduct this research. In consideration of the problem and purpose of this study, one justification for the use of a general qualitative approach was that a constructivist epistemology and ontology were relevant when giving voice to phenomena consisting of multiple complex personal narratives (Bacchi, 2016; Miller, 2015). Using a general qualitative approach aligned best with my problem and purpose because qualitative methodologies require researchers to explore the meaning and sense-making processes of individuals via the tenets of social constructionism (Beuthin et al., 2015).

This methodology was also aligned with my choice of theoretical framework (i.e., the ACF) because both have an emphasis on exploring the essence, structure, and meaning of the issues (Weible & Sabatier, 2018). Understanding the essence and structure of this problem was important because it was where I was able to gain a better understanding of the policy implications the population might experience, especially with respect to structurally reinforced syndemic stigma. Ultimately, the data gathered for this study informed the policy recommendations made later in this chapter.

The key findings of this study outlined in Chapter 4 are accompanied by three recommendations surrounding terminology, theory, and clinical practice, along with several opportunities for future research. To summarize, while all participants were passionate about the work of helping PLWH and SUD, none were specifically trained in public administration; therefore, it could be argued that they were less equipped at solving any of the public policy problems and the structurally reinforced stigma that the PLWH and SUD continue to face. In this chapter I provide an interpretation of the findings, discuss the limitations of the study, give some recommendations and opportunities for future research, discuss the implications for social change, and provide concluding remarks.

## Interpretation of the Findings

Starting with the first two policy concepts related to stigma and health services noted in Chapter 2, one part of the stigma process according to Pretorius et al. (2016) is "the outcomes of stigma" (p. 2). This part of the stigma process was the one I was most interested in because I wanted to know whether participants believed that mental health issues such as SUD were influencing any of the barriers to ART adherence among PLWH and SUD.

The findings in these sections of the policymaker interviews confirmed that not only was ART adherence problematic for PLWH and SUD, but also, according to most participants, some other mental health services were being denied "if the patient was consuming substances." The reasons cited by participants ranged from these individuals "being outside the program inclusion criteria of staying substance free," to "changing provincial mandates stretched funding resources for mental health services."

From the perspective of the last two policy concepts related to public policy and previous stigma reduction interventions in HIV research, several other types of stigma have been investigated. Common among these various stigma types found in the HIV literature are internal, external, hidden, structural, legal, and public (Mak et al., 2017; Pachankis, 2007). As noted in Chapter 2, some of the trusted and publicly available clinical guidelines for individuals newly diagnosed with HIV come from the BCCDC and the BCCE. Both organizations have stated in their respective guidelines to immediately offer and link PLWH with medical, medication, and mental health related support services (BCCDC, 2017; BCCDC, 2019; BCCE, 2009; BCCE, 2018).

Apart from ensuring that PLWH become linked to these services, the BCCDC guideline also specified that PLWH would benefit from being linked to other community services such as peer support groups (BCCDC, 2017; BCCDC, 2019). This study confirmed that individuals were provided information on these resources and that many PLWH use them. However, the participants in this study stated that people tend not to continue to use the services, and the extent to which they are comfortable seeking support when they are experiencing acute mental health concerns related to problematic substance use was low, due to the stigma they experienced when interacting with the service they had been referred to.

All policymaker participants in this study indicated that the above recommended services and referrals were ideal, but there was a shortage of available services with enough staff members specifically trained and experienced in nonstigmatizing care provision for this unique population. Furthermore, when a PLWH and SUD experiences stigma while accessing these services, three of the participants were unsure as to exactly how this patient or client was meant to self-advocate given the existing bureaucratic processes. This is especially poignant when considering that this population is being structurally stigmatized through underfunded programs that are provided by sometimes overwrought staff members.

As mentioned in Chapter 4, when asked about policy and previous stigma reduction interventions, most participants indicated they were not aware of any specific organizational policies or current initiatives that were meant to reduce stigma specifically experienced by PLWH and SUD. That said, all participants reported that the entire health system was currently focused on COVID-19 and the illicit opioid drug poisoning crises. One interpretation of this finding could be that the health care system is already stretched, but that most policies that may be in existence are less spoken about or used at this time.

## How and Why the Advocacy Coalition Framework Relates to This Study

In the ACF, coalitions are considered strategic actors seeking to influence policy change based on their internal and external relationships and are usually intent on furthering their agreed upon constructions of what ought to be part of a policy (Weible et al., 2011). In using the ACF as a framework for this study, I noticed while conducting the literature review in Chapter 2 how there were four main policy concepts that might affect the experiences of PLWH and SUD. To enable a better understanding as to what was most important to these policymakers, I chose to organize and orient my interview questions around these policy concepts. It was important to better understand which strategic actions they had previously made and which ones they might be intent on making in the future because it enabled me to later weave their policy demands into my recommendations that are found in the next section.

Another reason why the ACF was useful while making policy recommendations was because in applying the ACF, I was required to consider the system shock currently being experienced by all health care providers due to COVID-19. With the continuous paradigmatic changes in governmental priority from COVID-19, my policymaker participants were continually forced to make boundedly rational and strategic actions in response to this global system shock (Weible et al., 2011). This is related to my recommendations because if the ACF was being applied by a trained public administrator to organizational antistigma work, it would be strengthened by the longitudinal and strategic stability offered by this aspect of the ACF.

A longitudinal application of the ACF is common, as it allows for the emergence of multiple stakeholder perspectives and sensemaking to evolve over time (Weible et al., 2011). In the case of my study, I made the choice to align the policy concepts that emerged in Chapter 2 with the interview questions and the coding and analysis instrument in Chapter 3. Then the themes that emerged from the participant data in Chapter 4 and the recommendations in Chapter 5 were also possible through an application of the ACF. This was because within my structured application of the ACF, I continually strove to uncover the essence of the four policy concepts through the perspectives of the policymaker experiences.

## Limitations of the Study

Although reasonable saturation was reached, one limitation to the trustworthiness might be the number of participants for this study. Some factors affecting this number of participants might have been the timing of the study, being that it opened 1 month before the 2020 holiday season during a global pandemic. While it was open for 2 full months, it is possible that the study had fewer participants than other qualitative studies because the topic is one that is not considered high priority in the health sector at this time. One consideration from the previous and ongoing global HIV pandemic is that by using the ACF, the diverse representation of actors in this study would benefit from working together to arrive at a public policy to reduce syndemic stigma for PLWH and SUD. While there were only six participants in this study, the actors represented a mix of professionals that could have a powerful impact on any public policy for PLWH and SUD.

## Recommendations and Future Research

An overarching methodological recommendation for the widespread use of the ACF when creating complex public policies blankets the three recommendations in this section. When creating public policy to reduce syndemic stigma, the various types of stigma experienced by PLWH and SUD each have different contributing factors and would need to be considered when applying the ACF. These recommendations are also aligned with the theoretical tenets of the policy process described by Pierce et al. (2017)

that was mentioned in the ACF section of Chapter 2. Based on the triangulated themes found in the results section of Chapter 4, I put forth three recommendations for consideration by organizations and individuals who wish to positively affect the problem of syndemic stigma for PLWH and SUD. The recommendations that follow are related to terminology, theory, and practice. Each could effect positive social change, and if they were applied, they would require further research to be conducted as to their effectiveness.

### Recommendation 1: Use of Evidence-Based Terminology in Policymaking

When applying the ACF to the policy problem of syndemic stigma, coalitions from multiple public sector institutions and NGOs should consider using the terms and theoretical influences for both syndemic stigma and intersectional stigma when creating public policies (Ferlatte et al., 2015; GC, 2018; Logie et al., 2011). Only one-third of participants had a clear working definition of these terms; as such, organizations could educate all team members on these terms while cocreating meaning as to the policy and practice implications for the patients, clients, and residents they serve.

### Recommendation 2: Use of Public Administration Skillsets and Theories

Although the participants represented extensively diverse and highly skilled professional and academic backgrounds, in their day-to-day work, none specialized in law, public policy, and public administration. It would therefore benefit any coalition or group of policymakers to be supplemented by representatives who possessed this specialized skillset. This recommendation includes a second part, which is, for organizations to use public policy and public administration theory when creating their public policies. In the absence of this specialized skillset, organizations risk writing policies that are not able to be implemented as they do not account for the complex and extensive considerations woven into the policy process described by Pierce et al. (2017).

For example, one of the critiques of the ACF is that it is complex to apply, which would pose problems for individual actors who do not possess this skillset (Weible et al., 2011). Items such as ministerial mandates, external public organizations, standardized public and internal consultation efforts, legal and regulatory frameworks, and implementation strategies, all are standard for those who are using public policy, and public administration theory as part of their evidence-based practice.

### Recommendation 3: Use of Health Equity Theory in Clinical Practice

Finally, this recommendation is specific to the clinical practice of health care and is linked to the participant data on how important safety, trust, and trust building, were to the reduction of stigma and the improvement of health outcomes for their patients and clientele. Bauer (2014) described ways to reduce stigma by augmenting health equity, which would support trust building. To do this, I recommend for the main tenets of health equity to be woven into individual clinical practice, and that structural accountability to this approach be supported by organizational policy. The main tenets of health equity were described by Castillo et al. (2020) as being related to harm reduction, cultural safety, and trauma and violence informed practice. Each of these tenets when applied to the clinical interaction, will create a more trustworthy and safer environment and, ultimately, reduce the syndemic stigma experienced by PLWH and SUD.

## Future Research Opportunities

Thinking specifically about the opportunities for future research, apart from researching the effectiveness of my three recommendations and within the process of public policymaking, there exists an opportunity for researchers to learn more about the contributing factors causal of the structural gaps in the existing public policy infrastructures and between the health service institutions. Further research could also be conducted to learn more about whether there was a lack of cohesion between the education being provided within academic institutions, and the annual provincial mandates of health authorities, along with the longer term federal and global initiatives.

## Implications for Social Change

In consideration of the above three recommendations, one of the first things a public administrator using the ACF might do to affect positive social change is to initiate a strategic engagement campaign for letters to be written to their local ministerial representatives. This campaign would empower PLWH and SUD through their local NGOs and other public sectors to formally represent the will of their population using their own voice. Each letter would be logged, and the accountability tracking built into this would require a formal response to be written by the government to everyone who is strategically making policy change demands. Doing so would also require response within annual ministerial mandate letters, and multiyear bilateral agreements between provincial health authorities and other publicly funded health service organizations.

Hammett et al. (2018) conducted a case study on the empowering relationship between public policy and local interventions such as the one I have proposed. In creating a formal linkage between a community intervention and the creation of new public policy, health care providers would find the request from their citizenry strategically woven into the requirements of their respective funding agreements. This would empower organizations to allocate resources to the policy problem of syndemic stigma.

Were organizations to use the recommendations in the previous section, another implication for positive social change is found in the impact to the clinical interaction between health care provider and PLWH and SUD. This would be particularly true if all three recommendations were used by organizations in the allocation of resources, because the population level definition of syndemic stigma would be supplemented by individual level definition of intersectional stigma.

Furthermore, Durfee (2020) argued that institutions could benefit from better allocation of resources for individuals and for populations by using the theory of structural intersectionality. What this could mean for PLWH and SUD as well as for the health care providers, is that this population might benefit from less stigmatizing organizational policies. This would enable services that were structurally aligned with the needs of the individuals involved in the clinical interaction, as well as enable organizations to positively contribute to the 90-90-90 targets (GC, 2018).

## Conclusion

The purpose of this study was to explore Canadian policymaker experiences on reducing syndemic stigma for PLWH and SUD. The theoretical framework was the ACF and six participants shared their perspectives on this problem, and how to solve it with better policy. In the findings, it was demonstrated that while all participants were passionate about the work of helping PLWH and SUD, none were specifically trained in public administration; and therefore, it could be argued that they remain less equipped at solving any of the public policy and the structurally reinforced stigma problems that the PLWH and SUD continue to face. To have the biggest positive social change impact when attempting to solve complex policy problems such as this, three recommendations were made under one overarching recommendation of using the ACF. To conclude, the problem of syndemic stigma experienced by PLWH and SUD is one that can be positively affected, especially when organizations and other researchers view it as a public policy problem that is solvable when practicing evidence-based public administration.

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# Appendix: Complete Interview Protocol

## Opening Statement

Welcome __________, my name is Nickolas, and I will start by thanking you for participating in this research interview. The main objectives for today will be for you to share your experiences surrounding the policy implications of multiple stigmas experienced by people living with HIV (PLWH) and substance use disorder (SUD). Our discussion will be audio recorded, and you have been provided the interview questions (IQ) in advance of our meeting today. You have also been provided the Walden University consent to participate and have indicated to me that you consent to participating in this interview.

Regarding how the data will be used, I want to reiterate that your specific responses will be anonymized for privacy and security. To analyze the data, I will be creating a summary transcription your audio recording and I can provide you with a copy of this anytime you may request this. I have designed the interview around some specific policy concepts that we will follow as sections of the interview. The various policy concepts I will be asking about are intersectional stigma and syndemic stigma, health services for HIV and substance use disorder, public policy and other legal implications, and previous stigma reduction interventions.

The plan today is to work our way through the questions, and I may ask some follow-up questions in the moment to hear more about various things. The interview will likely take about 45 minutes. Before we start, I would like to make sure that you have found a space where you are able to have a confidential conversation where you are located and want to let you know that you are able to stop the interview at any time to take a break or to handle something urgent that might arise. Do you have any questions about anything that I have just mentioned? Thank you. If you are ready to get started, I would love to hear a bit about who you are, and where you are from. Please tell me anything that you would like me to know in this regard. Thank you so much for that, we can move into the first topic.

## Body of the Interview

### *Topic one: Intersectional Stigma and Syndemic Stigma*

To introduce this topic, I want to ask about how you view and define stigma. There are no wrong answers. While you are talking, I will be listening, but I may ask additional questions to hear more as needed.

1. "What does stigma mean to you?"
2. "Do you believe that you (or your patients / clients) experience stigma?"
    i. Possible prompt: "Can you give me a specific example?"
    ii. Possible prompt: "What did that experience mean to you?"
3. "What are your thoughts about internal and external stigma?"
4. "What role do you think stigma and / or syndemic stigma plays for your patients / clients while seeking help for HIV or SUD?"
5. "We will be moving to the next section now, but before we do, is there anything else that you want to share about this topic?"

### *Topic two: Health Services for HIV and Substance Use Disorder*

Moving to the next topic, I am going to ask about health care related to HIV and substance use disorder. I want to open it up for you to describe your way of viewing your role in how PLWH and SUD experience the health care system.

1. "When patients and clients are interacting with health providers on the topic of HIV or SUD, what are some of the most important principles of this interaction?"
2. "When accessing and / or moving between health services, what role does stigma / syndemic stigma play for PLWH and SUD?"
3. "What types of stigma reduction interventions do you think might make health services better?"
4. "We will be moving to the next section now, but before we do, is there anything else that you want to share about this topic?"

***Topic three: Public policy and other legal implications***

In this section, I will be asking about policy as it relates to stigma and health services.

1. "Are you aware of any policies that are related to the reduction of stigma, and protecting the rights of PLWH and SUD that might affect your patients / clients?".
   i. Possible prompt: "When does (or when should) a health care provider tell their patients / clients about organizational policies pertaining to their rights?"
2. "What elements or statements do you think a good stigma reduction policy must include?"

3. “We will be moving to the next section now, but before we do, is there anything else that you want to share about this topic?”

### *Topic four: Previous stigma reduction interventions*

In this section I will be asking about stigma reduction. I hope to better understand the ways in which we might use policy to effect positive social change.

1. “What have you witnessed or participated in within your organization that has intentionally affected stigma in a positive way?”
2. “What could your organization have done better to change or reduce stigma / syndemic stigma?”
3. “What are some things that you would be willing and able to do to change the stigma experiences that you are currently aware of?”
4. “We are nearing the end of the interview; I want to know if there is anything else that you want to talk about, or you think I should know about, regarding the various topics?”

## Closing Statement

We have now covered all the topics throughout the sections, and I appreciate the time you have taken for this interview. I want to acknowledge that this topic is important to you. I think I have everything I need, and want you to know that I will use the recording to the best of my ability, but would it be alright to contact you if I have any clarifying questions? Would you like me to send you a copy of the abstract as a summary once it is published, so that you can decide whether you would like to review any part of the full dissertation? Thank you again