

RESEARCH

Lauren Kaplan

People Living with HIV in the USA and Germany

A Comparative Study of Biographical
Experiences of Chronic Illness



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Table of Contents

Acknowledgments	5
Preface	9
1 Introduction	13
1.1 Biography and HIV as a Trajectory of Suffering.....	13
1.2 Research Questions.....	15
1.3 HIV as Life-Changing.....	19
1.4 HIV and Stressful Life Conditions.....	21
1.5 Stigma.....	26
1.6 Race/Ethnicity and Migration Context.....	35
2 Biographical Analysis Using Narrative and Topical Interviews	45
2.1 Brief History of Biographical Methodology, Debates, and Developments.....	45
2.2 Research Process of the Current Study.....	51
2.3 Process, Context, and Conditions in Biographical Perspective.....	56
2.4 Centrality of Comparison in Generating New Insights.....	58
3 Frankfurt am Main, Germany, and Miami, Florida, The United States of America: A Constant Comparative Case Analysis	61
3.1 Frankfurt am Main, Germany: Interview Setting and Case Overviews.....	61
3.2 Miami, Florida, the United States of America: Research Setting and Case Overviews ...	66
3.3 Part 1: Conditions for Trajectory of Suffering Potential.....	68
3.3.1 Circumstances and Social Context of HIV Diagnosis as Conditions for the Emergence of Trajectory of Suffering.....	68
3.3.2 Health Status at Diagnosis and Personal Histories of Medical Treatment.....	80
3.3.3 Mode of HIV Transmission as Providing Context for HIV.....	84
3.3.3.1 Voluntary versus Involuntary Sex.....	84
3.3.3.2 Gay versus Straight Sexual Contact as Mode of HIV Transmission.....	87
3.4 HIV as Existential Identity Threat.....	90
3.5 Part 2: Biographical Process Structures.....	99
3.5.1 Biographical Action Process Structures.....	101
3.5.1.1 “Helping Hand” and Support Seeking.....	101
3.5.1.2 Group Identification and Social Support.....	107
3.5.1.3 Medicine as a Source of Support: The Need for Information in Treatment and Positive Views of Current Care.....	108
3.5.1.4 Compassionate Love.....	111
3.5.1.5 Giving Social Support and Helping Others.....	117
3.5.1.6 Relations of Care and Social Support: Emotional and Financial Resources.....	118
3.5.1.7 Children and Compassionate Love.....	119
3.5.2 Transformational Biographical Processes.....	122
3.5.2.1 Psychoanalysis as Creative Metamorphosis of Identity.....	122
3.5.2.2 Creative Production, Innovation, and Entrepreneurship.....	125
3.5.2.3 Spirituality: HIV as a Spiritual Journey.....	129
3.6 Reversal of Agency: Denial and the Construction of Alternate Reality.....	136

3.7	Financial Freedom and Autonomy: The Importance of Economic Resources in Regaining Autonomy	142
3.8	Action Process Structures: Additional Comments	146
3.9	Part 3: Theoretical Aspects of Negotiating HIV	148
3.9.1	Disclosure and Living with HIV as a Secret	148
3.9.2	“Ethical Persuasion”: A Technique for the Management of Social Interaction	160
3.9.3	Fear of Rejection	163
3.9.4	Support and HIV Disclosure	167
3.9.5	The Decision to Disclose: A Consideration of Social Losses and Rejection	169
3.9.6	Stigma: Appearance, Privacy, and Visibility	172
3.9.6.1	Anticipated Stigma	172
3.9.6.2	Stigma, Appearance, and Problems in Intimate Partnerships	183
3.9.6.3	Stigma Proliferation	184
3.9.6.4	Stigma Experienced	186
3.10	Part 4: Structural Aspects of Negotiating HIV	199
3.10.1	Migration as Context and Biographical Position	199
3.10.1.1	Country of Origin and Role of Historical Racism in Views of Medicine: Conceptions of Truth and Deception	201
3.10.1.2	Migration Experiences: Asylum Seeker Social Policy and Barriers to U.S. Travel	203
3.10.2	Views of Medical Care	207
3.10.2.1	Medical Treatment as a Reminder of HIV	209
3.10.2.2	Concerns in Medical Care	212
3.10.2.3	Making Comparisons between the U.S. and Germany	212
3.10.2.4	Comorbidity of HIV, Physical and Mental Illness	214
4	Discussion	223
4.1	Summary of Findings	223
4.1.1	Biography and HIV as a Trajectory of Suffering	223
4.1.2	Awareness of Discredibility and Epistemological Struggle	225
4.1.3	Experiments and Visions: Construction of Social Meaning	229
4.1.4	Intersectionality and HIV Experience	229
4.1.5	Creative Production and Entrepreneurship as Rebellion	230
4.1.6	Financial Hardship and Medical Insurance Coverage	231
4.1.7	Compassionate Love and Social Support	233
4.1.8	Spirituality and Religion	235
4.1.9	Stigma and Appearance	237
4.2	Limitations	238
4.3	Policy Implications	240
	Bibliography	245

Preface

The purpose of this book is to illuminate the life experiences of people living with HIV. Challenges embedded in social policy such as access, cost, and availability of quality medical care and immigration policies which can restrict the freedom of people to travel, work, and live in different nations and regions are a focus of this book. Stigma and discrimination and existential struggles of identity, meaning, and reality are another major focus of this work. While these challenges are made visible in the examination of the biographical experiences of people living with HIV, they can also be considered as important issues for human rights more generally. In the context of a global recession and increasing social, cultural, and economic international interdependence, comparative transnational studies are of an ever growing importance to our understanding of what policies and conditions are supportive of health and promoting the development of human potential.

People living with HIV suffer from an infectious disease which they can contract in ways through which contrary to popular opinion, they are not to blame. It is the author's imperative that people with illnesses such as HIV and other chronic illnesses such as cancer not be stigmatized or discriminated against in our contemporary global society. The challenges of negotiating a chronic illness are vast, and stigma can render such experiences especially problematic for those suffering from chronic illness. Therefore, the stories of interviewees in this book were selected not only for their substantive theoretical content but also to challenge prevailing negative stereotypes of HIV. Powerful stories of people living with HIV from a range of backgrounds were examined to emphasize the important fact that HIV is something that can happen to us all. Images of drug addiction and sexual responsibility have plagued the HIV-positive community. Such images are linked to risky behaviors which can lead to infection, but these do not define all people living with HIV. Furthermore, even for those with histories of drug use or sexual risk taking we must be reminded of our own sexual experiences and the potential for people to trust others to not use protection due to feelings of familiarity, love, and infatuation. Importantly, while

injection drug use is a risk factor for the transmission of infectious diseases, having a history of drug use does not justify forsaking other's human dignity and rights and blaming and marginalizing those with such histories.

Human experience can be seen as a progression of our personal histories shaped in the context of broader social and economic historical context. Within each of our lives there is the potential for suffering, destruction, and for growth and transformation. Such potentialities highlight the fluid nature of our own existence and the important realization that our pasts, presents, and futures can unravel in unanticipated ways. HIV can be one of many unanticipated events in people's life stories. Moving away from blaming those suffering from chronic illness and moving towards a more nuanced, open, and compassionate understanding of human experience is essential to the protection of human rights and dignity. An important goal of the present work is to facilitate such an understanding.

Also important is that in the experience of HIV, aspects of social reality that otherwise may be hidden from our awareness are brought to the center stage. Issues in the negotiation of social interaction, threats to identity and mortality, and epistemological debates of the nature of truth, reality, and illusion are illuminated in the stories of people living with HIV with a vividness and urgency we may otherwise not encounter. Thus, this analysis is intended not only for the sociology student, scholar, or researcher, but for a broader audience of those concerned with human rights and the conditions and policies which govern their lives. It is the hope of the author that this work will help to facilitate a greater understanding of the lives of people with HIV, reduce stigmatizing views of those suffering from illness, and enhance an understanding of social reality both within and beyond the realm of HIV.

By engaging in a transnational comparison, we are better able to identify areas of strength and of weakness in domestic U.S. policy as compared to social policies in Germany. We also are able to understand how experiences of people are conditioned by their personal and collective histories and the broader social and economic context of their countries of residence. The areas of both convergence and similarity in experience, and of difference and departure in the lives of people living in Miami, the United States and Frankfurt, Germany, allow for an examination of how chronic illness can be understood by actors in distinct cultural contexts.

This book is organized in the following manner. First, a discussion of the regional and national contexts in Miami and Frankfurt, the concept of a trajectory of suffering, and other key concepts such as stigma in their relation to HIV are

discussed. Next, the methodology used to examine these biographies is presented. The biographical analysis utilized here grew in a transnational exchange between the U.S. and Germany. There is a deep interrelation between theory, methodology, and findings. Therefore, an understanding of the methodological approach used in this work frames the analysis in theoretical context.

Next, the findings are presented. These findings are divided into the following parts: (1) conditional aspects of the emergence of a trajectory of suffering; (2) biographical process structures; (3) theoretical aspects of negotiating HIV, and (4) structural aspects of negotiating HIV. Finally, the discussion summarizes key findings, unanticipated phenomena, policy implications, limitations, strengths, and directions for future research.

1 Introduction

1.1 Biography and HIV as a Trajectory of Suffering

The purpose of this study was to examine how people living with HIV/AIDS (henceforth referred to as PLWHA) experience their illness and negotiate constraints such as stigma and other forms of marginalization, such as racism and poverty, and work to overcome trajectories of suffering. A major aim of my research was to examine how HIV was coped with and negotiated. Accordingly, I utilized a biographical approach in this comparative study of interviews with people living with HIV in Frankfurt, Germany and in Miami, Florida, the United States of America. Since the advent of effective treatment, HIV has been redefined from a “death sentence” to a “chronic illness” (Antiretroviral Therapy Cohort Collaboration 2008). HIV is of particular interest and relevancy to the biographical research tradition due to its initial disruptive character upon diagnosis which requires people to integrate HIV into their biographies, confront issues of mortality and self, and to continuously contend with its enduring stigma. HIV presents a formidable challenge as people with HIV must confront issues relating to not only their health, but also of morality, conceptions of sin, and sexuality (UNAIDS 2005).

Importantly, the health care system in the United States has recently begun a major transformation with the implementation of the Affordable Care Act (ACA). This policy shift is so controversial that members of the Tea Party, a conservative Republican political party, actively shut down the American government in their negotiations with President Barack Obama. The recent governmental shutdown and ongoing controversy surrounding health care policy suggests there is a need for researchers to examine health care policy in order to provide governmental agencies with an evidence-based approach to the implementation and ongoing evaluation of health care policy.

Germany provides a useful comparison to the American health care system. In this work, I utilize a patient-centered approach to understanding the experiences of people living with HIV/AIDS both in the health care system and in the broader context of their personal histories and the cultural context in which they are embedded.

Furthermore, with increasing global interdependence, the importance of health care is heightened in the context of migration. The United Nations has expressed a deep concern for the welfare of asylum seekers who often must live in overcrowded housing and have limited access to employment opportunities and health care (UN 2012). Access to health care for asylum seekers in Europe has been problematic, as access to health care is often limited to emergency care and as migrants can face legal and practical barriers to care (Norredam et al. 2005). Recently, because of military conflict in the Middle East, there has been a wave of migration to Europe. The political conflicts in nations such as Syria and Libya have had widespread global consequences greatly increasing the numbers of migrants to Europe. As of October 2013, it has been reported that over 32,000 migrants from the Middle East and Africa immigrated to Italy and Malta (Reuters 2013).

This recent wave of migration has sparked debates between the Southern and Northern European Union States as nations such as Italy called for support in the “burden sharing” of asylum seekers and financial resources. Reports suggest that political debates and rising anti-immigration attitudes delayed assistance to migrants and that this delay in support has coincided with the deaths of many migrants (Reuters 2013). Migration experiences can be further problematized by HIV and, through the use of narrative interviews, the issues of asylum-seeking in Germany emerged as a critical part of biography. The importance of access to specialized care and the context of medication adherence in group housing with limited privacy emerged in this study and will be further discussed in later chapters.

An examination of both the strengths and limitations in different policies allows for an interchange between policies with the potential for improvement. For example, in Germany, the importance of mainstreaming or the integration of HIV into multiple policy sectors has been a great advance in combating the HIV epidemic (Deutsche Gesellschaft für Internationale Zusammenarbeit (GIZ) GmbH 2012). The successful implementation of HIV policy into workplace programs for families in low- and middle-income countries has been accomplished through the work of Germany’s Federal ministry for Economic Cooperation and Development (BMZ) (GIZ 2012). The close political ties between Germany and their partners in Sub-Saharan Africa have been paralleled by economic cooperation and intensive policy work to combat the HIV epidemic in Africa. The successful implementation of HIV programs into policies within multiple sectors suggests that in order to facilitate effective HIV policy, research done in comparative context can inform the work of various nation’s efforts to improve health locally and globally.

Therefore, in the context of the contemporary global problems and events related to HIV, health care policy change, and migration in Europe, this comparative study contributes to an increased understanding of challenges faced by people living with HIV/AIDS. By engaging in a biographical analysis centered on patient experiences from a range of social backgrounds grounded in transnational comparative context, valuable insights were gained into the context of health care and migration issues that require an integrated, rigorous, and ongoing evidence-based approach to social policy.

1.2 Research Questions

Prior to initiating the analysis, stigma and social support were concepts of central interest. However, in order to gain a deeper understanding of interviewee's life experiences, open-ended narrative interviews were utilized. As the narrative interviews completed in Frankfurt, Germany were analyzed using the biographical approach, unanticipated phenomena and important biographical processes emerged, which informed the analysis of the Miami interviews. Throughout this process, research questions and analysis shared a dynamic interplay and my original questions became more open and flexible to accommodate new insights generated by the analysis. The research questions of this study are:

- (1) How do people with HIV/AIDS (PLWHA) experience their illness?
- (2) In which ways does HIV become a part of one's biography?
- (3) Under what conditions can trajectories of suffering be overcome and what types of biographical action schemes are related to coping with HIV?

Because HIV can present both an immediate mortality threat upon diagnosis and yet can be lived with over time as a chronic illness, understanding how HIV is integrated into existing frames of reference and meaning can clarify how the initial existential threat of HIV can be negotiated into one's biography. HIV diagnosis can be stressful, shocking, and charged with emotional upset and feelings of being thrown into a new life against one's will (Kelly et al. 1998; Saffren et al. 2003). Therefore, I examine HIV using a biographical perspective and examine HIV as an experience involving biographical processes. Gerhard Riemann and Fritz Schütze's (Riemann and Schütze 1991) conceptualization of a trajectory of suffering guided the analysis of how HIV was coped with over time. They defined trajectory of suffering as:

“A generalized concept of trajectory as a central category denoting *disorderly social processes and processes of suffering*, a category that makes it possible to identify, reconstruct and understand phenomena [...] We have in mind structural processes structured by conditional chains of events that one cannot avoid without high costs, constant breaks of expectations, and a growing and irritating sense of loss of control over one’s life circumstances. One feels that one is driven, that one can only react to ‘outer forces’ that one does not understand anymore. There are conditions or seeds for the emergence of a trajectory (first just as potential), a step of crossing from the sphere of intentional action to the sphere of just reacting, different phases a trajectory is passing through, and, of course, there are ways out, too.” (p. 377)

Importantly, biographical processes can overlap, and trajectories of suffering can be overcome. The experience of trajectory from its inception to its unfolding and the mastery of life circumstances were a major focus of this analysis. Therefore, I also examined the “ways out” of trajectory and focused on biographical action schemes. Biographical action schemes involve purposeful action aimed at the achievement of regaining control over one’s life (Schütze 1981; 2007). This emphasized biographical action schemes as a means of understanding how participants became aware of their agency and enacted their agency in the working world (Schütz 1962). Agency must be enacted in the working world in order to initiate change in personal and collective social space. The importance of HIV disclosure in situating action out of the realms of phantasm and into the working world emerged as important to action. The enactment of agency can be fundamentally shaped by biography and socio-historical context. Therefore, a comparison of narratives created in a diverse sample was especially useful in the examination of agency. Biographical analysis is a useful approach that facilitated an analysis of agency by focusing on biographical action schemes. The conceptualization of trajectory as a structural process as involving “inner events” related to changes in personal identity allowed the interplay between individual experience and social structural conditions to be analyzed (Riemann and Schütze 1991, p. 339). The biographical constructions of people living with HIV were examined in the current study while also focusing on the social and historical context within which their personal biographies were embedded.

Identity and sense of belonging emerged in both samples as multidimensional concepts that were intimately tied to personal history. By focusing on identity, potentialities and constraints for overcoming the stigmatized social status of HIV, and even turning a marginalized position into an activist identity were identified. Qualitative researchers have used the term identity and emphasized the importance of the self in relation to suffering (Charmaz 1999) and have identified biographical processes for example the metamorphosis of identity to understand biography (Riemann and Schütze 1991). Importantly, in my analysis

conceptions of the self and struggles with identity emerged as central to biographical experiences. Biographical researchers have also focused on the concept of mental space and the importance of the construction of a sense of belonging by relating to collective frames of reference and meaning in orienting the self and biographical development (Schütze et al. 2010). Accordingly, in my analysis, interviewees emphasized collective frames of reference in relation to their social positions and HIV status. The intersectionality of social positions and meanings ascribed to collective group membership emerged as important in processes related to the development of a sense of belonging. Accordingly, when describing the characteristics of a trajectory of suffering Riemann and Schütze (1991) described:

“The overwhelming and long-lasting process of suffering gives the person the chance of systematic reflection, of finding a deep relationship to her- or himself and to the world and to significant others, and of mobilizing biographical work and creativity. This can be followed by well-organized biographical action schemes for controlling the dynamics of disorder and by the exploration and development of hitherto unseen personal capabilities, that is, by a creative metamorphosis of the state of biographical identity.” (p. 343 f.)

Therefore, the use of the term identity was not considered to be antithetical to the biographical approach. Rather, identity emerged as a temporally and culturally based concept integral to personal growth and development and was interrelated with issues related to action, empowerment, and integrating HIV into one’s biography. Creativity, innovation, and the integration of HIV status into one’s self-concept were emergent phenomenon that became a major focus of this study.

Importantly, the term identity was conceptualized as fluid and not static in this study. Identity was seen as a dynamic concept, involving a changing sense of belonging to different social statuses that was interrelated with personal and collective history, other life experiences, and concepts such as stigma. A sense of belonging has been defined in prior research “as the experience of personal involvement in a system or environment so that persons feel themselves to be an integral part of that system or environment” (Hagerty et al. 1992) and as a “sense of personal involvement in a social system so that persons feel themselves to be an indispensable and integral part of the system” (Anant 1966, p. 21). According to Hagerty and colleagues (1992), such systems can be organizations or relationships and therefore can involve social groups sharing particular social statuses, such as the status of being HIV-positive, gender, or sexual orientation. Sense of belonging involves both the feeling that one’s involvement is valued and accepted and that

one's characteristics fit with the social group (Hagerty et al. 1992). Sense of belonging is related to other concepts such as social support, feeling loved versus feeling alienated and isolated, and is related to identity and group membership (Hagerty et al. 1992). The interplay between sense of belonging, group identification, identity, and stigma were critical aspects of biological adjustment to living with HIV in interviewee's narratives. Specifically, these emerged as important concepts in the process of acceptance of HIV status and of coming to terms with illness.

Stigma was conceptualized as a process-based concept which involved more than a definition of a mark that is "deeply discrediting" (Goffman 1963). Stigma can involve numerous processes, such as processes in: identity, group identification, access to resources (economic and social), disclosure, and fear of identification. Prior research on stigma emphasizes the importance of focusing on power dynamics when analyzing stigma and of analyzing stigma as a process rather than as a static concept (Parker and Aggleton 2003; Link and Phelan 2001). Access to a collective identity can be a means to power. Having access to a collective identity in a positive, supportive context can help to transform stigmatized, marginalized self-concepts into empowered, activist identities or "project identities" (Castells 1997; Parker and Aggleton 2003).

By accessing and redefining collective identity from a marginalized group to an active, empowered group, collective identity of HIV can be transformed into a "project identity" (Castells 1997). Project identities involve the construction of a new identity that redefines a group's position in society and by transforming itself also aims to change the overall social structure (Castells 1997). By adopting a project identity, members can be empowered to initiate social change. Participation and membership in a community of mutual respect and support can provide access to power, contributing to empowerment, and helping people who are stigmatized to mobilize and spread awareness and understanding of their condition. Therefore, the concept of identity was important in understanding the meaning of taking part in "Helping Hand" an on-site support group. The Helping Hand support group is discussed in more detail in the description of the research setting in Frankfurt, Germany.

Drawing on Anselm Strauss (Strauss 1993) and his discussion of biographical work and processes in his seminal work "Permutations of Social Action," this analysis demonstrates that Strauss' formulation of processes central to biographical work were involved in participants' descriptions of their narratives. Strauss maintained that work is tied to all action and that all action may be conceptualized as a form of work. PLWHA are faced with a multitude of

challenges and thus an analysis of HIV using a biographical perspective allows us to delve deeper into biographical processes and their relation to coping. Corbin and Strauss (1988) described the processes in biographical work as:

“Four separate but overlapping *biographical processes*. Though analytically different, each process occurs simultaneously and feeds directly into the others. The processes are (1) *Contextualizing* (incorporating the [course of illness] into biography), (2) *coming to terms* (arriving at some degree of understanding and acceptance of the biological consequences of actual or potential failed performances), (3) *reconstituting identity* (reintegrating identity into a new conceptualization of wholeness around the limitations in performance), and (4) *recasting biography* (giving new directions to biography). Each of these processes evolves over time...[I]t is important to recognize analytically that [each of these processes] rests inevitably on the *biographical work* entailed in it.” (p. 68 f.)

Therefore, coping with HIV was examined using this conceptualization of coping as involving biographical processes as they were intertwined with contextual experiences as discussed by participants.

1.3 HIV as Life-Changing

Anselm Strauss' (Strauss 1997) discussion of transformations of identity and turning points as the awareness that “I am not the same as I was, as I used to be” and involving misalignment or “surprise, shock, chagrin, tension, bafflement, self-questioning -- and also the need to try out the new self, to explore and validate the new and often exciting or frightening conceptions” highlights the importance of understanding life experiences such as HIV as a turning point with the potential for fundamental challenges and changes in life stories (Strauss 1997, p. 95). Prior research indicates that HIV can be a major life-changing event (Kremer et al. 2009). According to Kremer et al. (2009), HIV can serve as a positive or negative life-changing event with corresponding changes in behavior, self-view, worldview, and spirituality. Furthermore, they found that even when HIV was experienced as a negative turning point, a secondary positive turning point often occurred. They described two exceptional cases, one exemplifying a negative turning point and the other of HIV as a positive turning point. HIV as a negative turning point was described by participants in a manner consistent with the conceptualization of HIV as a trajectory of suffering. Interestingly, HIV as a positive turning point was discussed by participants in a manner fitting a biographical action scheme where they felt empowered to take action and to improve their own lives and even the lives of others.

Other studies suggest that people can experience post-traumatic growth or perceive positive changes since HIV diagnosis, which has also been referred to as “thriving” (O’Leary and Ickovics 1995; Siegel and Schrimshaw 2000; Milam 2006; Kremer and Ironson 2009). The concept of thriving has also been recognized in sociological research as being rooted in social positions and history (Blankenship 1998). This suggests that a biographical analysis was appropriate to further assess the role of HIV as a life-changing event that can involve numerous biographical processes as it is experienced in the context of personal biography and social context.

With the advent of highly active retroviral therapy (HAART) medication regimens, HIV has been transformed from a death sentence to a chronic illness (Scandlyn 2000; Siegel and Krauss 1991). This major shift in the definition of the meaning of having HIV as being transformed into a chronic illness that can be negotiated with over time highlights the importance of understanding how people negotiate their HIV condition in their everyday lives and work to incorporate their HIV diagnosis into their pre-existing social positions and their corresponding senses of belonging and self-views rooted in their biographies and social context. Indeed, Kremer et al. (2009) found that only 37 percent of their sample reported that HIV was a key turning point in their lives suggesting that HIV, while life-changing, should be examined in the context of personal experience and biography and not in a social vacuum. Researchers have suggested that a biographical approach to the study of coping with HIV is an important avenue for generating knowledge of HIV (Siegel and Krauss 1991).

Researchers have applied a biographical approach to understanding the lives of PLWHA and have found that people do work to reconstruct their identities in response to HIV diagnosis (Carricaburu and Pierret 1995). Biographical reconstruction has been argued to involve the construction of an identity that integrates HIV into biography and often reinforces aspects of identity prior to HIV diagnosis (Carricaburu and Pierret 1995). Notably, Pierret (2001) found that PLWHA often distinguish between their lives before and after HIV diagnosis thus incorporating a temporal dimension to their understanding of illness. Interestingly, as HIV became redefined from an initial death sentence to a chronic illness, research demonstrates that PLWHA wrestled with the question of why they were still alive (Pierret 2001). Existential struggles with mortality thus were not removed from the experiences of PLWHA even after the advent of effective HIV treatment.

Furthermore, Ciambone (2001) in a study of HIV-positive women found that HIV should be considered in the broader context of women’s lives. Ciambone

(2001) found that the relative negative impact of HIV was dependent on other life experiences such as domestic violence, drug use, and separation from their children; and these life experiences were often discussed as more problematic than their HIV infection. The perception that HIV was not the main cause of biographical disruption in these women's lives was contextualized by whether or not they had access to social support, their racial/ethnic backgrounds, and drug use. In another biographical analysis of women with HIV/AIDS in Africa, Burchardt (2010) found that these women had to develop strategies of action to cope with the ontological uncertainty that their HIV diagnosis initiated in their lives. Burchardt (2010) emphasized the relationships between biographical context and action strategies and their relation to personal transformation, the search for normality, and social support. These action strategies were enabled and constrained in the context of religious discourse and AIDS activism (Burchardt 2010).

These biographical studies highlight the embeddedness of life experience, the deep interrelation between life experiences, and the contextual conditions in which these experiences occur. Overall, prior research suggests that chronic illness can be a biographical disruption, upsetting notions of the self, the body, mortality, social relationships, and normality (Bury 1982; Burchardt 2010; Ciambro 2001; Carricaburu and Pierret 1995; Charmaz 1983; 1995; Wilson 2007). Chronic illness can entail a deep suffering related to the self and is rooted in moral discourse (Charmaz 1999). Charmaz (1995) argued that the openness of others to hear the stories of those suffering can be affected by moral sentiments linked to the type of illness. This moral dimension can be especially problematic for PLWHA due to drug use and sexual behavior as commonly known causes of infection. These studies suggest that HIV can present an existential suffering that should be examined in the context of personal and collective biographies. PLWHA can experience a multitude of challenges and these are discussed below.

1.4 HIV and Stressful Life Conditions

Approximately 33 million people were living with Human Immunodeficiency Virus (HIV) in 2008, and AIDS has been identified as a cause of an estimated 25 million deaths worldwide (UNAIDS 2009; 2008). Estimates suggest that the extent of this epidemic has been underestimated and report that 40% more people than previously estimated became infected with HIV in 2006 (Hall et al. 2008). In addition, many PLWHA live in poverty, increasing their vulnerability to HIV/

AIDS (United Nations 2005). Living in a context of socioeconomic disadvantage can worsen the life conditions of those living with HIV. Specifically, research demonstrates that socioeconomic disadvantage can heighten levels of stress and decrease psychological resources such as social support, which can in turn lead to more adverse mental and physical health outcomes (Aneshensel 1992; Turner et al. 1995). Prior research indicates that stress can affect disease progression among PLWHA (Ironson et al. 2005; Leserman et al. 2000; 2002). Coping interventions among people living with HIV have been found to increase immune functioning and to reduce levels of anxiety and stress (Antoni et al. 2000). Research also suggests that social structural factors such as housing and poverty are associated with disease progression (Milloy et al. 2012). Furthermore, personality and physiological characteristics can interact with social context in their relationship to immune functioning (Capitanio et al. 2008). Importantly, stigma has been found to mediate the relationships between AIDS orphanhood and mental health outcomes such as psychological distress (Cluver et al. 2008). This suggests that the stigma of HIV can proliferate to family members and communities and demonstrates the impact that stigma can have on health and social functioning.

This emphasizes the importance of adopting a biopsychosocial model of health and engaging in interdisciplinary work informed by sociological approaches to understand HIV as a biographical experience. Biographical analysis allows for an examination of individual and social structural phenomena as interrelated and as mechanisms through which people can construct social reality. Biographical illness experience can have biological consequences for health and biographical research could inform future research on the interconnections between broader social conditions and personal experience. Specifically, the discovery of the meaning of illness and social positionality, as it occurs within the context of personal history and biography incumbents' broader social and economic life conditions, can help to unearth the processes linking the experience of illness, health behaviors, and health outcomes. For example, in my analysis, internal processes of denial were related to engaging in nondisclosure and unprotected sex and to a broader context of historical racism. Also, beliefs about the nature of medicine were related to participants' approaches to their medical treatment and were deeply embedded in their life histories. Interestingly, transformative processes such as resolving spiritual struggle emerged as important to the overcoming of drug addiction, which can affect health trajectories and utilization of care.

The World Health Organization's (1948) definition of health as complete physical, mental, and social well-being and not merely the absence of disease highlights the importance of the development and utilization of social resources (e.g. social networks and support), and material resources (e.g. financial security and medical care) in personal growth and development in the face of HIV. Personal growth and empowerment can be related to the biographical processes of action and metamorphosis of identity and to the development of sense of control, inspiration, and creative production. Resources can be conceptualized as factors that could be material (e.g., income and employment) or psychosocial (e.g., social support) and can serve to mitigate the negative impact of stressors on well-being. Resources can include social capital, psychosocial resources such as self-esteem, and economic resources. Pierre Bourdieu defined social capital as "the aggregate of the actual or potential resources which are linked to possession of a durable network of more or less institutionalized relationships of mutual acquaintance or recognition" (Bourdieu 1985, p. 248). Social networks and social capital can help to reduce stress, and prior research indicates that social resources are related to thriving (Blankenship 1998; Gächter et al. 2009; Massey et al. 1998). However, due to the stigmatized nature of HIV, people can prefer to live in secret with HIV, preventing their access to valuable social relationships and their corresponding resources.

Both initial HIV diagnosis and living with HIV as a chronic condition can be stressors. Stressors have been defined as "experiential circumstances that give rise to stress" and include life events (e.g. death of loved one) and chronic stressors (stressors which are enduring over time such as persistent poverty) (Pearlin 1989, p. 243). Because a major aim of this study was to understand how people, when faced with the existential crisis of life with HIV, work to succeed and to live meaningful and fulfilling lives, the roles of resources were analyzed as they emerged in the interviews. Social support and resources, agency, and social context were assessed in order to understand how people with HIV regained control over their lives. Social support and self-esteem have also been found to be related to posttraumatic growth or thriving and social positions rooted in race/ethnicity and gender also have been linked to thriving (Abraído-Lanza et al. 1998; Blankenship 1998; O'Leary 1998). An understanding of the processes involved in both the negative experience of stigma in tandem with coping and the conditions under which these processes unfold was a central aim of this analysis. Therefore, related issues of identity, adjustment to new social groups, and the negotiation of multiple social worlds such as intimate relationships, occupational careers, family relations, and importantly the interplay

between the HIV-negative and HIV-positive social worlds are discussed. Biographical action schemes were therefore useful analytical concepts in this process.

A substantial number of those living with HIV can experience violent victimization, discrimination, social exclusion, engage in substance use and risky sexual behavior, and lose faith in themselves, society, and the spiritual (Bing et al. 2001; Michels et al. 2007; Kremer et al. 2009). Yet, despite “hitting rock bottom,” many people living with HIV can manage to significantly change their lives and to improve their quality of life and social relationships. Siegel and Schrimshaw (2000) found in their study of women living with HIV that a majority of these women reported stress-related growth or thriving in response to HIV. These women reported positive changes in their health behaviors, spirituality, interpersonal relationships, self-view, value of life, and career goals. Thriving has been defined as “the ability to go beyond the original level of psychosocial functioning, to grow vigorously, to flourish” (O’Leary 1998, p. 429). Blankenship (1998) emphasized the applicability of a sociological perspective on thriving and urged future sociological research to focus on thriving. Massey and colleagues (Massey et al. 1998) emphasized the importance of using qualitative methodology when examining and conceptualizing thriving as a process rooted in personal and social history. They further argued that using qualitative methodology to examine thriving allows for an examination of context and of thriving as a process without imposing values a priori in the research process and asked:

“How can researchers take seriously individuals’ subjective experiences and also allow room for the powerful social, cultural, and political contexts within which these experiences occur? That is, how can we celebrate an individual’s accomplishments and well-being in adverse situations without either blaming those whose lives show less cause for celebration, or dropping the critique of the contextual structures that promote the adversity? [and] How do we recognize that there may indeed be moments in which an individual in an adverse situation experiences joy, the successful completion of a meaningful piece of work, a sense of physical vigorousness, or other signs of thriving, but that there are also moments, in that very same life, absent of these desirable states?” (Massey et al. 1998, p. 338)

A biographical analysis can help to provide answers to these questions. As Massey and colleagues argue, by not restricting an analysis to a-priori variables of interest, researchers can identify structural factors that are theoretically relevant within participants’ life stories. This process of discovery can facilitate theoretical development and the identification of important factors that can interact with experiences of adversity and thriving (Massey et al. 1998).

Indeed, unanticipated factors and processes emerged in the current study highlighting the usefulness of a biographical approach when examining thriving or biographical adjustment to HIV. Importantly, thriving can be a process and therefore is well-suited to a qualitative approach focusing on biography. Narratives allow us to examine trajectories of agency as ongoing processes that intersect with other biographical processes. These trajectories are grounded in the context of personal history and involve continued decision-making and biographical work. This provides us with an opportunity to engage in an analysis of the negotiation of stressors and challenges that is not framed in a static atheoretical framework. Instead, we are granted access to the temporal and contextual dimensions of theoretical concepts as they develop over time in biographical experience. This allows for a more process-oriented understanding and can stimulate theoretical developments in the production of knowledge (Massey et al. 1998).

Biographical processes involved in thriving in the face of adversity, specifically those related to action, can be of great import to the sociological study of stress, coping, and health. These processes were a major focus of this study. Survival, recovery, and thriving have been distinguished as distinct responses to hardship (O'Leary and Ickovics 1995). Thriving has been conceptualized as developing in an interactive and transformative process in coping with challenge (O'Leary, 1998, p. 429). By focusing on biographical experience, meaning making, and processes of suffering, transformation, and action a more nuanced understanding of thriving can be developed.

In addition, Pearlin and colleagues (Pearlin et al. 2005) applied a life course perspective to examine how and why those in disadvantaged social positions experience health disparities, such as higher levels of morbidity and mortality. They discussed three processes that can link stress to health outcomes. These included: status and status attainment, early life experiences and later life outcomes, and stress proliferation throughout the life course. These processes can be examined using narrative interviews. Pearlin et al. (2005) also focused on how educational deficits can lead to occupational disadvantage, which is linked with economic strains, and how life circumstances can lead people to live in disadvantaged neighborhoods, which can further expose them to other ambient stressors. However, their analysis was strictly quantitative and did not allow for a more nuanced analysis of how disadvantage and stress can constitute a detailed social pattern and reinforce each other in everyday life.

It is essential for stress-related research to focus on thriving. That is, given adversity, how and why do people overcome hardships and in some cases even go on to do extraordinary and exceptional things in their lives and in the lives of

others? It is critical to understand how and why people experience transformative growth in the face of disadvantage in order to foster the development of positive change and empowerment among disadvantaged populations. An analysis of biographical action schemes allowed for an examination of how trajectories of suffering related to HIV were worked at to be overcome. This study advances this area of research and contributes to a more refined approach to these questions. Stigma can be a major challenge to biographical adjustment and thriving and is discussed below.

1.5 Stigma

Because HIV poses a multitude of challenges, a biographical analysis was especially useful in examining how hardship was negotiated in the current study. Those living with HIV often experience stigmatization and discrimination that can expose them to additional stressors and further undermine their mental and physical health (Devine et al. 1999; Herek 1999; Liu et al. 2006). According to AVERT (2010), HIV-related discrimination can occur within the domains of the government (e.g. mandatory testing, criminal sentencing for transmission of infection, restricted immigration), the healthcare system (e.g. restricted access to medication or facilities, non-consensual HIV testing, and breaches of confidentiality), employment (e.g. social isolation, termination/refusal of employment), immigration and travel (e.g. restricted entry, stay, and residence), and social exclusion in the family and community. The issue of HIV-related discrimination is a global health concern. Indeed, in approximately sixty countries, people living with HIV are faced with institutionalized discrimination hindering their access to entry, stay, and citizenship status (AVERT 2010). Recent longitudinal research utilizing a path analysis framework has demonstrated that HIV stigma among youth orphaned by AIDS in South Africa significantly predicts anxiety and depression overtime (Boyes and Cluver 2013). Their research indicates that interventions targeting stigma have great potential for improving the mental health outcomes (Boyes and Cluver 2013; Cluver et al. 2008).

Clearly, such widespread discriminatory practices occurring in a multitude of settings can serve as stressors, exacerbating the impact of negative life events and daily stressors in the lives of those living with HIV. Three phases of the HIV/AIDS epidemic were identified by a former director of the World Health Organization (WHO), which he termed the epidemics of: (1) HIV, (2) AIDS, (3)

and of stigma, discrimination, and denial (Mann 1987). Therefore, stigma has been acknowledged as an important global health concern to be targeted by program initiatives. Furthermore, the Vienna Declaration and Program of Action (1993) clearly established the importance of the protection of human rights as a major international agenda and explicitly targeted the problem of discrimination as an international human rights issue. In my study, participants perceived stigma as a structural feature which limited their freedom, basic rights, and was felt as damaging to their health and social well-being. The problem of stigma and discrimination transcended national boundaries and was made clear in this transcontinental comparison as being related to various social positions and life conditions.

Stigma remains a persistent problem of the HIV/AIDS epidemic which still has not been resolved despite decades of research and international initiatives aimed to reduce HIV stigma (Parker et al. 2002). Stigma initiatives may not have been fully effective in eliminating stigma due to the multifaceted nature of stigma rooted in social, cultural, and historical context and due to the complex, process-based nature of stigma. Below, a discussion of definitions of stigma, types of stigma, and its potential causes and consequences is provided.

The concept of stigma was introduced by Erving Goffman in his seminal work "Stigma: Notes on the Management of Spoiled Identity" as an "attribute that is deeply discrediting" which diminishes the possessor of the attribute to a discounted, tainted, and no longer whole and usual person (Goffman 1963, p. 3). Goffman (1963) emphasized the importance of the management of stigma as the management of social information present in the form of symbols, which are associated with negatively valued characteristics. Such symbols or marks were argued as varying in regards to their visibility and concealability and their degree of intrusiveness and disruption in social relationships and interaction (Goffman 1963). Goffman (1963) highlighted the role of information control in the management of stigma and strategies of concealment which can produce strain in the continual maintenance of secrecy, rendering one as not yet discredited but as having potential for discredibility. Once identified by others, the negotiation of stigma was described as a fundamental management of tension by Goffman (1963). Goffman (1963) also emphasized the importance of biography and life history as components of uniqueness forming social identity. Therefore, I focused on the biographies of PLWHA to examine how experiences rooted in biography were related to the experience of HIV stigma and the consequences of HIV stigma for identity and biographical adjustment. The strain in the maintenance of HIV as a secret draws attention to the challenges of coping with the potential for