

**Patriarchal and Medical Discourses
Shaping the Experience and Management of
HIV-related Stigma in Turkey**

Pınar Öktem

Submitted for the degree of Doctor of Philosophy

University of East Anglia
School of International Development

January 2013

This copy of the thesis has been supplied on condition that anyone who consults it is understood to recognize that its copyright rests with the author and that use of any information derived there from must be in accordance with current UK Copyright Law. In addition, any quotation or extract must include full attribution.

Abstract

The stigma attached to HIV/AIDS remains a pervasive problem, despite the progress that has been achieved in the global response and the expectations that universal access to treatment will reduce it. This thesis explores how HIV-related discourses are shaped and how people living with HIV (PLHIV) experience and manage stigmatization in Turkey, where HIV prevalence is low and the stigma attached to HIV/AIDS is powerful and widespread.

The aim of this thesis is to contribute to the understanding of the social construction and management of stigma, by offering an empirically informed discussion of the management of the biological body and social identity in relation to broader discursive power relations. Self-management of HIV and its stigma is considered in this thesis as a process of identity construction in which actors are constantly negotiating with the discursive power relations that exercise control over them. The roles of patriarchal and medical discourses are discussed as the main components of the power structure underlying HIV-related stigma in Turkey. Exploring the ways in which PLHIV manage physical health, social relationships and social identity, the thesis focuses on the potential of PLHIV as active agents, who react to, resist or challenge HIV-related stigma.

Primary data were generated through biographical narrative interviews with PLHIV. Participant observation in the networking activities of PLHIV and non-governmental organisations provided additional data. Semi-structured interviews with key informants were conducted, to explore the power structure underlying stigma further. Additionally, HIV-related policy documents and statements were reviewed.

The research provides data to contribute to the development of HIV-related stigma-reduction policies in Turkey. Considering criticisms of the dominant conceptualisation of stigma addressed in the existing literature, the main theoretical contribution to the overall literature on chronic illness and stigma management is the investigation of the link between social identity and discursive power relations, with a specific focus on the active role of the individuals in negotiating and challenging stigma.

Table of Contents

Abstract.....	2
Table of contents	3
List of tables and figures	6
List of appendices	7
List of abbreviations	8
Acknowledgements.....	9
Chapter One	
Introduction.....	11
1. Introduction	11
2. The research rationale, objectives and questions.....	13
3. Thesis outline	19
Chapter Two	
Conceptual Framework.....	24
1. Introduction	24
2 Discursive approach to HIV/AIDS.....	24
2.1. Medical discourse	27
2.2. Patriarchal discourse	34
3. Management of HIV and its stigma.....	39
3.1. Intersectionality	45
3.2. HIV-related stigma	48
3.3. Stigma management.....	49
3.4. Chronic illness self-management.....	54
4. Conclusion	56
Chapter Three	
Methodology.....	58
1. Introduction	58
2 Epistemological approach.....	58
3. Research design	62
4. Methods of data generation	68
4.1. Biographical narrative interviews with PLHIV	69
4.2. Semi-structured interviews with key informants.....	75
4.3. Review of key documents and statements	75
4.4. Participant observation and informal interactions	76
5. Data analysis	76
6. Ethical considerations	78

Chapter Four
HIV/AIDS in Turkey.....83

1. Introduction	83
2. HIV prevalence and data	83
3. Test and treatment	86
4. State structure for sexual and reproductive healthcare and the country response to HIV/AIDS	88
5. Civil society response to HIV/AIDS	89
6. The role of international organisations and state-civil society relations in shaping the country response	91
7. Public knowledge of HIV/AIDS and the stigmatisation of PLHIV	93
8. Conclusion	95

Chapter Five
The social construction of HIV/AIDS: Contesting discourses and their implications for framing policies and public perspectives.... 97

1. Introduction	97
2. 'Not our disease': the cultural immunity discourse and public perception of HIV/AIDS	98
3. Rights-based approaches to HIV/AIDS: claiming individual rights for the sake of public health.....	107
4. Social perception of sexuality	115
5. Medical discourse: production of disease through epidemiology.....	120
6. Conclusion	126

Chapter Six
Family and healthcare as institutions shaping the initial meanings attributed to a life with HIV.....128

1. Introduction	128
2. Stigma in healthcare settings.....	130
2.1. Discriminatory attitudes of healthcare providers	133
2.2. Effects of stigmatisation in healthcare settings on internalised stigma, trust in health professionals and health-seeking behaviour.....	145
3. Stigmatisation related to the institution of the family in Turkey	150
3.1. Experiences of stigmatisation in the family	152
3.2. The attribution of meaning to HIV and the construction of its stigma within the family	157
4. Conclusion	163

Chapter Seven**Management of health: Perceptions of illness and treatment experiences.....166**

1. Introduction	166
2. Knowing and understanding the disease: The 'HIV-positive disease'...	168
3. Perceptions about ART	175
4. The need for information and managing uncertainties.....	178
5. Adherence to treatment and self-care.....	181
6. 'The system' as a barrier to adherence and self-care	184
7. Conclusion	186

Chapter Eight**Managing social life and the shift in identity.....189**

1. Introduction	189
2. Motives and strategies for concealment and disclosure	190
3. Management of changes in social relationships	197
4. Perception of the 'shift' in identity.....	204
5. Reduction of negative emotional states	209
6. Maintaining or enhancing a positive self-concept	212
7. Conclusion	223

Chapter Nine**Implications of discursive structures on agency:
Illness identities and social activism.....225**

1. Introduction	225
2. 'Politicized illness experiences' and 'biological citizenship'	226
3. Gender, illness perceptions and political activism.....	235
4. ART, normalisation and activism	242
5. Conclusion	249

Chapter Ten**Conclusion.....252**

1. Introduction	252
2. Contributions to existing theories and understanding	253
3. Areas of further research and policy implications	262
4. A concluding remark.....	263

Appendices	264
References.....	277

List of Tables and Figures

Figure 1: Research questions	17
Table 1: Required data and methods of data generation for the key research questions.....	63
Table 2: Purposive sample design	66
Table 3: Participants of the research (PLHIV) according to the sample categories	67
Table 4: Key informants participated in the research	68
Table 5: Summary data on HIV/AIDS in Turkey	84
Table 6: Participants' reasons and consent for testing.....	131
Table 7: Incidents of stigmatisation in healthcare settings	133
Table 8: Household structures of the participants	152
Table 9: Participants' perceptions of HIV and ART according to length of time since diagnosis, health status and access to peer-support.....	169
Table 10: HIV as a self-expressed turning-point	205

List of Appendices

Appendix 1: Formulation of 'narrative-seeking questions' for generating Particular Incident Narratives (PINs) in BNIM sub-session two	264
Appendix 2: Transcription and display of verbatim quotes from participants	265
Appendix 3: Invitation letter and consent form for the research participants (PLHIV)	266
Appendix 4: Invitation letter and consent form for the research participants (key informants)	268
Appendix 5: Interview guide for semi-structured interviews with key informants	270
Appendix 6: Sample data sheet on HIV/AIDS in Turkey released semi-annually by the Ministry of Health	273
Appendix 7: Stories of the two men who publicly disclosed their HIV status: Selahattin Demirer and Halil Ekerbiçer	275

List of Abbreviations

<u>Abbreviation</u>	<u>Meaning</u>
AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral therapy
BNIM	Biographical Narrative Interpretive Method
ER	Emergency Room
EU	European Union
FSU	Former Soviet Union
GDPHC	General Directorate of Primary Health Care
GF	Global Fund
GNAT	Grand National Assembly of Turkey
HIV	Human Immunodeficiency Virus
HSM	Health-related social movements
IO	International organisations
IDS	Infectious disease specialist
IDU	Intravenous drug use
KI	Key informant
LGBT	Lesbian Gay Bisexual Transgender
MARP	Most-at-risk populations
MCHFP	General Directorate of Mother and Child Health and Family Planning
MD	Medical Doctor
MENA	Middle East and North Africa
MOH	Ministry of Health
MP	Member of the Parliament
MFSP	Ministry of Family and Social Policies
MSM	Men having sex with men
MTF	Male-to-female
NAC	National AIDS Commission
NGO	Non-governmental organisation
PLHIV	People living with HIV/AIDS
PYD	Positive Living Association (Pozitif Yaşam Derneği)
PM	Prime Minister
SIT	Stigma Index Turkey
SRH	Sexual and reproductive health
STD	Sexually transmitted disease
THPSP	Turkey HIV/AIDS Prevention and Support Programme
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNGASS	United Nations General Assembly Special Session
WHO	World Health Organisation

Acknowledgements

Many people have helped me through the process of clarifying my ideas, designing and conducting research and writing this dissertation from the very first day I had decided to work on HIV/AIDS in Turkey in 2004, and especially since my registration for the PhD programme in UEA in 2009.

First and foremost, I owe my deepest gratitude to my supervisors Dr Steve Russell and Dr Catherine Locke for their invaluable advice, comments and encouragement. I am grateful to them for their inspiring and dedicated guidance in both theoretical, methodological, ethical and time management issues. Taking the time to help me whenever I needed, trusting me and providing me with continuous moral support throughout my time in UEA, they both have been more than supervisors to me.

I am also extremely grateful to Prof Janet Seeley and Dr Virginia Bond, who were my internal and external examiners respectively, for providing detailed comments, insightful suggestions and an atmosphere for a stimulating and pleasurable Viva experience.

I would like to extend my sincere gratitude to my former supervisors in the Department of Sociology of Hacettepe University (HU) and in the Department of Sociology of Middle East Technical University (METU) who have always been an inspiration and mentors to me. The expertise and guidance of Prof Yakın Ertürk enriched the gender aspect and the interdisciplinary perspective on HIV/AIDS in my literature review during my time in METU. I am also indebted to Assoc. Prof Aslıhan Öğün Boyacıoğlu from HU, who wholeheartedly encouraged me to undertake this research in the early years of my PhD studies and introduced me to the essentials of health and stigma literature.

I am thankful to Prof Yıldız Ecevit and Prof Mehmet Ecevit from METU for helping me with clarifying my ideas and structuring my thesis proposal and to Dr Colette Harris from DEV for sharing her knowledge and expertise in health and development, through long and friendly conversations.

My friends and colleagues have been a continuous source of both intellectual and technical but most importantly, emotional support. I am thankful to Emek Can Ecevit, Dr Ceyda Kuloğlu Karslı, Dr Ayça Gelgeç Bakacak, Dr Ayşe Şimşek, Hale Babadoğan and Ayşe Emel Akalın, who shared their PhD experiences, discussed

my work and provided moral support to me. I also would like to thank the DEV PhD community for providing a productive and friendly working environment.

Many thanks are due to Arabella Beckett, Çiğdem Gedikli, Emanuela Lezzi, Burçak Yalçın, Antoni Wojcik and Okan Yılmaz, who have become my family in Norwich. I also wish to thank Merter Burak Arıkan for being such a motivation for me to keep going and for his patience. I am grateful to them not only for their invaluable help with the thesis but also for being there in my difficult times, for their belief in me and for celebrating every little milestone.

There are many individuals whose support during the fieldwork has made the completion of this dissertation possible. I am deeply grateful to the individuals who helped the research as gatekeepers. Their names must not be mentioned here for the sake of confidentiality. I am also indebted to Çiğdem Şimşek İşçi and Arzu Rezzan Kaykı for facilitating my entrance into the field and letting me benefit from their experiences and expertise.

This dissertation would not have been possible without the support of my parents. I am forever indebted to my father Melekzat Öktem and to my mother Nevin Fatoş Öktem for the tremendous financial sacrifices they have made, their encouragement and their unconditional trust in me. I thank my mother and my brother Kerem Öktem also for their bright ideas and interpretations about my research. I am also indebted to my grandmother Hikmiye Koparal, to whom I dedicated this dissertation, for offering me her home and care during the fieldwork.

Most of all, I would like to extend my deepest gratitude to the participants of this research. I am thankful to the key informants of this research who accepted to share their ideas and knowledge with me. I am heartily grateful to all people living with HIV whom I have met during my fieldwork, regardless of their participation of this research, for trusting me enough to let me into their lives.

I dedicate this thesis to my grandmother
and to Baby E.
with love.

Chapter One: Introduction

1. Introduction

The stigma attached to HIV/AIDS remains a pervasive problem, despite the progress that has been achieved in the global response to the epidemic and the expectations that universal access to antiretroviral therapy (ART) will reduce stigma (Castro & Farmer, 2005). HIV/AIDS has been linked to stigma in terms of cause and effect (Finn & Sarangi, 2009). As a cause, previous research concludes that HIV-related stigma provides ground for the spread of the epidemic by limiting the impact of interventions through deterring people from being tested, seeking help and adhering to treatment (de Bruyn, 1998; Adam, 1992; van Brakel, 2005; Goudge et al., 2009). In terms of its effects on people living with HIV (PLHIV) stigma has important negative consequences, such as physical and social isolation, violence, loss of livelihood and housing, differential treatment in educational and health institutions, disruption of social identity and loss of agency (Ogden & Nyblade, 2005; DFID, 2007; UNAIDS, 2009).

Previous research suggests common points about the perceived characteristics of HIV/AIDS to explain the stigmatisation of individuals based on their HIV status. These include, the association of HIV with behaviours that are considered 'deviant', 'immoral', 'voluntary' and 'irresponsible'; consideration of the disease as a fatal condition, and one that leads to the perception of PLHIV as a reminder of an 'undesirable and unaesthetic' form of death; perception of the disease as both a moral threat to social fabric and a more basic threat to society because of its communicability; the cost and burden of care on other members of society; and the lack of correct and adequate knowledge about the disease (Alonzo & Reynolds, 1995; de Bruyn, 1998; Herek, 1999; Parker & Aggleton, 2003; Ogden & Nyblade, 2005).

While the negative attitudes towards PLHIV and the effects of the stigma on individuals living with HIV and their acquaintances and care givers have been documented globally (see e.g. Ogden & Nyblade, 2005 and Mahajan et al., 2008 for a review of previous research and findings across contexts), understanding of the strategies developed by PLHIV to manage the process of stigmatization

remains limited, especially in terms of understanding the agency of stigmatized individuals and linking the experiences of PLHIV to macro structures of power relations. In addition, there is an evident lack of empirical data to inform our understanding of the experiences of PLHIV living in Turkey and its region (UNAIDS, 2001; 2007), as I explain in the next subsection.

This research explores how HIV-related discourses that generate processes of stigmatization are shaped, and how people living with HIV experience and manage stigmatization in Turkey. After a brief introduction on the research setting, I explain the rationale and objectives of this thesis and present my research questions. I then outline the structure of the thesis, highlighting the key theoretical strands that inform the discussions in each chapter.

In Turkey, official figures show low rates of HIV/AIDS incidence and prevalence (Ministry of Health (MOH) 2008a; UNAIDS/WHO, 2008). However, the figures are considered to be underestimates, because of the low level of HIV testing and the inadequacy of surveillance and registration systems (Ay & Karabey, 2006; Tümer, 2008). As in the region of Eastern Europe and Central Asia, in which the country belongs according to the UNAIDS categorisation, the rate of new infections remains on the rise, despite the global decline (UNAIDS, 2012). The main route of transmission of HIV is unprotected heterosexual intercourse. The epidemic is not considered as a priority issue within health policies nor among the general public, whose HIV/AIDS-related knowledge is very low (see e.g. Çok et al., 2001; Duyan et al., 2001; GFK/PYD, 2008). HIV/AIDS-related educational campaigns, activism and advocacy led by non-governmental organisations (NGO) and academic and non-academic research have started rather late, in the early 21st century. The coordination of the state with civil society and private sector actors has accelerated in the recent years, mainly after 2003, within the programmes supported by international organisations (IO), such as the Global Fund (GF), European Union (EU) and the UN (Çokar, 2008; Kaplan, 2008).

The stigma attached to HIV/AIDS is powerful and widespread in Turkey and human rights of PLHIV are being violated, mostly in healthcare settings and workplaces (Pozitif Yaşam Derneği (PYD) 2007; 2008; 2009). HIV/AIDS is associated with socially disapproved forms of sexuality and is considered as a consequence of the integration of 'foreign' and 'immoral' elements into Turkish society which threatens traditional values. There is no specific legislation or national policy or programme

aimed at stigma reduction or at improving access to support and protection for PLHIV. To date, very little research has been done with the aim of understanding the experiences and perceptions of PLHIV in Turkey, and to inform interventions to mitigate stigma in this setting.

2. The research rationale, objectives and questions

The rationale for this research can be stated in relation to its theoretical and empirical contributions and its policy implications for the research setting. The literature on stigma management in general has been criticized for picturing stigmatized individuals as passive victims of stigmatization and the stigmatized identity as their 'master status'. Additionally, stigma is often discussed without referring to the power structures in which it is occurring; thus the linkage between micro and macro needs to be developed in this literature (Riessman, 2000; Link & Phelan, 2001; Parker & Aggleton, 2003; Shih, 2004; Campbell & Deacon, 2006; Howarth, 2006). Considering these criticisms, I aimed to contribute to the research on stigma management and related aspects of chronic illness management, by emphasizing the agency of the individuals and by linking the biological body and social identity to discursive power relations.

Another rationale for the research is the need for improved conceptualization and further knowledge on the experiences of PLHIV in the research setting. PLHIV's experiences in Turkey have been documented by a limited number of NGO reports (PYD, 2007; 2008; 2009). Academic research that has aimed to understand HIV-related stigma in relation to broader social inequalities is lacking in Turkey, with the exception of two studies on the gender dimension of HIV stigma; a masters thesis by the former representative of the UNAIDS Turkey Office (Aşar-Brown, 2007) and a project funded by UNDP (Kasapoğlu & Kuş, 2008). An urgent need for social scientific data on HIV/AIDS in Turkey is emphasized in the UNAIDS Country Situation Analysis of Turkey (2007). This research is the first empirical study that examines the subjective experiences of individuals living with HIV in Turkey in relation to the social construction of HIV-related stigma. Considering the lack of a policy aimed at stigma-reduction in the country I aimed to provide empirical data that could contribute both to the understanding of the perceptions and management of stigma by PLHIV and to the development of HIV-related policies in Turkey.

Empirical data on the discursive formation of HIV/AIDS and the experiences of PLHIV in Turkey could also contribute to existing knowledge on other settings with similar epidemiological patterns, treatment structures and cultural characteristics. The scarcity of empirical data on PLHIV and on HIV-related discourses is not unique to Turkey but also evident in other areas with low HIV/AIDS prevalence. The majority of the research on HIV-related stigma to date has focused on the areas with high prevalence. In low prevalence settings, there is often a substantial lack of data partly because HIV/AIDS is not considered a priority issue. In such settings, stigma continues to inform public perceptions about HIV/AIDS, thus affecting the success of related interventions and contributing to the invisibility of PLHIV (UNAIDS, 2001). Experiences of PLHIV in low prevalence contexts, in which stigma may be intensified due to greater fear of HIV/AIDS (Zukoski & Thorburn, 2009) and lower awareness, need further exploration.

With regard to the 'global rhetoric of hope' that treatment access will reduce stigma, it is important to investigate how the restorative effects of ART may be hindered by the broader power relations underlying HIV-related stigma, which has received little examination (Bernays et al., 2010, p.14). Being an upper middle income country with a high estimated ART coverage (WHO, 2008) since the early years of the epidemic, Turkey offers a fertile area to discuss the link between stigma and local treatment experiences.

While Turkey is categorised in Eastern Europe and Central Asia by UNAIDS, it has commonalities with the countries in the Middle East and North Africa (MENA) region in terms of its conservative culture. MENA's conservative cultural structure has been seen as partly responsible for low prevalence in these countries (Roudi-Fahimi, 2007). Whether culture is a means of protection or instead contributes to the spread of HIV through aggravating stigma (Abu-Raddad et al., 2010) remains a speculative discussion, due to the lack of comprehensive data that could contribute to this discussion.

My aim in this thesis is to contribute to the understanding of the social construction and management of stigma, by offering an empirically informed discussion of the management of the biological body and social identity in relation to broader discursive power relations, with a focus on the agencies of stigmatised individuals.

To achieve this aim, the thesis has two main objectives. My main objective is to build an understanding of self-management of HIV and its stigma by PLHIV as a process in which actors are constantly negotiating with the discursive power relations that exercise control over them. In doing so, I focus on the potential of PLHIV as active agents, who react to, resist or challenge the discourses underlying HIV-related stigma. To be able to discuss the internalisation of or resistance to stigma in relation to broader social inequalities and power relations, the overarching discourses around HIV/AIDS should be identified. Therefore, my second objective is to provide an analysis of the construction of the discourses around HIV/AIDS, referring to patriarchal and medical discourses as the main components of the power structure underlying HIV-related stigma. The research questions and the main theoretical strands that guided the thesis are presented below.

The research seeks to answer the main research question: 'How do people living with HIV in Turkey react to, resist or challenge the process of stigmatisation?' This overarching question is explored by addressing three key questions:

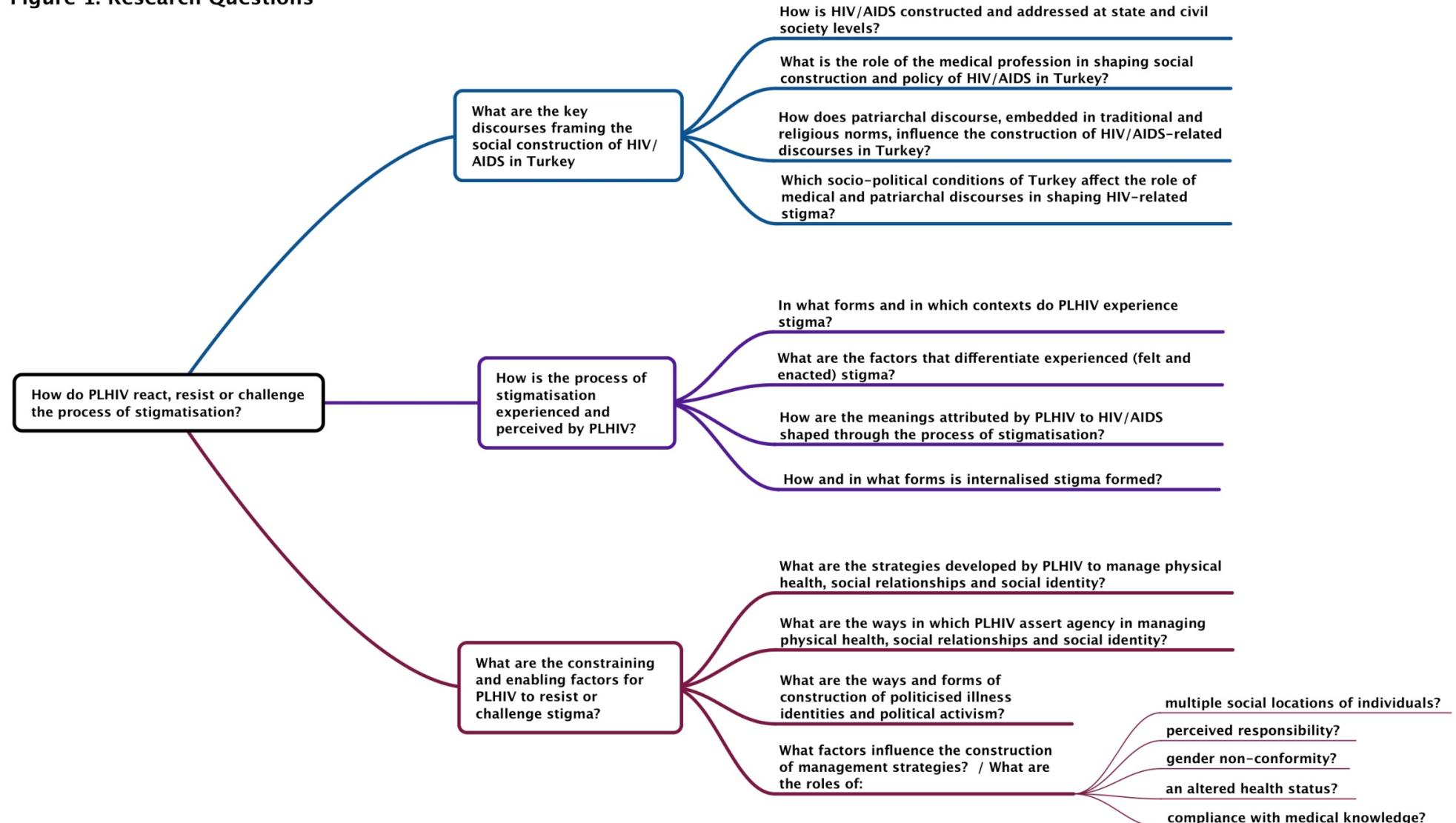
- 1) What are the key discourses framing the social construction of HIV/AIDS in Turkey?
- 2) How is the process of stigmatisation experienced and perceived by PLHIV?
- 3) What are the constraining and enabling factors for PLHIV to resist or challenge stigmatisation?

These three questions are formulated to address three processes, respectively: the formation of HIV-related stigma, the lived experience and perception of stigma by the people who are subjected to it, and the ways in which PLHIV are responding to it. Accordingly, the first key question addresses the construction of the discursive and macro structural aspects of the stigmatisation process, while the second and third questions are related to the understanding of subjective meanings and agency of the stigmatised individuals in process. This is considered as an analytical deconstruction of a whole process of stigmatisation, in which these three processes are intersecting.

The key questions and the sets of sub-questions are illustrated in Figure 1.

The first set of questions aims at identifying the key discourses around HIV/AIDS, the role of medical and patriarchal discourses in framing the social construction of HIV/AIDS and the socio-political conditions of Turkey which are influential in these processes. The second set of questions addresses the forms and the ways in which PLHIV encounter and give meaning to HIV-related stigma. The last set of questions explores the management of HIV and its stigma, by asking how PLHIV manage their physical health, social relationships and social identity. Those questions are focused more on agencies of PLHIV and on the factors that constrain and enable the potential of PLHIV as active agents in resisting stigma. Based on the conceptual framework, some of the factors that I specifically examined are the multiple social locations (intersectional identities) of PLHIV, the altered health status due to HIV/AIDS, compliance with medical knowledge and practice, perceived responsibility for HIV status and gender non-conformity.

Figure 1: Research Questions



My intentions for this research have been formed throughout the years I have been interested in gender, social stigma, health and human rights from a sociological perspective. After graduating from the Department of Sociology at Hacettepe University in Turkey in 2001, I started working as a research assistant and writing my MSc dissertation at the same department. My dissertation, on the principles and epistemological foundations of qualitative social research, broadened my methodological interest in 'understanding the subjective experience'. Gender and human rights issues have always been a matter of interest to me, stemming from my personal experiences as a woman in the society that I lived in and from my voluntary involvement in a children's rights organisation. In my PhD thesis, I was determined to explore how individuals deal with situations of injustice or inequality. In the meantime, my fieldwork experiences in a large-scale research project on disability in Turkey deepened my interest in the sociology of health and illness. I also became familiar with the gaps in the stigma literature that I observed while co-conducting a study on labelling attitudes towards young homosexuals in Turkey. HIV/AIDS appeared as a cross-cutting issue of stigma, gender, health and human rights and as a field which is not adequately addressed in Turkey.

Soon after I decided to write my PhD thesis on HIV/AIDS-related stigma, in 2006, several projects on HIV/AIDS started in Turkey, sponsored by the Global Fund. I had the chance to participate in their education/training programs, research and NGO activities as a volunteer. Although I started my PhD in Hacettepe University and submitted my first draft proposal there, I have changed my programme, in the search for a more suitable academic milieu for my intended research. First I was transferred to Middle East Technical University in Turkey, where I continued literature review, and then to UEA in 2009.

My aims and questions in this thesis have been guided by both the literature and my observations in the field throughout those years. I have sought to address the above outlined research questions through a year of fieldwork in Ankara and Istanbul, generating biographical narrative interviews with 24 PLHIV, semi-structured interviews with 32 key informants (KI), reviewing key documents, and participating in PLHIV networks, project meetings and the advocacy work of NGOs representing and working with PLHIV.

3. Thesis outline

In Chapter 2, I present the theoretical framework of the thesis. This chapter is composed of two parts; first on the discursive approach towards the understanding of the social construction of health and illness, and second on the theoretical concepts of stigma management and chronic illness self-management. The first part starts with introducing the social constructionist perspective on body, health and illness. I then focus on the construction and use of medical and patriarchal discourses in relation to the meanings attributed to health and illness in general and to HIV/AIDS in particular. I discuss the control and regulation of the individual body and public health by the medical discourse based on Foucault's (1977; 2003) conceptualisations and I explain the implications of medical discourse for the perception of and intervention to HIV/AIDS with reference to Brandt's (1988) analysis of the history of sexually transmitted diseases (STD). Stating my critical position towards the little attention given to the agency of individuals in resisting the power exercised over them (Parker & Aggleton, 2003; Gabe et al., 2006), I introduce a discussion around the possible ways in which HIV-related medical discourses are challenged.

The first part of Chapter 2 then focuses on the role of patriarchal discourse in the formation of HIV-related stigma. I first outline the feminist perspective I take in the social constructionist understanding of health and illness. I extend the discussion beyond the explanations around the regulation of women's bodies through medical discourse and underline the social construction of masculinities (Herek, 2004; Connell, 2005) in relation to men's health. Here I explain my motive behind the use of the term 'patriarchy' rather than gender (Kandiyoti, 1988; Ertürk, 2004). Finally I outline the relationship between the regulation of women's and men's sexuality through patriarchy with the gendered experiences of individuals affected by HIV/AIDS.

In the second part of Chapter 2, I introduce the second set of concepts used in this thesis, based on the literature on stigma and chronic illness self-management. I first present the criticisms towards the use of the concept stigma in the literature. I define the term stigma as used in this research in line with Link and Phelan (2001), in a way that it contains both micro and macro social processes. Focusing on the power relations in the formation of stigma, I argue that the discursive approach presented in the previous part of this chapter offers an appropriate perspective for

understanding HIV-related stigma in relation to broader social inequalities (Parker & Aggleton, 2003). I then introduce the intersectional approach adopted in this research (West & Fenstermaker, 1995; Crenshaw, 1997; Collins, 2003; McCall, 2005; Denis, 2008; Choo & Ferree, 2009).

After briefly outlining the various forms and consequences of HIV-related stigma, I focus on the 'management' of stigma by PLHIV. Here I first clarify the difference between the terms 'coping' and 'management' in the general literature on stigmatised individuals, criticising the former for picturing stigmatised individuals as 'passive victims' whose main purpose is to 'avoid' the negative consequences of being stigmatised (Shih, 2004). I review the literature on resistance to stigma, presenting my critical position towards polarised (active vs. passive) and linear (for example from concealment and to political activism) understandings of stigma management strategies. While the management of HIV as a chronic illness and management of stigma are intertwined, I review the literature of chronic illness self-management in a separate subsection, focusing on the concepts of the health psychology literature and referring to the more agency-oriented approaches (Kralik et al., 2004). Finally I highlight the ways in which stigma constrains the management of health.

In Chapter 3, I describe the methodology of the thesis. This chapter starts with a section on the epistemological approach I take. Here I present my understanding of social reality, based on social constructionist and feminist epistemologies, and outline the implications of these for the methods used, my interpretation of the data, my focus on agencies, and my views on positionality, objectivity and subjectivity. I then explain the research design, including the selection of particular methods for specific types of data required to answer particular research questions, and also the theoretical sampling based on an intersectional approach. In the section on the methods of data generation and analysis, I first explain the recruitment of the participants and the different forms of interviews I conducted with PLHIV and with the KIs. I present the technique of the Biographical Narrative Interpretive Method (BNIM) (Wengraf, 2009) I used for generating the life stories of PLHIV. I discuss this method in terms of its usefulness for gaining a better understanding of the changes in their lives and identities, not only relating to their HIV status, but also to their other experiences, multiple social locations and broader social inequalities. Finally, I describe the principals of narrative and thematic methods of data analysis

I used and explain how the analysis guided me to structure the organisation and presentation of the data in this thesis. This chapter also includes a section on the ethical considerations, related to both collecting and presenting the data. Ethical considerations form an important part of this thesis. In addition to the procedures of securing confidentiality and anonymity here I also discuss my own impact in the field and my relationships with some of the participants and actors in the field, which have a history dating back before the start of this thesis.

The main objective of Chapter 4 is to provide background information on HIV/AIDS in the research setting. I describe the situation of the epidemic in Turkey, briefly explain the country response to HIV/AIDS at the state and civil society levels and overview the level of knowledge and attitudes towards HIV/AIDS and PLHIV among the general public, based on previous research findings. I argue that the perceptions of HIV/AIDS in Turkey and the country response to the epidemic are shaped by both the country's own national socio-political context and its position in the global world. However, I introduce these contextual factors briefly in this chapter, since I present an extensive analysis on the country response in relation to cultural and socio-political features of the country in Chapter 5.

I analyse and interpret my findings in chapters 5 to 9. Chapter 5 addresses the first key question of the thesis. Accordingly, I identify the key discourses framing the social construction and policy of HIV/AIDS in Turkey. I argue that the main driver of the state response is a 'cultural immunity' discourse fed by the exclusionary representation of HIV/AIDS as coming from 'foreign' sources and the denial of behaviours that can lead to HIV transmission among society. On the other hand, rights-based discourses are represented in developing civil society responses. Different rights ideas, such as the right to health and the rights of most-at-risk populations (MARP), are negotiated by different actors. I investigate the roles of the medical profession and the social perceptions of sexuality in these processes, with reference to the coexisting discourses of conservatism and modernism in the country.

While Chapter 5 is based on the data generated from the semi-structured interviews with key informants and the review of documents and statements of the main actors in the field, from Chapter 6 to Chapter 9 I draw upon the analysis of the life stories of PLHIV.

Chapter 6 is concerned with the second key-question of the thesis: How is the process of stigmatisation experienced and perceived by PLHIV? The data suggested that the two main areas of detailed investigation for understanding PLHIV's perceptions of stigma are the institutions of the family and healthcare. Accordingly, this chapter is organised around PLHIV's encounters with stigma, both in felt and enacted forms, in these two institutions. The focus on these two institutions also coincides with my objectives of investigating the role of medical and patriarchal discourses, since the former is seen in PLHIV's experiences in healthcare settings and the latter in the institution of the family. The main purpose in looking at PLHIV's experiences of stigmatisation in these institutions is to understand the processes in which PLHIV attribute meaning to living with HIV.

I address the third key-question of the thesis throughout Chapters 7, 8 and 9. These chapters derive mainly upon narrative analysis and are concerned with how PLHIV manage HIV and its stigma, with a focus on exploring the ways in which they assert agency in managing physical health, social relationships and social identity.

In Chapter 7, I discuss the management of physical health, including not only self-monitoring of health and adherence to treatment but also the formation and reconstruction of 'illness perceptions' by PLHIV, as a way of internalisation of or resistance to HIV-related stigma in illness narratives. I investigate how meanings attributed to HIV and its treatment change, with the post-diagnosis turning points (Baumgartner & David, 2009; Baumgartner, 2012) and with the effects of 'framing agents' (Watkins-Hayes et al., 2012). I outline the challenges to the management of physical health created by the uncertainties about the disease, its treatment and the expertise of medical profession, the cultural characteristics of doctor-patient relationships and the 'health system-level' obstacles (Bernays et al., 2010; Musheke et al., 2012) that PLHIV face in Turkey. In line with the main objectives of the thesis, I highlight the ways of asserting agency in overcoming these challenges and link the emerging forms of agencies with the main discourses presented in Chapter 5.

In Chapter 8 I look at the strategies that PLHIV construct to manage their social relationships and social identity. Motives and strategies of concealment and disclosure, the management of the changes in social and sexual relationships are explained in this chapter. I then focus on the cognitive and emotional aspects of

management of identity, in light of the literature on health psychology. My intention in this chapter is not to identify 'successful' or 'unsuccessful' management of stigma, but to understand the process and the extent to which HIV is perceived as 'life changing', leading to the construction of a 'new', 'valued' identity or to a motivation for 'normality'.

Chapter 9 focuses on a particular sub-question, aimed at linking the resistance to stigma at the personal and collective levels with the overarching discourses shaping HIV-related stigma: What are the ways and forms of construction of politicised illness identities and political activism? Introducing the concept of 'biological citizenship' (Rose & Novas, 2003; Robins, 2004), I first discuss how HIV-related stigma experienced by PLHIV contributes to a reconstruction of illness through narratives of injustice and neglect. Secondly, I focus on the involvement in activism and identify the roles of intersectionality, politicised illness identity and the particular treatment experiences on the formation of HIV/AIDS activism in Turkey. Finally I highlight the ways in which cultural immunity and right-based discourses are negotiated by PLHIV in the emerging forms of individual and collective resistance to stigma.

Chapter 10 sums up the thesis by drawing together the main arguments and reiterating the key themes. Returning to some key debates covered in the literature review, I highlight the ways that the findings of this thesis contribute to the understanding of the discursive formation of HIV/AIDS and the management of HIV and its stigma by PLHIV. Finally I suggest areas for further research and the policy agendas which the thesis informs.

I present the theoretical framework of the thesis in the next chapter.

Chapter Two: Conceptual Framework

1. Introduction

The conceptual framework of this research is composed of two sets of concepts related to the main arguments. The first is based on the discursive approach to health and illness, and is used to understand the role of medical and patriarchal discourses as components of the power structures shaping HIV-related stigma. The second set of concepts is related to the understanding of the process of stigmatisation, with a focus on stigma management strategies constructed by people living with HIV (PLHIV). The research argues that PLHIV are active agents who react, resist or transform the processes of stigmatisation. This conceptual framework is used to discuss the potential of social identity to resist the discursive power relations within which the identity is constructed.

2. The discursive approach to HIV/AIDS

This section discusses the discourses related to the construction of knowledge of and meanings attributed to health in general and to HIV/AIDS in particular. Medical and patriarchal discourses are the main conceptual focal points. Since the discursive approach to HIV/AIDS is rooted in the social constructionist perspective on health and illness, I briefly introduce the social constructionist perspective and general understanding of body, health and illness in relation to broader social contexts and power relations from this perspective. I will state my critical position within this perspective with regard to the main questions asked in this research.¹

The social constructionist perspective on health and illness considers the body, health and illness as 'discursively constructed, produced through subjective, historically determined human interests, and subject to change and reinterpretation' (Gabe et al., 2006, p.130). Discourses are understood as 'regimes of truth' or 'bodies of constructed knowledge' that create 'things of which they speak', such as identities, experiences, subjectivities and bodies (Finn & Sarangi, 2009, pp.51-52). Discourses define and reproduce socially-constructed categories linked to

¹ Social constructionist and discursive approaches are critically reviewed; and my standpoint regarding these approaches is presented in more detail in the epistemology section of the next chapter.

stigmatisation and thus can be used to reinforce social hierarchies and sustain power structures. This approach, then, is concerned with power relations that are diffused through discourses (ibid).

This approach is closely linked to and has been substantially shaped by the work of Foucault. Foucault's analysis of the 'power/knowledge unity', together with his analysis of the functions of the medical profession, are his major contribution to the social study of health and illness; that is, understanding of the medical discourse as a means of social control and regulation (Cockerham, 2001, p.4). This understanding is the topic of the next subsection, but first, an introduction to Foucault's influence on the discursive approach to health and illness is presented below.

Before Foucault's contribution, social constructionism was already in use in the sociology of health and illness, mainly in the criticism of medicalisation. Foucault's work has taken the medicalisation critique further, questioning the 'acknowledgement or acceptance of an underlying "natural" or "bio-physical" reality' (Williams, 2006, p.7). In *The Birth of the Clinic*, Foucault (2003/1963) says that '...the solid, visible body, is only one way ... in which one spatialises disease. There have been and will be, other distributions of illness'. Pointing out the diffused nature of power and the unity of power/knowledge, Foucault understands body, health and illness as the product of 'strategic, shifting, historically contingent configurations of power-knowledge' (Williams, 2006, p.7). As he indicates below, for Foucault (1980, p.93), power/knowledge relations that produce our bodies display themselves in discourses:

... in any society, there are manifold relations of power which permeate, characterize, and constitute the social body, and these relations of power cannot themselves be established, consolidated nor implemented without the production, accumulation, circulation and functioning of a discourse.

Accordingly, body, health and disease are considered 'discursive matters' in the social constructionist perspective (Williams, 2006, p.7).

How then, can health and illness be understood in broader social contexts through the lens of the discursive approach? What makes a discursive approach different from a general understanding of health and illness in relation to broader social contexts?

One way of approaching the social meanings around illness has been to focus on metaphors surrounding illness. For example, Susan Sontag (2005) famously draws attention to the negative connotations around illness – mentioning the use of military metaphors about AIDS and related understanding of HIV ‘as an enemy’ – and their stigmatising effects on individuals. Similarly, Gilmore and Sommerville (1994 cited in Berger, 2004, p.28) mention seven metaphors for disease as death, punishment, crime, war, otherness, horror and villain. However, according to Brandt (1988), the positivistic view of illness metaphors, such as Sontag’s, that illness has to be cleaned from metaphors denies the notion that disease is a social construct. According to Brandt, ‘disease cannot be freed of metaphors’. It raises questions of ‘dependence, debility, and death’ and is literally ‘loaded with affect and social values’. Accordingly, rather than discussing the possibility of eliminating the metaphors around disease, the main task of social constructionism is to analyse the processes by which disease is given meaning. To do so, the social construction of disease can be analysed by revealing the points where ‘biology and culture interact’ (Brandt, 1988, pp. 416-418).

The main aim of the use of the discursive approach, as mentioned above, is to reveal the power relations under which this interaction of biology and culture takes place, which are regarded as constituted and shifting according to socio-historical and political contexts (Finn & Sarangi, 2009, pp.51-52).

Health, sexual health and accordingly HIV/AIDS are recognised today as a cross-cutting political, economic, development, gender and human rights issue (Ertürk, 2005; Fathalla, 2008; Cornwall et al., 2008). Since the first diagnosis of the virus it had been well documented that both the prevalence of HIV/AIDS and the responses of nation-states, societies and international organisations to the epidemic have been shaped by national and/or global socio-economic, cultural and political contexts. From the discursive approach, these contexts can be understood in terms of arenas of various discourses (for example liberalism, conservatism, nationalism, etc.). The focus of this research is on medical and patriarchal discourses. The construction and use of medical knowledge and the construction of femininities and masculinities by the patriarchal discourse are considered here as the main components of the power structures that produce and maintain HIV-related stigma.

Before continuing with medical and patriarchal discourses in relation to HIV/AIDS, criticism of the constructionist approach should be briefly noted here. This approach has been criticised for ignoring non-discursive (or extra-discursive or material) aspects of the body, health and illness, and for overemphasising the role of the structure over individuals (Joffe, 1997; Kuhlmann & Babitsch, 2002; Williams, 2006; Gabe et al., 2006). Considering these criticisms, this research seeks to avoid a 'form of reductionism or "discourse determinism"' (Williams, 2006, p.9). Besides, since the thesis is focused on the agency of individuals, it keeps a distance from the social constructionist 'pessimism about de-stigmatisation' (Gabe et al., 2006, pp.71-72) and seeks to understand the tension between discursive power relations and the construction of social identity in negotiation with these discourses. Additionally, it approaches the social constructionist perspective from a feminist standpoint, taking into consideration the social construction of both femininities and masculinities in discursive power relations.

2.1. Medical discourse

The construction of medical knowledge and its role in the meanings attributed to illness and the person with ill health are discussed below. The discussion on the control and regulation of the individual body and public health by the medical discourse is based on Foucault's conceptual framework. The health-related, social and policy consequences of 'scientific' explanations of HIV/AIDS are mentioned, focusing on the concept of risk groups. The possibility of constructing alternative identities or knowledge that challenge medical discourse is also discussed.

According to Foucault, scientific explanations as discourses are not truths but claims or regimes of truth that are socially produced and maintained by the 'power/knowledge unity'. The construction and use of scientific explanations were never driven by a pure concern for scientific knowledge. Before the 19th century, physicians were setting standards for medical practice in order to preserve their privileged position in society. In the 19th century, according to Foucault, the state started to employ the profession of medicine as an institution of social control. The state was firstly concerned with illness in terms of its effects on people's participation in the labour force. The norms of health were created from this perspective by the state and the medical profession simultaneously. In the process of this medicalisation, which defines and treats non-medical issues as medical

problems (Gabe et al., 2006, p.59), many aspects of social life such as family size, beauty and happiness became subjects of medical practice.

Foucault identifies two distinct trends in the role of medical discourse in social control in the history of medical practice: the ‘medicine of social species’, which is concerned with the diagnosis, classification and cure of disease, sees the human body as an object of medical analysis. The ‘medicine of social spaces’ is concerned with the prevention of disease and makes public health the object of regulation (Cockerham, 2001, p.15). Thus, ‘bio-power’ – power exercised upon the body to systematically manage the life of a population, including the control and regulation of population growth and reproductive health – became a new form of social control.

The early dominant perspective on social control in labelling theories focused on ‘the stake had by particular professional groups or moral entrepreneurs in defining certain behaviours as deviant and subjecting them to social control’ (Weinberg, 2007). By contrast, Foucauldian understanding of social control is based on the conceptualisation of power as decentralised and omnipresent. Power is not in the hands of a specific group, institution, or the sovereign state; but it exists in independent, various, local social settings. Within this conceptualisation, Foucault’s analyses of bio-power, as a form of power/knowledge, shows how social control works to discipline the individual body through the process of normalisation.

A two-way process exists in the power/knowledge unity: on one hand, instruments of control make the people controlled the object of scientific analysis; on the other, knowledge gained from scientific observations of the controlled people provides the basis of power. For instance, in the process of the ‘great confinement’, the ‘mad’ are isolated and thus controlled; at the same time they became objects of scientific research. New observations about the ‘mad’ created new ‘normalising judgments’ and served to identify various behaviours as the signs of madness. In other words, by reference to gathered knowledge, medical discourse gives meaning to health and defines what is ‘normal’. This in turn, provides ground to power relations upon which knowledge is used for controlling the abnormal.

In relation to the construction of social identities, the important point is that for Foucault, the conduct of the body according to the ‘normal’ is maintained by people themselves. Foucault (1977) argues that people control their lives through their

bodies and that power can be exercised 'only and insofar as they are free'. In this sense, his definition of power contains a 'freedom' component. The bodies and identities of free individuals are the domains through which power can be produced and maintained.

This explanation about the freedom of individuals (which seems paradoxical) has not prevented Foucault's works from being criticised for leaving little space for – or at least not clarifying – the agency of the individual. According to Parker and Aggleton (2003, p.17), in the Foucauldian approach power is exercised through the production of 'conforming subjects and docile bodies'. This approach does not give enough attention to how lay thinking can resist or produce alternatives to medical knowledge (Gabe et al., 2006, pp.127-128). Similar criticism while not directly of Foucault, is also made in arguments about the exaggeration of the idea of medicalisation. It is stated that a great number of people in the world (especially the non-western world) live in direct contact with neither medical institutions nor their cultural and/or commercialised implications. The literature on 'lay health workers' who reject the knowledge of medical science (Stacey, 1988) and 'health-related social movements' (HSM) (Brown et al., 2004) also show the possibility of critical lay thinking about the policies, research, practice and knowledge of the medical profession.

Another criticism of Foucauldian understanding can be put forward in relation to the role of the state in power and health. Even if power is considered as diffused and not just state-centred, it can be argued that the state controls the institutions with the authority to allow or prevent the implementation of medical knowledge, especially in contexts where state authority is traditionally considered fundamental and in less individualistic cultures.

The implications of medical discourse for the perception of and intervention to HIV/AIDS can now be discussed with reference to the history of the social construction of the STD in the first decades of the 20th century, which can shed light on cultural and historical understanding of HIV/AIDS (Brandt, 1988, p.431).

According to Brandt (1988), medical explanations of gonorrhoea and syphilis in the USA during the early 20th century reflected cultural values and fears about disease, sexuality, contagion and social organisation in western society of that time. This period was characterised by the value given to discipline, restraint and

homogeneity, the 'search for new technical, scientific answers to social problems and the search for a set of unified moral ideals' (p.418). The 'crises' of gonorrhoea and syphilis were related to those values and ideals. These diseases were seen as a threat to the main values and ideals and became metaphors for the concerns of the era about not only the collapse of sexual and familial values but also 'the urban masses, the growth of the cities', that were considered major societal problems (p.422). In the USA, the early 20th century was an intensive period of immigration. Many doctors argued that immigrants were bringing STDs into the country, and to explain how the immigrants were spreading STDs to 'native, middle-class, Anglo-Saxon Americans' (p.421), they also suggested that the majority of sex workers were immigrants. Furthermore, to be able to continue blaming immigrants and to separate them from other, 'blameless' people who were infected such as women and children, doctors defined what was called the 'venereal disease of the innocent'. To provide a scientific base for this, they asserted that these diseases could be contracted in many ways which are known now to be unrelated to the spread of these disease. In this way medical explanations created and maintained a distinction between the 'innocent' and the 'guilty', depending on how the infection was obtained. As a consequence, 'innocents' deserved attention, sympathy and medical care while others did not (Brandt, 1988, pp.419-422).

Like Brandt's (1988) analysis of the history of STDs, the analysis of HIV/AIDS should also be situated historically, as Parker and Aggleton (2003, p.19) indicate:

...the epidemic has developed during a period of rapid globalization linked to a radical restructuring of the world economy and the growth of 'informational capitalism' ... These transformations have been characterised by rapidly accelerating processes of social exclusion, together with an intensified interaction between what might be described as 'traditional' and 'modern' forms of exclusion. (Parker & Aggleton, 2003, p.19)

With the emergence of HIV/AIDS, the process of dividing infected people into blameless and blamed has been reactivated (Brandt, 1988, pp.429-430) in a way that it corresponds to existing grounds for social exclusion. The identification of the first cases among Haitian-Americans and homosexual men in the US provided a basis for 'scientific' theories about the cause and origin of the disease that served to blame immigrants and homosexuals. Moreover, early theories asserting that the disease originated in Africa reflected the perceived association between disease and 'primitiveness'; thus serving to conceptualise the disease as external to modern US society (Sontag, 2005, pp.150-151).

The basic scientific explanations of the transmission of HIV indicate that the virus can be transmitted through unprotected sexual intercourse with an infected person; through sharing unsterilised needles/syringes with an infected person; through transmissions of blood/blood products/organs from an infected person; and from an HIV-positive mother to her child during pregnancy, birth or breastfeeding. The 'sex' component of the routes of transmission and the high prevalence rates among homosexual men can provide grounds for the expression of socially unapproved sexual behaviour as causes of transmission. Despite the fact that sexual intercourse is a route of transmission when unprotected, homosexuality, anal sex and multiple sexual partners in themselves are sometimes declared to be causes of transmission. Especially, homosexuality has been associated with infection, as can be seen in the expressions of 'gay-related immune deficiency' (GRID) and 'homosexual cancer' (Seidman, 1988, p.190), which were used in the early years of the disease. In addition, it can be observed that rather than emphasising 'shared' use of needles, the use of drugs in itself (sometimes referring to drug use without injection) is mentioned among the causes of transmission. On the other hand, infection through blood transfusion and the infection of children of HIV-positive mothers are regarded as causes of the infection of 'innocent victims' (Alonzo & Raynolds, 1995, p.305).

Based on explanations of the routes of transmission, some behaviours have been defined as 'risky', and their perpetrators, such as homosexual men, sex workers and intravenous drug users (IDU), have been defined as 'risk groups'. The definition of 'risk groups' has had several consequences. Firstly, it has exacerbated the stigmatisation of already stigmatised and excluded populations. Secondly, in the Foucauldian sense, the consideration of 'risk groups' provides grounds for gathering further scientific knowledge about these populations and related behaviours as subjects of medicine and public health. Related to this, homosexuality, which was removed as a disease from the psychiatric diagnostic manuals nearly a generation before the emergence of the epidemic, re-entered the domain of medicine as 'as an infectious, terminal disease' (Brandt, 1988, p.429). Consequently, although in a different form, homosexuality has become partially 'remedicalised' (Gabe et al., 2006, p.60).

On the other hand, while 'risk groups' constituted the main populations on which prevention policies were focusing, the prevailing social bias towards these groups

restricted certain interventions. The provision of sterile needles for IDUs and safe sex education in schools for instance, are rejected in some countries, including Turkey. According to Brandt (1988, p.427), the reason behind this rejection can be explained in terms of governments' fear of being regarded as officially approving or encouraging drug use, homosexuality or teenage premarital sex. Brandt (1988, p.428) also argues that there is a latent idea behind the reluctance to implement this kind of intervention: the idea 'that the disease itself must be *used* to discourage risky behaviours' (original emphasis).

The definition of the category of 'risk groups' has also affected people outside it. For instance, because of the attribution of the disease to homosexual men, women remained invisible in the first decades of the epidemic (Weber, 2006, pp.28-29). In a broader sense, according to Weber (2006, p.29), the biomedical approach in the health-promotion policies did not consider social aspects that affect people's vulnerability to HIV, and 'led to the underdiagnosis, lack of care and treatment, and increased death and burden of disease among less powerful groups'.

Nevertheless, more recently vulnerability to HIV has been acknowledged as a central issue and the use of the term 'risk groups' has come to be regarded as politically incorrect. 'UNAIDS Terminology Guidelines' (UNAIDS, 2008b, p.5), for instance, states that instead of risk groups, the term 'key populations at higher risk' should be used to refer to the situation of these populations as 'both key to the epidemic's dynamics and key to the response'. UNAIDS defines key populations as people who 'engage in behaviours such as unprotected sex or exchange of contaminated needles that put them at higher risk of becoming infected. These communities include men who have sex with men, people who use injection drugs and sex workers' (2010, *my emphasis*). According to this definition, 'key populations are distinct from vulnerable populations, which may be *subject* to societal pressures or social circumstances which may make them more vulnerable to exposure to infections, including HIV' (UNAIDS, 2008b, p.5, *my emphasis*). Although the importance of making this kind of conceptual distinction cannot be denied, it is possible to interpret these definitions as the continuation of a separation between people who are responsible for their infection and people who are victims of the disease.

Perceptions of risk and responsibility can be understood from a Foucauldian perspective as products of discourses. Materialistic and deterministic discourses

intrinsic to modernity see dangers and epidemics as human faults, and attribute the responsibility to individuals (Gabe et al., 2006, p.87). In the 'political ethos of advanced liberalism', individuals are seen responsible for making the 'right choices'; not only for protecting themselves from risks, but at the same for 'constructing the self as "normal" and distinguishing the self from risky others' (Gabe et al., 2006, p.90).

However, it is not possible to assume that lay thinkers always accept the idea of responsibility for their health. For instance, when explanations based on personality or social phenomena seem inadequate, people can have more fatalistic ideas about the causes of their illness (Gabe et al., 2006, p.89). Then it can be argued that in cultural settings where individualism is not powerful, people are not necessarily seen as responsible for their illness and illness is not always seen as individual pathology.

Apart from the idea of responsibility, the uncertainties about HIV/AIDS can be seen as another factor related to the possibility of challenging (or differently interpreting) medical knowledge about HIV/AIDS by lay thinkers. According to Brandt (1988, p.426), an important aspect of HIV/AIDS which differs from other STDs is that it 'has threatened our sense of medical security' and the confidence of medical science in an era when the authority of experts is already in decline. Uncertainty, comprising both doubt and anxiety about medical explanations, practice and the experience of illness (Gabe et al., 2006, pp.101-102), can be seen as opening the door to lay thinkers' alternative interpretations of medical knowledge on HIV/AIDS.

The involvement of lay thinkers in 'scientific' discussion can contribute to changes in discursive power relations, as seen in Seidman's (1988) analysis of the effect of HIV/AIDS on the construction of homosexuality. According to Seidman, while the medical discourse promoted new forms of social control over homosexuality, bringing homosexuality into the scientific context and opening it to public discussion 'allowed an appeal to empirical evidence to challenge stereotypes and, ultimately, to contest the medical model itself'. With the involvement of the homosexual community in discussion and gathering of scientific knowledge, 'medical discourse contributed to creating a common homosexual consciousness and culture that eventuated in a politic aimed at legitimating homosexuality' (Seidman, 1988, p.202).

2.2. Patriarchal discourse

The second main focal concept of this thesis, for the discursive understanding of the power relations shaping the stigma attached to HIV/AIDS is patriarchy. I take the feminist perspective in social constructionist theory as the basis of the discursive approach to gender and health in this thesis. Feminist theory's implications for this research are mentioned in the epistemology section in the next chapter, but I discuss the feminist social constructionist approach's main concerns about health and illness here and then discuss women's vulnerability and experiences of HIV/AIDS in relation to the norms and meanings embedded in patriarchy. However, the discussion is not limited to women's experience; I also consider the social construction of multiple masculinities in relation to men's vulnerability and experiences of HIV/AIDS.

The social constructionist feminist theory of health and illness is mainly concerned with the construction and regulation of women's bodies through medical discourse (Williams, 2006, p.8). It shows how the use of medical knowledge leads to the devaluation of women and neglect of their health-care needs (Kuhlmann & Babitsch, 2002, p.437). Women's health research conceptualises health behaviour as social behaviour that 'questions the social order of the sexes and interpretations of "femininity" and "masculinity"' (Kuhlmann & Babitsch, 2002, p.437-438). According to Williams (2006, p.8), this Foucauldian problematisation of the notions of the 'sexed' body provides 'important new opportunities for resistance through a feminist body/politics' in which bodies may be constructed differently.

Nonetheless, because of the exclusive emphasis on women's health in early feminist works, 'gender and health' has been understood as synonymous with 'women's health'. Masculinity and men's health, on the other hand, are theorised in early studies with a focus 'primarily on the hazardous influences of "the male sex role"'. The social constructionist perspective criticises the sex-role theory for seeing gender basically in terms of fixed, static and mutually exclusive roles; for assuming that women and men have innate psychological needs for gender-stereotypic traits; and for fostering the notion of a singular female or male personality. Conversely, social constructionist perspectives conceptualise both femininities and masculinities as products of cultural dynamics (Courtenay, 2000, pp.1386-1387). In the same way, this research takes into consideration the social construction of both multiple femininities and masculinities in relation to HIV/AIDS. Hegemonic

masculinity and heterosexism, which Connell (2005) and Herek (2004), respectively, see as among the main elements of patriarchy, are introduced. But first, the motive behind the use of the term 'patriarchy', rather than 'gender relations', should be clarified here.

Patriarchy, which has been brought to the centre of feminist critique by radical feminism (Demir, 1997), is defined as 'a form of social organisation in which cultural and institutional beliefs and patterns accept, support, and reproduce the domination of women and younger men by older or more powerful men' (Levy, 2007). Family is accepted as the fundamental institution of patriarchy (Demir, 1997). However, Kandiyoti (1988, pp.275-278) draws attention to different forms of patriarchy, stating that unlike the sub-Saharan model, where 'relative autonomy of mother-child units' is observed, 'classic patriarchy' is characterised by the 'operations of the patrilocally extended household' that give the senior man authority over everyone else, including younger men. According to Kandiyoti, this system of male dominance is characteristic of South and East Asia and Muslim Middle East. Indeed, when we consider the setting of this research, while the laws suggests that Turkey is relatively liberal with respect to gender equality, family remains influential in the construction of norms and values and patriarchy impacts strongly on everyday life, including women's health-related experiences (Öğün-Boyacıoğlu & Türkmen, 2008, p.279). Ertürk (2004) argues that 'bringing patriarchy back' to the study of gender relations and the analysis of masculinities in particular is useful for capturing 'the interlinkages between the various status hierarchies that lead to shifts in hegemonic forms of masculinity'. Therefore, patriarchy is considered a suitable term with respect to both the characteristics of the research setting and the aim of including men's experiences to the analysis.

'Control of women's sexuality is patriarchy's most powerful tool to maintain women's oppression and the imbalance in gender power relations in most societies' (İlkkaracan & Ronge, 2008, p.226). Written laws, customary norms and religion are also powerful instruments of the normalisation and naturalisation of the patriarchal discourse on sexuality. Upholding taboos about sexuality (including women's sexual pleasure, sexuality outside reproduction or wedlock, sex work, desire and love between women and virginity) is one of the methods used to control women's sexuality. Myths about gender differences in sexuality, such as 'men being "naturally" more active or having more sexual desire than women' (İlkkaracan &

Ronge, 2008, p.226) also remain influential in the construction of the meanings about sexuality.

With regard to women's vulnerability to HIV/AIDS, these norms have effects on women's limited ability to control over their sexuality and negotiate safe sex (WHO, 2003). The norms that disapprove of sex outside marriage, which are at the core of patriarchy, put unmarried women and girls at high risk of HIV by restricting their access to information and services about sexuality and sexual health (WHO, 2003). Early and forced marriage (Bruce & Clark, 2004; Clark et al., 2006) and violence against women (Ertürk, 2005) are also documented as directly related to women's vulnerability to HIV. Restrictions to women's education, participation in economic life and mobility, which are relatively invisible forms of control over women's sexuality within the patriarchal system (İlkkaracan & Ronge, 2008, p.227), also increase their risk of HIV infection.

Gendered power relations not only affect women's vulnerability to HIV but also affect their experience when infected. Women generally have fewer resources for coping with the physical and social consequences of the disease (DFID, 2007, p.16). As Seeley et al. (2004) state, interventions aimed at mitigating the impact of the epidemic are not effective for women living with HIV due to the existing gender inequalities. Patriarchal norms about motherhood, the division of labour in the household, the patrilineal system of inheritance and gender-based violence are some of the factors shaping the gendered experience of living with HIV.

Gender-based violence is seen as not only a cause but also a consequence of HIV/AIDS (Ertürk, 2005). Women and girls living with HIV face increased violence when they request the use of condoms, refuse sex within or outside marriage, seek counselling and want to be tested or diagnosed as HIV positive (DFID, 2007, p.16).

Meanings around motherhood put women living with HIV in a double bind. On one hand, social expectations prescribe that women should be mothers; on the other, despite the advance in HIV treatment that can prevent mother-to-child transmission, the assumption that women living with HIV should not be mothers – in order not to harm the child and society – prevails. Thus women living with HIV find themselves caught between two different 'reproductive obligations' which negate one another (Barnes & Murphy, 2009, p.481). In this situation they often make their reproductive decisions by weighing the potential social consequences.

As Barnes and Murphy (2009, p.486) show, HIV-positive women may decide to have a child mainly in order to gain a socially-valued identity. As Russell and Seeley (2009, p.10) demonstrate, in settings where the influence of patrilineal inheritance systems is strong a woman can be pressured to have a male child in order to continue the bloodline and to protect her right to stay on the land.

Women are unequally affected by the epidemic in terms of the care-giving workload (Fathalla, 2008). As Aga et al. (2009, p.46) demonstrate, because of the demanding expectations of the care-giving role, women and girls in HIV-infected households may be forced to discontinue their schooling and/or unable to take part in employment. This responsibility creates a 'double burden' for women living with HIV. HIV-positive women may be forced to 'sacrifice' their own health, even when they are equally as sick as their care recipient (Aga et al., 2009, p.46). With regard to child care, Russell and Seeley's study (2009) shows that in the process of transition to living with HIV, the effect of having a child to look after can be different for women and men. Because of the norm that child care is the role of women, while HIV-positive women 'renew' their role of child care as before, HIV-positive men mostly feel the need to find a wife to take care of the children (Russell & Seeley, 2009, p.10).

Men's experiences of living with HIV are also considered in this research in relation to patriarchal discourse, since masculinity and the power relations between its different forms are also 'an important part of how a patriarchal social order works' (Connell, 1987, p.183). The term 'hegemonic masculinity' (Connell, 1987) refers to the culturally, spatially and historically idealised form of masculinity that subordinates not only femininities but also other forms of masculinity. Developed in response to the traditional view of masculinity as fixed and uniform male behaviour (Scott-Samuel et al., 2009, pp.288-289), the term emphasises the multiplicity of masculinities and the fact that certain groups of men are marginalised and subordinated (Connell, 1987). This term – while 'rarely acknowledged in mainstream discussion' – is used for the investigation of the relations of inequality that affect both women's and men's health (Scott-Samuel et al., 2009, pp.287-288).

The implications of the use of this concept in the understanding of men's health can be seen as having two components. Firstly, the concept is used to explain the differences between women's and men's health-related behaviours. Hegemonic masculinity is characterised by attributes such as toughness, aggressiveness,

excessive risk-taking, emotional illiteracy, strength, protectiveness, decisiveness, courage, individualism, competitiveness, rationality and a practical orientation (Scott-Samuel et al., 2009, p.289). Accordingly, Fathalla (2008) argues that young men in particular may feel pressure to engage in risky behaviour 'to show that they are real men'. With regard to HIV/AIDS, it is argued that the 'social pressure to take risks, be self-reliant, and prove their manhood by having sex with multiple partners' can influence men's risk of infection and their use of HIV/AIDS prevention, care and support services (WHO, 2003, p.5).

Secondly, hegemonic masculinity contributes to the understanding of 'the exclusion and subordination of homosexual men' (Connell & Messerschmidt, 2005, p.837) in relation to HIV/AIDS. Patriarchy and hegemonic masculinity necessitate compulsory heterosexuality as the dominant regime of sexuality. Herek (2004) offers a conceptual model to understand three aspects of hostility based on sexual orientation. 'Sexual prejudice' is defined by Herek (2004, pp.14-16) as 'individual's negative attitudes based on sexual orientation'; 'sexual stigma' refers to 'the shared knowledge of society's negative regard for any non-heterosexual behaviour, identity, relationship, or community'; and 'heterosexism' is the 'cultural ideologies - including beliefs about gender, morality and danger - that perpetuates sexual stigma and prejudice'. Because of the heterosexist understanding of homosexuality as 'deviant, sinful, and threatening' (ibid, p.15), AIDS was seen, especially early in the epidemic, as 'a just punishment for homosexuals since they have violated a basic law of God, Nature and Society' (Seidman, 1988, p.192).

Heterosexism has consequences for homosexual men in terms of both their vulnerability to and experiences of living with HIV. Denial of the human rights and even the existence of homosexuals by communities and/or governments (UNAIDS, 2006b) is a consequence of heterosexism which leads to the insufficiency of addressing homosexual's rights and needs in interventions for HIV/AIDS prevention. In addition to stigmatisation and discrimination, the criminalisation of sex between men is also one of the causes of increased vulnerability, as 'men are either excluded from, or exclude themselves from, sexual health and welfare agencies' out of fear (UNAIDS, 2006a, p.112).

The experiences of homosexual men living with HIV are understood in this research in terms of the intersection of multiple stigmatised identities. The resistance of the homosexual community to HIV-related stigma is mentioned later

in this chapter. But before concluding this chapter, it should also be noted that hegemonic masculinity affects not only the HIV-related stigmatisation of homosexual men but also the experiences of transgendered individuals, since especially male-to-female transsexuality is perceived as threatening and overthrowing masculinity (Berghan, 2007).

3. Management of HIV and its stigma

To clarify the definition of stigma used in this research, early approaches and the shortcomings in the literature on stigmatisation should be reviewed. Goffman's classical work, *Stigma: Notes on the Management of Spoiled Identity* (1963) has been the key reference point for studies on social stigma. Here Goffman defines stigma as 'an attribute that is deeply discrediting' and that 'constitutes a special discrepancy between the 'virtual' and the 'actual' social identity' of an individual. Goffman makes a distinction between stigmatised individuals as 'discreditable' and 'discredited'. Discreditable individuals are defined as persons whose differentness is not known by the 'audience'. The main dramaturgic problem for those persons is to avoid being defined as a member of a stigmatised group by managing the information that others may obtain about them. Discredited individuals, on the other hand, whose differentness is known, try to 'manage tension' between themselves and the audience (Goffman, 1963). Goffman's understanding of the stigmatised individual has been criticised for assuming that the latter holds the same beliefs about the rest of society, and for picturing a stigmatised individual who 'reacts rather than resists or rejects the critical appraisals of others' (Riessman, 2000, p.114).

Nearly 50 years' history of stigma research shows that the concept has been used in different senses and contexts and subjected to various criticisms. These criticisms are summarised below, based on Link and Phelan's (2001) main points for discussing the shortcomings of the literature on stigma:

- 1) According to Link and Phelan (2001, p.366), the term 'stigma' is too vaguely defined; often in confusion with labelling and discrimination, or without referring to the power structures in which the stigma is found.

Although stigmatisation and discrimination should be distinguished, discrimination will not be conceptualised as detached from stigma in this research (as explained below). In order to clarify the meaning of stigma, some writers suggest a distinction

between stigma and discrimination, but their distinction is different to what I am aiming for in this research. For instance, Deacon (2006) argues that stigma and discrimination are different because stigma refers to negative ideologies or attitudes and is not something that has to result in discrimination. According to this view, anyone can stigmatise, regardless of their social position (Deacon, 2006, pp.420-421). However, as Link and Phelan (2001) state, we cannot call it stigma if a relatively powerless group creates stereotypes about a more powerful group and treats the members of the more powerful group in accordance with those stereotypes. Such a process can be called 'labelling'. In order to be conceptualised as stigma, this process must lead to the loss of status and discrimination of the labelled persons. This clarifies why the definition of stigma must involve reference to power.

The term discrimination is used in this research to refer to the differential treatment of people, often leading to denial of opportunities and resources for reasons that are not related to their merits, capacities or behaviour but are primarily about their perceived membership of a group (Law, 2007). The term 'social exclusion' is also seen as similar to discrimination. However, even tough exclusion from opportunities is included in this term; the emphasis in social exclusion is on inadequate social participation and integration (both in micro social interactions and at the societal level, such as exercising the social rights of citizenship) (Silver, 2007).

2) Another shortcoming of the literature on stigma emerges when stigmatised persons are seen as passive victims of the stigmatisation process who accept and absorb societies' constructions of themselves. This view, according to Howarth (2006, p.449) is an overstatement of 'the case that stigma cannot be resisted, disrupted and even transformed' and results from a simplistic understanding of power. It should be acknowledged that 'where there is power, there may also be the potential for individual or collective resistance' (Campbell & Deacon, 2006, p.413). Indeed, as Howarth (2006, p.450) states:

Stigma is as much about the resistance of identities as the reduction of identities; it is a dialectical process of contestation and creativity that is simultaneously anchored in and limited by the structures of history, economics and power.

As in the general literature on stigma, HIV-related stigma research in both highly industrialised and less industrialised settings has paid limited attention to complex

stigma management and/or resistance strategies developed by PLHIV (Goudge et al., 2009, p.95). Nonetheless, the possibilities of resisting or transforming the process of stigmatisation at the individual and collective levels are increasingly acknowledged and investigated in agency-oriented research on stigma. This criticism is one of the major bases on which the main argument of this research is built, and I discuss it in more detail in the following sections.

- 3) Another point related to considerations about stigmatised individuals is the assumption of the stigmatised identity as central to the self-definition of the person (Link & Phelan, 2001). In this research, the differentness attributed to individuals as the basis for stigmatisation (i.e. HIV-positive status) is not regarded as constituting the 'master status' of individuals. Closely related to this point, I refer neither to a stigmatised identity nor a stigmatised group. Conceptualising 'stigmatised groups' as homogenised groups is a problematic issue, especially in the research on management of stigma. For example, according to Crocker et al. (1998), who offer a social psychological framework for the understanding of the stigmatisation process, to compare the self with the *in-group* and disidentification of the self with the *in-group* are strategies for coping with stigma. However, when HIV-related stigmatisation is considered, it can be argued that there is no single 'in-group', and moreover there are differences and conflicts between sub-groups (as in the case of the distinction between 'blameless' and 'blameful').
- 4) The criticism of the individual- (or micro-) level investigation of stigma is one of the major problematic points in stigma research. Often drawing on social psychological approaches, individualistic explanations of stigma focus primarily on the 'psychological attributes of perpetrators or targets, or inter-individual interactions between them' (Campbell & Deacon, 2006, p.412). In the field of health-related stigma, individualistic approaches have been generally based on the interactionist perspective, which focuses on labelling, and have tended to understand chronic and stigmatised illness in terms of 'personal tragedy' or 'deviance' (Scambler, 2009, pp.441-444). Early works on the investigation of HIV-related stigma were also dominated by individualistic approaches that tended to understand stigma in 'highly emotional terms - for example, as "anger and other negative feelings" toward PLHIV. Other research, on stigmatising 'attitudes', focused on the determinants of these attitudes, such as the level of knowledge

about transmission routes and negative attitudes toward groups more affected by the epidemic (Parker & Aggleton, 2003, p.15).

Consequently, the implementation of this approach in stigma reduction policies has sought to 'provide people with "the facts" about an illness or about stigmatised groups'. In relation to the management of stigma, this approach gives 'individual-level models of coping', focusing on 'individual abilities to adapt to the stress of stigma' in the process of coping (Campbell & Deacon, 2006, p.412).

Nevertheless, to criticise individualistic approaches does not mean to deny the importance of understanding the social-psychological aspects of stigmatisation. The critical point is the inability of individualistic approaches to pay attention to power relations (Campbell & Deacon, 2006, p.412), or in other words, the lack of linkage between stigma and wider macro-social inequalities (Link & Phelan, 2001).

Parker and Aggleton (2003) draw attention to another, equally important shortcoming of the individualistic approaches:

[Although the consideration of stigma as an individual process] may seem logical in highly individualized cultures (such as the modern-day USA and parts of Europe) where people are taught to believe they are nominally free agents, they make little sense in other environments. Throughout much of the developing world, for example, bonds and allegiances to family, village, neighbourhood and community make it obvious that stigma and discrimination, when and where they appear, are social and cultural phenomena linked to the actions of whole groups of people, and are not simply the consequences of individual behaviour. (Parker & Aggleton, 2003, pp.16-17)

The criticism of individualistic understandings of stigma makes sense for this research because of its both discursive and power-related approach and the characteristics of the research setting. Thus I adopt a definition of stigma that pays attention to both macro and micro social processes for 'a better understanding of individual compliance, change and resistance to stigmatisation' (Campbell & Deacon, 2006, pp.412-413).

In response to the criticisms summarised above, Link and Phelan (2001) define stigma as existing when the following interrelated components converge:

- 1) People *distinguish and label human differences*.
- 2) Dominant cultural beliefs link labelled persons to undesirable characteristics – to *negative stereotypes*.
- 3) Labelled persons are placed in distinct categories so as to accomplish some degree of *separation of 'us' from 'them'*.
- 4) Labelled persons experience *status loss and discrimination* that lead to unequal outcomes.
- 5) Stigmatisation is entirely contingent on access to social, economic, and political *power* that allows the identification of differentness, the construction of stereotypes, the separation of labelled persons into distinct categories, and the full execution of disapproval, rejection, exclusion, and discrimination.

Following this definition, the term 'stigma' is used in this research when elements of labelling, stereotyping, separation, status loss, and discrimination co-occur in a power situation that allows the components of stigma to unfold. In accordance with the discursive approach of the research, the power component of this definition is particularly important. As Link and Phelan (2001) state, when the term is conceptualised in this way, the critical issue is to understand the elements of this power structure and to ask how they are sustained.

While using Link and Phelan's (2001) definition of the term as the main conceptual model of stigma in this research, I find it beneficial to use the terms 'discrimination' and 'prejudice' when addressing specific processes in which the components mentioned in the above explained model do *not* co-occur. As mentioned earlier, 'discrimination' is used in this research when referring to the differential treatment of stigmatised individuals, as a 'consequence' of stigmatisation (Law, 2007; Mahajan et al., 2008). 'Prejudice' on the other hand, is used in this research following Phelan et al. (2008, p.365), when referring to the 'attitudinal components' of the broader process in which stigmatisation occurs as described in Link and Phelan's (2001) model.

Prejudices are defined as negative attitudes held toward a group as a whole and toward an individual mainly because of their perceived membership of that group (Crisp & Turner, 2010). Prejudices are based on the endorsement of negative

stereotypes about a group as real (Martin et al., 2008, p.1). Conceptual models of prejudice that are concerned with social-cognitive explanation of the formation of prejudices proposed some factors that foster and maintain prejudices, such as personality and individual differences, group conflict, social categorisation and social identity (Phelan et al., 2008; Crisp & Turner, 2010; Dovidio et al., 2010).

Although the concept of prejudice is narrower in scope than the concept of stigma, because of its specific focus on the attitudes of 'perpetrators', the conceptual models of stigma and prejudice are considered in this research as complementary rather than in contradiction (Phelan et al., 2008). Exploring the commonalities and distinctions between these two sets of models, Phelan et al. (2008) conclude that the conceptual models of stigma and prejudice do not differ much in terms of the 'functions' of stigma and prejudice. Phelan et al.'s (2008, p.360) review suggests that while stigma models focus more on the 'targets', prejudice models place more emphasis on the 'perpetrators', exploring the stereotypes, expectations, identities, emotions and personalities which play important roles in the formation of their attitudes towards the stigmatised individuals. Therefore, I consider beneficial to use the conceptual framework of prejudice when addressing the attitudes of perpetrators, as well as individual discriminatory beliefs occurring outside direct social interactions (*ibid*, p.360).

According to Parker and Aggleton (2003), the Foucauldian approach discussed in the previous section can provide an appropriate perspective from which to understand HIV-related stigma in broader power structures. Although Foucault does not explicitly express a concern with the concept of stigma, his works highlight the role of the cultural construction of difference in the establishment and maintenance of social order. In addition to the social construction of difference, stigma should also be analysed in relation to broader systems of social inequality (*ibid*, p.17). When stigma is understood in this way, the internalisation of or resistance to it should also be understood in relation to broader social inequalities and power relations. As Parker and Aggleton (*ibid*, p.18) state:

To untie the threads of stigmatization and discrimination that bind those who are subjected to it, is to call into question the very structures of equality and inequality in any social setting – and to the extent that all known societies are structured on the basis of multiple ... forms of hierarchy and inequality, to call this structure into question is to call into question the most basic principles of social life.

This affirms that, beyond being a personal reaction the resistance of stigmatised individuals to the process of stigmatisation can be regarded as the construction of a social identity that confronts, in a variety of forms and degrees, a system of power and inequalities within which the identity is subjected to control at the same time. This is why this research introduces the concepts of patriarchy, medical discourse and intersectionality (explained below) in the investigation of the potential of PLHIV to challenge stigma.

3.1. Intersectionality

An intersectional approach is used in this research as both a theoretical and a methodological tool. Theoretically, it is considered parallel to the understanding of HIV-related stigma as 'layered' and related to multiple social inequalities. The methodological implications are explained in the 3rd Chapter.

The intersectional approach takes into consideration multiple, intersecting sources of subordination/oppression, and is based on the premise that the impact of a particular source of subordination may vary depending on its combination with other potential sources of subordination (Denis, 2008, p.677). The approach is based on the idea that gender, race, class and other forms of social stratification are closely intertwined and need to be studied in relation to each other. The idea is rooted in the standpoint and black feminism of the 1980s and 1990s, which challenged the homogenised concept of gender identity and pointed out the differences among women. As a theoretical outcome of this idea, the assumption that 'each discrimination has a single, direct and independent effect' has been challenged (Choo & Ferree, 2009). The understanding of intersecting social situations and structural forces has been conceptualised in different ways, such as 'axes of oppression' (Crenshaw, 1997), 'matrix of domination' (Collins, 2003) or 'complex inequalities' (McCall, 2005). Criticising the 'mathematical metaphors' and 'additive' understandings of experiences of different categories of social difference, West and Fenstermaker (1995, p.9) offered a conceptualisation of 'difference' as 'an ongoing interactional accomplishment'. The 'non-additive way of understanding social inequality' is conceptualised by Crenshaw (1989, cited in 1997) as 'intersectionality'. Overall, the conceptual framework of the intersectionality approach argues that different axes of social identity coalesce to shape individuals' experiences.

The concept of intersectionality has been addressed in health research especially around the topic of health disparities. In this approach, the main focus is on understanding 'the ways in which gender, race, and class relations intertwine and are expressed in disparate chances for health, illness, and well-being' (Mullings & Schulz, 2006, p.6). An application of this approach in HIV/AIDS research is the consideration of the intersections of multiple social identities in affecting individuals' 'vulnerability to HIV and their access to treatment, care, and support' (AWID, 2004; Mullings & Schulz, 2006; Weber, 2006).

Another use of the intersectional approach related to the study of stigmatisation is the application of the concept of 'intersectional stigma', which considers HIV-seropositivity status as *one* of the multiple and overlapping positions of oppression that affect the experience of the stigmatised. In her work on political participation by HIV-positive women, Berger (2004) considers the political participation of her research subjects, who are lower-income women, who use crack cocaine and have a commercial sex background, to challenge HIV-related stigma in relation to the intersection of their multiple stigmatised social locations. According to Berger, 'what makes their experiences different from other counterparts of people with HIV is the influence of intersectional stigma' (ibid, pp.3-4). Because these women were already socially positioned as 'deviant women', the effect of the HIV was to dramatically add to and combine with their existing social marginality. According to the intersectional approach, the combination of multiple oppressions can create new and often unrecognised forms of discriminatory encounters in everyday life. Accordingly, Berger concludes that 'HIV acted as a catalyst which made women recognise and act on other aspects of stigma in relation to their identity' (ibid, pp.18-19).

In terms of considering HIV-related stigma as overlapping with other sources of exclusion, marginalisation or discrimination in society, the concept of intersectional stigma is also parallel to the concepts of 'structural violence' and 'layered stigma' (also referred to as 'multi-layered' or 'double stigma'). According to Castro and Farmer (2005, p.54) structural violence, which is defined by large-scale social forces such as racism, sexism, political violence and poverty, affects the experience of stigma. 'Layers of stigma' on the other hand are defined as the 'co-occurrence of multiple stigmatising attributes'. Accordingly, the stigma of HIV is seen as 'layered with other stigmas, such as those associated with the routes of transmission (e.g.,

sex work and injecting drug use) and personal characteristics (e.g., race, religion, ethnicity and gender)' (Reidpath & Chan, 2005, p.425); that is to say, the social positions of PLHIV in other social divisions in society shape the extent and type of stigma that they face.

However, within the conceptualisation of layered stigma it is also argued that people who are already socially excluded have fewer resources with which to cope with the consequences of stigma (DFID, 2007). For example, Campbell and Deacon (2006, p.414) state that '[in the UK] whilst the experiences of gay white men with AIDS are extremely negative, the experiences of black African migrants with AIDS are even worse in the face of additional layers of marginalisation'. But as seen above, Berger's study shows that the intersection of multiple stigmatised locations can sometimes create a new experience that mobilises the individual to actively confront the process of stigma.

In this research, an intersectional approach is used to analyse and demonstrate the complexity and diversity of PLHIV's experiences and management of stigmatisation. It is considered as a useful conceptualisation also to emphasise that there is no single group identity in terms of 'being' HIV-positive and experiencing HIV-related stigma. Instead of the narrower definitions of 'intersectional stigma' and 'layered stigma', the above explained broader conceptualisation of intersectionality is adopted in this research, since the multiple social locations of PLHIV, which intersect and affect the individual experience, are not necessarily their 'stigmatised' identities. Adopting an intersectional approach, I see the impact of HIV in PLHIV's lives and their potential to resist or challenge HIV-related stigma as varying, depending on the combination with their other social identities and structural forces affecting their lives. From this perspective, I investigate the ways in which different dimensions of individuals' lives, when combined with the HIV-positive status, can constrain or enable the individuals to challenge stigma.

3.2. HIV-related stigma

Data from several countries show that stigma has consequences in various forms in various settings as summarised below (based on Ogden & Nyblade, 2005; DFID, 2007; UNAIDS, 2009²):

- 1) Physical forms of stigmatisation: physical isolation (such as refusing to share living, sleeping and eating areas and utensils, refusal to be in physical proximity in public places, separation from children, abandonment by family) and physical violence (including arrests and physical abuse by the police)
- 2) Social forms of stigmatisation: social isolation (such as the reduction of daily interaction, exclusion from family and community events, loss of social networks), voyeurism (increased visits from neighbours with the aim of mocking the individual or reporting back to the community), loss of social identity and agency (such as being regarded as having no future, being associated with 'social evils', being expected to adopt a new role teaching others about HIV and disclosing status, loss of power and respect in the community, loss of right to make decisions about own life, loss of marriage and childbearing rights and opportunities)
- 3) Verbal forms of stigmatisation: gossip, taunting, expressions of blame and shame, labelling
- 4) Institutional forms of stigmatisation: loss of livelihood (such as loss of employment, of customers and business and denial of loans, scholarships, visas), loss of housing, differential treatment in educational institutions, healthcare settings and public spaces, stigmatisation in media and public health messages and campaigns, unequal consideration in government policies and laws

Although the stigma attached to HIV is universal (Herek, 1999; UNAIDS, 2006), its level, form and specific targets vary across settings. Apart from pre-existing cultural prejudices, other factors affect stigmatising attitudes towards PLHIV. Lower levels of stigmatising attitudes are documented in younger individuals and in those higher levels of education and better knowledge about HIV transmission. Personal contact with someone living with HIV and 'more favourable attitudes' toward homosexual

² Data displayed in these sources contained results of research conducted in Vietnam, Senegal, South Africa, Indonesia, India, Nigeria, Lesotho, Jamaica, Botswana, Ethiopia, Tanzania, and Zambia.

men are found to be related to lower levels of HIV stigma (Herek, 1999, pp.1107-1109). Local characteristics of the epidemic can also affect HIV-related stigma. Although stigmatisation exists in both high and lower-prevalence settings (DFID, 2007, p.15), the routes of transmission can affect which populations are most targeted by stigma (Herek, 1999, p.1107). The transformation of HIV/AIDS from a fatal disease to a chronic health condition with the availability of ART, it has been argued to decrease stigma (Castro & Farmer, 2005, p.57). However, results of studies investigating the effect of taking ART on the experience of being stigmatised are contradictory (Alonzo & Raynolds, 1995; Makoae et al., 2009). PLHIV's greater participation in prevention programmes has also been reported to have a beneficial impact on reducing stigma in both western and non-western countries (Finn & Sarangi, 2009, p.48).

3.3. Stigma management

In this section I discuss the ways in which stigmatised individuals deal with the effect of stigma, with a focus on empowering stigma-management strategies and a review of the problematic points of the conceptualisation of HIV-related activism. To begin, the use of the term 'stigma management' in this research should be clarified to demonstrate the difference between the terms 'coping' and 'management' in the general literature on stigmatised individuals.

'Coping strategies' refer to strategies adopted to avoid the negative consequences of being stigmatised. In other words, the primary motive for using coping strategies is to protect oneself from the effects of stigmatisation (Shih, 2004, pp.2180-183). The 'coping model' has been criticised for picturing stigmatised individuals as passive recipients of the stigmatising social environment and ignoring more positive, empowering strategies. This model was the dominant understanding in the early literature on stigmatised individuals. Allport (1958) for instance, enumerates various strategies used by 'victims' of stigmatisation, 'to defend their ego' (Allport, 1958, pp.139-140).

Similarly, Crocker et al. (1998, pp.521-531), who offer one of the standpoints that are frequently referred to for understanding of the experience of being stigmatised from a social psychological perspective, mention strategies used by stigmatised individuals to 'manage the threats to self-worth'. For example, individuals can make different attributions to prejudice and discrimination, such as linking most of their

negative experiences to prejudice and discrimination or denying the effects of prejudice and discrimination. Secondly, they may protect their self-esteem by making favourable comparisons between their personal or group identity and those of others. Thirdly, they can adopt strategies of psychological disengagement from and disidentification with their group or from the negative consequences of being stigmatised. Crocker et al. (1998, p.531) state that these strategies are also used by nonstigmatised individuals in response to self-threats that they experience, and are adoptive strategies.

Other frequently used categorisations of coping strategies, as suggested by Snow and Anderson (1987, cited in Kusow, 2007), include 'covering' (attempting to conceal signs commonly considered as stigma symbols), 'distancing' (disassociating from the roles, associations, and institutions that may be considered as stigmatising), 'compartmentalisation' (living in two different worlds where the identity is concealed in the one and open in the other) and 'embracement' (expressive confirmation of the social roles and status associated with stigma).

From the coping perspective, the strategies used by PLHIV as defence mechanisms can be concealment of HIV status, avoidance of situations and environments where their HIV status may be identified (Alonzo & Raynolds, 1995, p.313) and withdrawal from social interactions or 'retreatism' (Taylor, 2001, p.795).

However, studies have also demonstrated other strategies such as 'educating others about AIDS, developing nonstigmatising theories of illness causation', working for community organisations, speaking for the media, becoming resources for acquaintances (Weitz, 1990), or political activism in a broad sense (Taylor, 2001, p.795). To understand these more positive, empowering strategies, the term 'management' is preferred to 'coping'. The term 'management', according to Mason (2001, p. 37), 'involves strategies of self-regulation, as well as a sense of command, stewardship, and the manipulation of events that comes with being in a position that demands, and allows, this kind of control.' Thus this term hints at the agency of subjects who not only control themselves in the face of danger but also 'take control' of certain situations (Mason, 2001, p. 38).

Beyond taking control of or making changes to their lives or social environment, studies also reveal that people who are stigmatised at one stage of their lives can

later construct new, positively valued social identities (Bell, 2000, p.192). According to Parker and Aggleton (2003, p.19), the construction of social identities, that gained central importance in social theory for the understanding of 'contemporary experience' in today's global world, can have a key role in the conceptualisation of both the experience of and resistance to stigmatisation. Correspondingly, this research understands empowering stigma management strategies in relation to the construction of valued social identities.

Goudge et al. (2009, p.103) demonstrates how the ability to resist stigma derives from a new identity with a social value or meaning. According to Goudge et al. (2009, pp.100-102), PLHIV can respond to stigma in varied forms including 'passive acceptance', 'strategic avoidance' (concealment of identity in, or avoidance of, some contexts), 'resistance thinking' (resistance to the idea of fault or responsibility), 'active resistance' (revealing HIV status to some people to confront negative labelling) and 'activism' (being publicly open about the status; seeking public discussion or confrontation). The study shows that individuals who are able to find a new, meaningful social role in their lives such as child care, counselling and supporting their family are more likely to adopt resistance strategies than to use avoidance or passive strategies. Goudge et al. (2009, pp.102-103) also state that finding new social roles definitely requires social support (within the family and in the broader social arena), as well as financial and physical resources.

Social support is one of the most important factors that enable PLHIV to resist HIV-related stigma. Apart from immediate family and friends, institutions such as non-governmental organisations (NGOs) and religious institutions can create spaces for resistance and social change (Campbell & Deacon, 2006, p.414). Campbell and Deacon (2006, pp.415-416) also mention the possible intervention of an 'external change agent' for facilitating resistance strategies, who can work with members of stigmatised communities to develop skills, support networks and resources. This kind of intervention may be necessary to facilitate resistance, especially when the stigma overlaps other forms of social devaluation and constrains the possibility that resistance to stigma can emerge spontaneously and individually. Furthermore, in some cases different marginalised groups (even very dissimilar ones) can collaborate to share similar strategies (Howarth, 2006, p.448), contributing to the formation of a ground for collective resistance to stigma.

A crucial point about resistance to stigmatisation is related to improvement in health status. Before effective ART became available, Alonzo and Raynolds (1995, p.313) drew attention to the relationship between the ‘trajectory’ of HIV/AIDS and the trajectory of stigmatisation. They considered HIV/AIDS as a continuum from a healthy immune system to a severely-damaged health system. According to them, in the final, ‘manifest’ phase of the disease, as the individual experiences severer bodily changes, the stigma expands and becomes the individual’s ‘master status’ (Alonzo & Raynolds, 1995, p.313). In an era of ART, in which HIV is defined as a chronic illness it is not possible to conceptualise the relationship between the health status of the HIV-positive person and the stigmatisation that they experience in terms of a continuum. Yet the recovery of health on ART is important for the construction of a new identity, especially if the individual has had a ‘near-death’ experience (Robins, 2005), which is perceived as a key ‘turning point’ in their lives (Kremer et al., 2009, p.374; Baumgartner & David, 2009. p.1737). However, it should be noted that the effect of the recovery of health on the construction of a new identity cannot be considered a relevant factor for people who resisted the treatment, began the treatment before getting physically ill, or were active even when ill.

Apart from these two prominent factors related to the construction of a new identity that can challenge stigma, the literature also demonstrates some problematic issues for consideration when defining and analysing empowering stigma-management strategies. The linear understanding of empowerment leading to activism, some interpretations of activist participation of women and homosexual men and the possible re-stigmatising effect of emphasising ‘the positive HIV-positive’ identity are mentioned below.

Goudge et al.’s (2009) study shows that stigma management strategies cannot be conceptualised as a one-way continuum (i.e. from passive to active) as individuals often switch between various ranges of strategies. For this reason it is important to avoid conceptualising activism as the final stage of the empowerment process. Based on a study of the participatory activities of an HIV prevention project for sex workers in India, Cornish (2006) offers a critique and a conceptualisation of participation and empowerment in HIV/AIDS activism. According to Cornish (2006, p.304), defining empowerment as a process by which individuals are becoming able to participate to the community and to produce change is inadequate unless it

recognises 'the multiple and contradictory nature of the powers and disempowerments which people experience and enact'. She suggests that people may be empowered in one specific domain of action while being disempowered in another. For instance a person might be active in lobbying and at the same time unable to negotiate with her partner about safe sex practices. Cornish's suggestion is to ask what 'concrete domain of action' the person is empowered to engage in. Her approach does not conceptualise empowerment as a mental state, and limits it to the ability to take concrete action; but it makes it clear that power is not 'measurable on a linear dimension' and that different actions may necessitate 'qualitatively distinct forms of power' (Cornish, 2006, p.305).

One linear approach to the explanation of activism can be seen in Brown et al.'s (2004) accounts of the emergence of health-related social movements (HSMs). Brown et al. state that HSMs are based on 'politicised collective illness identities'. A 'collective illness identity' can emerge when people living with an illness develop a 'cognitive, moral, and emotional connection with other illness sufferers'. In addition, for a 'politicised' collective illness identity to form, first, the illness must be linked to a broader social critique that views structural inequalities and the uneven distribution of social power as responsible for the causes and/or triggers of the disease. According to Brown et al., at this stage people living with the disease no longer focus primarily on access to treatment, support groups and expanded research and instead focus on seeking structural explanations and the requisite structural changes (Brown et al., 2004, pp.55-60). This understanding seems to assume that every participant engaged in HIV/AIDS activism is primarily concerned with challenging broader power relations. However, in most settings where access to treatment and support is not readily available they may constitute the main focus of struggle. Furthermore, the main motive of an individual to engage in activism may be more related to self-management than to seeking structural changes. Similarly, Robins (2005, p.11) states that conventional social movement theories that 'focus on rational and instrumental behaviour and the political process of mobilisation' offers a limited perspective for understanding engagement in HIV/AIDS activism. According to Robins, commitment to a 'new life' and activism can be perceived by PLHIV as a 'quasi-religious' experience that leads to radical transformation of identity (Robins, 2005, p.1).

Activism also needs to be questioned as a normative concept. The negative policy implications of the approaches that see stigmatised individuals as passive victims were mentioned above. However, there may be some problematic implications of overemphasising the 'positive HIV positive identity'. Finn and Sarangi (2009) offer a critical review of the 'positive speaking' strategy, which is increasingly used in HIV/AIDS campaigns for stigma reduction or as a means of support for PLHIV. This strategy involves PLHIV's participation in prevention and support programs, openly speaking about themselves and their experiences with a focus on positive aspects. PLHIV are represented in these speeches in an idealised form: healthy, perfectly fulfilling social functioning, publicly open while at the same time they are survivors. Finn and Sarangi state that this 'can be seen to have significant (re)stigmatizing effects by way of ambivalent and hyper-real configurations of HIV "positive" identity and life' .Because the positive identity is represented as the PLHIV 'responsibly managing' their health and social life, these representations reaffirm irresponsibility, blame and stigma on a new basis: the inability to 'successfully manage and live with HIV in survivor-like terms' (Finn & Sarangi, 2009, p.59). In resource-stretched settings, 'the ability to even sustain life is therefore very much in question ... let alone being able to demonstrate responsibly a 'normal' and 'heroic' identity' (Finn & Sarangi, 2009, p.62).

This analysis represents a case in which a new identity is offered to PLHIV as a template (Finn & Sarangi, 2009), prepared by what Howarth (2006) terms, 'external change agents'. Therefore when analysing resistance strategies it is important to question the resources that individuals use when constructing a new identity and to ask whether they attribute a superiority or generality to their new identities.

3.4. Chronic illness self-management

When stigma is associated with a disease, stigmatised persons' responses are related to a set of strategies used for managing identity in an altered-health situation. The literature on chronic illness self-management provides rich data and perspective for the analysis of stigma-management strategies, since the self-management of chronic illness also involves a search for meaning (Goudge et al., 2009) that contributes to the construction of identity.

The management of identity when living with a chronic illness has been conceptualised in the psychology literature around the term 'coping'. Coping

strategies are defined as 'a wide range of cognitive, emotional and behavioural strategies deducted at both external stressors and internal demands and needs'. The psychology literature on coping emphasises that a coping strategy should not be confused with its outcomes; rather it should be seen as the 'moderator' of an outcome (Livneh & Martz, 2007, pp.4-10). Several often inconsistent efforts have been made with the aim of explaining what 'successful' coping means. A number of categorisations have been put forward, often with a dichotomy between categories. Some of the categorisations used in the literature on coping with chronic illness are 'mature/immature defences', 'coping/defending', 'task-focused/emotion-focused' coping, 'disengagement/engagement' coping (Livneh & Martz, 2007), acceptance/denial (Kübler-Ross, cited in Telford et al., 2006) and approach behaviours/avoidance behaviours (Miller, 1989, pp.24-25). Dichotomic understandings of coping strategies that refer to successful and unsuccessful coping have been criticised for creating a basis for labelling individuals in terms of being unsuccessful in coping with the illness (Telford et al., 2006, p.458) and for describing the coping process as a 'phased process in which the person follows a predictable trajectory' (Paterson, 2001, p.22).

The concept of coping itself has also been challenged, in a similar way as it has been in the stigma management literature. According to Kralik et al. (2004), 'coping' defines processes that do not refer to control or mastery of the individual such as tolerance, minimization, acceptance or ignorance. The term 'self-management', on the other hand, refers to the agency of individuals in creating 'order, discipline and control in their lives' (Kralik et al., 2004, p.260). An agency-oriented self-management (or self-agency) model contains individuals' efforts to take control of their own life, such as identifying own responses to illness instead of strictly following health professionals' orders; planning daily routines and developing alternative lifestyles (Koch et al., 2004, p.489). Self-management is seen as central to the 'transition' process in which people living with a chronic illness 'incorporate the consequences of illness into their lives' (Kralik et al., 2004, p.259).

When comparing the self-management of other chronic illness with that of HIV, the stigma is considered among the most important constraints to fulfilling the above-mentioned tasks in terms of preventing disclosure, hindering the incorporation of HIV status into the identity and threatening to control one's life (Paterson, 2001; Swendeman et al., 2009; Baumgartner & David, 2009). Uncertainty also appears to

challenge self-management as it does managing stigma. On the other hand, the most-mentioned factors that facilitate the tasks of self-management are the recovery of health – as in the case of managing stigma (Kremer et al., 2009; Trainor & Ezer, 2000; Robins 2005; Russell & Seeley, 2009) – internal locus of control (Schüssler, 1992, Russell & Seeley, 2009), meaning of illness as integrated in the self concept (Schüssler, 1992) and spirituality (Robins, 2005, Russell & Seeley, 2009; Kremer et al., 2009, p.374).

4. Conclusion

Resistance strategies are understood in this research - with regard to both managing stigma and self-managing the disease - as related to the construction of valued social identities. I take into account that resistance to stigma in one aspect or context do not necessarily mean being empowered in all possible aspects and contexts of resistance and control. Resisting or challenging stigma is not defined in this thesis as limited to ability to 'act'; but questioning the basis of stigmatization, such as 'resistance thinking' (Goudge et al., 2009) is also understood as asserting agency in the face of discursive basis of HIV-related stigma.

Finding new meanings in life for constructing a new identity is seen as a motive behind activism; thus, activism is not defined solely in terms of explicit and rational concern with challenging power relations in a way that is suggested in the HSM literature. As I stated earlier, resisting stigmatization is inevitably related with resisting broader power relations. These two arguments do not contradict each other; since the discursive approach of the thesis claims that power is diffused, thus can be resisted in micro interactions in everyday life, as well as in decisions related to one's own body.

When seeking to understand the possible ways in which PLHIV resist or challenge stigma, I take into account the discussions around the agency of individuals in the face of medical and patriarchal discourses that exercise control over them. As represented in the research questions, non-conformity to patriarchal norms of femininity and hegemonic masculinity are considered as a significant factor, since it can contain the potential for the individual to question an important basis of the HIV-related stigma. With regard to the resistance to medical discourse, the perceived responsibility for being infected and the feeling of uncertainty about the

knowledge on and the treatment of HIV are considered in this thesis among the factors that can be influential to individuals' reactions to stigmatization.

Chapter Three: Methodology

1. Introduction

This research is qualitative and interpretive, since it aims to understand the social construction and the perceived meanings and experiences of the process of stigmatization. The broader aims and questions that guided this thesis started to emerge throughout my academic and voluntary work experience in the field of HIV/AIDS in Turkey since 2006. Thus the research questions presented in Chapter 1 were formed prior to conducting fieldwork and were based on both the literature and my personal observations. I conducted the fieldwork between February 2010 - February 2011 in Ankara and Istanbul. My experiences in the field, the conceptual framework, the research design, preliminary analysis and the emerging themes from the field informed each other throughout the fieldwork.

In this chapter I provide an account of the epistemological approach I take in this thesis and comment on their methodological implications for this research. It is followed by the introduction to the research design, including the sampling procedure and the choice of research settings and methods. In the third subsection on the methods of data generation and analysis I describe in detail the methods I used and reflect on the whole fieldwork process. This chapter ends with a subsection on ethical considerations, which is a very important and an ongoing part of this thesis.

2. Epistemological Approach

This research is based on the claim that social reality is a domain of power relations that are always gendered and that lead to oppression of individuals, but at the same time are open to change by human actors, who are creative beings. This understanding of social reality is based on the social constructionist and feminist epistemologies. The conceptual framework that these approaches provide to this research is explained in the previous chapter. Here, I focus on the understanding of social reality and knowledge that is claimed by these approaches, in order to explain why it is suitable for this research. I mention the problematic issues that arise from these approaches and state their implications for this research. The key points mentioned are the existence of pre-given categories (such as pre-social, biological body), the creative role of actors, the weight of women's and men's

experiences in the process of knowledge generation, the relationship between the researcher and the research subjects, and the question of objectivity/subjectivity.

As Guba and Lincoln (1994, p.108) state, research is guided by the answers that the researcher gives to the interrelated questions of ontology, epistemology and methodology. Therefore to explain the epistemological approach of the research it is necessary to begin by answering the ontological question: 'What is the nature of social reality that we are seeking to know?' Yet when it comes to social constructionism, the distinction between the answer to this question and the answer to the epistemological question: 'What is the nature of the relationship between the knower (or would-be knower) and what can be known?' (Guba & Lincoln 1994, p.108) seems to be blurred.

Social constructionist ontology rejects the existence of pre-given categories of social phenomena that are independent of the construction of human actors (Bryman, 2008, p.19). In this sense, it may seem that this is 'the conflation of the ontological with the epistemological' (Williams, 1999, p.805), because if there is nothing as a 'being' without knowledge about it, the nature of social phenomena is simply the constructed knowledge about social phenomena.

In the field of health and illness, there is a debate between the social constructionist approach – also labelled the discursive or representational (Joffe, 1997) – and the phenomenological approach (Williams, 2006) – also termed material (Joffe, 1997) or non-constructionist (Turner, 1992 cited in Williams, 1999). While social constructionism defends body, health and illness as social constructs, the phenomenological approach claims that there are material or non-discursive aspects of the body, health and illness that 'exist independently of and prior to the discursive level' (Joffe, 1997, p.134). In this sense, the constructionist approach is criticised for not giving enough consideration to the 'extra-discursive' aspects (Williams, 2006, p.9) or 'the fleshy matters' of the lived body (Gabe et al., 2006, p.75). In other words, this is criticism about reducing the biological body to what is known about it (Williams, 1999, pp.805-806) or 'to the social, *qua* power/knowledge' (Williams, 2006, p.9; original emphasis). Therefore there is a call in the literature for an approach that incorporates both social *and* biological facts (ibid, p.11; original emphasis).

I agree that this call is particularly important in the field of chronic illness, since the self-management of chronic illness, as mentioned before, involves a change in social identity which is 'reciprocal to bodily experiences' (ibid, p.11). In other words, biological and physical facts are important for understanding the experience of chronic illness, in terms of both restricting the actions of individuals and as indicators for the construction of identity (Gabe et al., 2006, p.74). Therefore an approach that conceptualises the body 'as both a living set of animating forces and principles and a (legitimate) disciplinary form of knowledge' (Williams, 2006, p.22) is needed. Despite the fundamental difference between the ontological positions mentioned above, it is still possible to take this kind of position.

It is suggested in the literature that 'critical realism' can be an appropriate position from which to take social and biological facts into equal consideration (Williams, 1999; 2006). However, this research, which aims to link the bodily experience of illness and stigma to broader power relations, cannot adopt a critical realist approach, mainly because critical realism sees constructed and non-constructed aspects as separate domains of social life (Williams, 1999). This research does not deny the importance of the physical 'realities' related to HIV/AIDS, but claims that these make sense to individuals, not as pure physical facts but through the meanings attributed to them; in other words, through a 'discursive frame of reference' (Williams, 2006, p.9).

Another consideration about the social constructionist rejection of pre-existing categories as the subject of knowledge relates to the application of an intersectional approach in this thesis. Since the multiple social positions that an individual occupies are important for an intersectional approach, these social positions will need to be defined in terms of categories. Although some state that the rejection of the existing categories poses a problem in conducting empirical intersectional research (Hancock, 2007, p.66), it is not necessary to assume social categories as predefined and static in order to conduct intersectional study. A constructionist intersectional approach can work with categories as long as it reveals the ways in which these categories are constructed, reproduced and transformed, in specific contexts and by the actors themselves.

An important criticism about social constructionism that is relevant to this study is the understanding of 'oversocialised' individuals (Cockerham, 2001, p.18), leading to overemphasis on the control exercised over individuals. Social constructionism in

general does not contribute to understanding the active role we play as individuals in affecting the social control exercised over us. In this sense, a distance is kept from the dominant view of the passive stigmatised individual and social constructionist 'pessimisms about de-stigmatisation' (Gabe, 2006, pp. 71-72). This thesis considers the individual body not only as a 'surface for the inscription of discourses' but also as an 'agent' in itself (Kuhlmann & Babitsch, 2002, p.439).

The equally important epistemological approach in this research is based on feminism. This is a feminist study because it claims that human experience is always gendered and cannot be known without taking into account different constructions of femininities and masculinities. In this sense, the feminist approach here is different from both modernist (liberal, radical, socialist and Marxist) and some forms of post-modernist feminism – not in terms of the views about women's emancipation but in terms of its ontological and epistemological positions.

The ontological claims of feminism are that both the natural and the social worlds are social constructions, constructed differently by people who, in different social locations, have had different life experiences (e.g. men and women) (Blaikie, 1993, p.100). This research claims that in addition to the differences between men and women, differences 'among' women and men are also important in the construction and understanding of social reality. The approach is post-structuralist in the sense that it questions the very category of 'woman', sees gendered identities and bodies as constructions of discourse, and emphasises the agency of gendered identities and bodies. Unlike standpoint feminism, which aims to place women's experiences at the centre of the research process (Brooks, 2007, p.56), this research affords importance to the construction of both femininities and masculinities and claims that the experience of subordinated men is equally important.

Feminist epistemology has methodological implications on the relationship between the researcher and the research subjects. Denzin (1997, p.273) argues that feminist methodology requires that the researcher 'step into the shoes of the persons being studied'. This point is also questionable, as mentioned in contemporary feminist critiques. For example, Young (1997, cited in Edwards & Mauthner, 2005) argues for an 'asymmetrical reciprocity' between the researcher and the research subjects which refers to the acknowledgement that there are aspects of another person's position that the researcher cannot understand, 'yet [is] open to asking about and listening to'. In this sense, while the research aims to

understand the experiences of PLHIV from their perspectives, this understanding may be limited, because of the different social positions we occupy.

An important implication of the constructionist and feminist epistemologies is related to objectivity. Both approaches reject the view that there is an objective truth about social reality to discover (Crotty, 2003) independent of the beliefs and behaviour of the researcher (Bryman, 2008). The introduction of this subjective element into the analysis does not devalue objectivity but rather insists that reflexivity about the researcher's own position is vital (Harding, 1987, p.9).

3. Research Design

In line with my research objectives presented in Chapter 1 and the epistemological approach presented above, the research has been designed towards generating data available to explore the social representations of HIV/AIDS and the experiences and perceptions of PLHIV on HIV-related stigma. Accordingly, I aimed at gathering detailed personal accounts of PLHIV and the perspectives of a range of different actors in the field of HIV/AIDS in Turkey. Table 1 presents the type of data I needed for addressing each research question and the chosen methods of data generation.

Table 1: Required data and methods of data generation for the key research questions

Main research question, key questions and sub-questions	Data needed	Method of data generating
<p>How do people living with HIV in Turkey react to, resist or challenge the process of stigmatization?</p> <p>What are the key discourses framing the social construction of HIV/AIDS in Turkey?</p> <p>How is HIV constructed and addressed at state and civil society levels?</p> <p>What is the role of the medical profession in shaping social construction and policy of HIV/AIDS?</p> <p>How does patriarchal discourse, embedded in traditional and religious norms, influence the construction of HIV/AIDS-related discourses?</p> <p>Which socio-political conditions of Turkey affect the role of medical and patriarchal discourses in shaping HIV related stigma?</p>	<p>Official policy documents and statements related to HIV/AIDS, sexuality, sexual and reproductive health, regulation of sex work, and education related to HIV/AIDS.</p> <p>Medical explanations about HIV/AIDS that are disseminated to public in the forms of campaign posters, brochures, or educational materials.</p> <p>Documents and statements of NGOs.</p> <p>Statements, evaluations and reflexive accounts of key actors related to HIV/AIDS.</p> <p>Reference to idealized forms of femininity and masculinity and emphasized “scientific facts” in above mentioned documents and statements.</p> <p>Representations of HIV/AIDS in the media.</p>	<p>Review of the current and historical policy documents and implications of the policies and activities maintained by the official institutions and other key organizations</p> <p>Identification of the main documents and statements and analysis of how idealized norms of femininity and masculinity are constructed and how medical explanations are used in these documents and statements.</p> <p>Semi-structured interviews with key informants.</p> <p>Observations in related meetings, conferences, network activities.</p>

Table 1- continued

Main research question, key questions and sub-questions		Data needed	Method of data generating
How do people living with HIV in Turkey react to, resist or challenge the process of stigmatization?			
How is the process of stigmatization experienced and perceived by people living with HIV?	<p>In what forms and in which contexts do PLHIV experience stigma?</p> <p>What are the factors that differentiate the experience (felt and enacted) of stigma?</p> <p>How are the meanings attributed by PLHIV to HIV/AIDS shaped through the process of stigmatisation?</p> <p>How and in what forms is internalised stigma formed?</p>	<p>Narratives – stories, anecdotes, reflexive accounts – of PLHIV about their experiences and perceptions of HIV-related stigma and of other sources and forms of stigmatization, subordination or marginalization.</p> <p>Detailed personal accounts on the meanings attributed to HIV; its implications on their lives; the changes they made or wanted to make in their lives to manage their health condition.</p>	<p>Biographical narrative interviewing</p> <p>Observations</p>

Table 1- continued

Main research question, key questions and sub-questions	Data needed	Method of data generating
<p>How do people living with HIV in Turkey react to, resist or challenge the process of stigmatization?</p> <p>What are the constraining and enabling factors for people living with HIV to resist or challenge stigma?</p>	<p>What are the strategies developed by PLHIV to manage physical health, social relationships and social identity?</p> <p>What are the ways in which PLHIV assert agency in managing physical health, social relationships and social identity?</p> <p>What are the ways and forms of construction of politicised illness identities and political activism?</p> <p>What factors influence the construction of management strategies?</p> <p>(the roles of intersectionality, perceived responsibility, gender nonconformity, an altered health status, compliance with medical knowledge)</p>	<p>Narratives of people living with HIV about the ways in which they manage or aim to manage the consequences of stigmatization; the parts of their lives that they are or feel to be able to control; the motives beyond taking or avoiding a particular action related to HIV/AIDS.</p> <p>Narratives on their experiences and perceptions of stigmatization, subordination or marginalization based on different sources other than their HIV status.</p> <p>Narratives, reflexive accounts and argumentations on subjective gender identity.</p> <p>Narratives and personal accounts on their experiences related to the altered health condition and their relationship between different actors and institutions for managing the health status.</p>

The rationale and the procedure of each method of data generation mentioned in the table are explained later in this chapter. In the first place I state the theoretical background of the sampling procedure, the initial sample design and the actual sample of the research.

The primary participants of the research are women and men living with HIV. The sampling procedure was purposive, based on an intersectional approach, which states that the experience and management of stigma differ according to the individuals' multiple social locations. I anticipated that the effect of the HIV-positive status on the stigmatization of the already stigmatized identities and the stigma management strategies developed by those individuals to be different. Therefore, I considered having 'an already stigmatised identity' as one axis of difference in the sample design. Involvement in sex work, intravenous drug use and sexual minority status have been considered as sources of stigmatised identity prior to HIV. I called this group of participants the 'Sample Group A'. The second, 'Sample Group B' was aimed to be consisted of an approximately the same number of individuals who did not belong to any of the three categories mentioned above. In total, I planned to reach approximately 24 people living with HIV. I aimed to maintain the balanced number of women and men in each of the groups.

In the purposive sample design presented below in Table 2, my aim was to recruit equal numbers of participants who were involved in sex work, IV drug use and belonging to a sexual minority group.

Table 2: Purposive Sample Design (March 2010)

	GROUP A			GROUP B	TOTAL
	Sex worker	IV drug user	Sexual minority		
Female	3 – 5	2 – 3	2 – 3	5 – 7	12 - 14
Male	-	2 – 3	2 – 3	5 – 7	9 - 13
Total	3 – 5	4 – 5	4 – 5	10 - 12	21 - 27

The targeted sample size was reached. I conducted interviews with 24 PLHIV as the main participants of the research. As I explain later in this chapter, the composition of the sample is slightly different than anticipated due to the difficulty in reaching female sex workers, HIV-positive individuals with IV drug use history and women living with HIV in general. In addition, the life stories of four other PLHIV (1 woman and 3 men) who were initially recruited as key informants (KIs) were

included in the analysis, while not included in the Table 3 (below), which shows the number of participants in each sample category. In order to secure anonymity and confidentiality, a table that shows the demographical and other characteristics of individual participants is not provided in any part of this thesis.

Table 3: Participants of the research (PLHIV) according to the sample categories

	GROUP A			GROUP B	TOTAL
	Sex worker	IV drug user	Sexual minority		
Female	2 (transgender)	-	-	7	9
Male	-	0	8	7	15
Total	2	0	8	14	24

Before moving forward, I need to briefly reflect on the sample categorisation shown in the table. This categorisation does not mean that people recruited in the second group have been regarded necessarily as having 'non-stigmatized identities', which is not possible in my view, considering my understanding of the social world as always marked with gender and power relations. In order not to overlook other potential sources of differences, I paid attention to heterogeneity of each of the groups during the recruitment process. As stated in the epistemological approach of the research, the categories are not considered as static. I also considered that some of the persons in one category might also belong in another one. As I explain throughout this thesis there are many other important axes of differences that affect the experience and management of stigma. The purpose of the initial categorisation in the sample design was to allow comparisons between individuals occupying different social locations, especially with regard to the sources of HIV-related social perceptions, and based on the intersectional approach explained in the previous chapter.

The other group of participants of this research is the key informants. In order to gain a broader perspective of the power dynamics related to the perceptions of HIV/AIDS in the research setting, potential participants were selected based on their positions in key institutions, such as NGOs working on health, sexual health and sexual orientation, public and private hospitals, counselling services, related departments of the Ministry of Health, Turkey offices of international organisations (IO), and universities. The number of the KIs to be interviewed was anticipated to be around fifteen. As I explain in the next subsection, the total number of KIs that I

interviewed is 32. Table 4 demonstrates the number of KIs interviewed. The recruitment and interview process will be explained in the next subsection.

Table 4: Key informants participated in the research

Key informants	Number of participants
Infection disease specialist (IDS)	12
Other health professionals	2
PLHIV-NGO representative	6
Other NGO representative	7
International organisations (IO)	2
Ministry of Health	2
Independent lawyer	1
Total	32

The research was conducted in two urban settings, the cities of Ankara and İstanbul. HIV/AIDS is concentrated in urban areas in Turkey and these two cities are top of the list of the reported HIV/AIDS cases, as explained in Chapter 4. The main rationale for the choice of these cities is related to the opportunities present in these cities for PLHIV. The major NGO supporting PLHIV and more social networking opportunities are based in İstanbul, while more equipped health institutions with specialized health professionals are present in Ankara. Although I did not aim to make an analytical comparison based specifically on the settings, I expected that the experiences of PLHIV in these cities to differ from each other. Considering that PLHIV from smaller cities and rural areas come to these cities to receive medical care and social support, I decided to recruit them in case of encounter.

4. Methods of data generation

The main methods of data generation used in this thesis are: biographical narrative interviews with PLHIV, semi-structured interviews with the KIs, participant observation in PLHIV networks and civil society activities, review of key documents and statements and informal observation and conversations. Secondary sources such as online blogs and forums written by PLHIV and news appeared in the media were also reviewed. In the following section I explain the use of each method, along with the process of recruitment of the participants, the interview procedures and my interactions with the participants.

4.1. Biographical narrative interviews with PLHIV

I aimed to reach PLHIV firstly through contact persons (gatekeepers), who are NGO members and health professionals working with PLHIV. Some of them were informed about the research and have agreed to cooperate prior to the start of the fieldwork. Others were approached throughout the fieldwork process. The ethical considerations about the gatekeepers and informed consent forms are discussed further in this chapter. Here I explain the process of recruitment of the participants, but I should state in advance that the names of the NGO and health professionals who acted as gatekeepers are not provided in this thesis, with a view to protect confidentiality and anonymity.

I was able to contact most of the participants through an NGO which offers support to PLHIV. I prepared informed consent forms, which is explained in detail later in this chapter (also provided in the Appendix 3&4). The gatekeepers in the NGO reviewed the consent form and contacted some of their clients to invite them to participate in the research. In addition, because I was often present at the NGO's support centre as a volunteer, I met people personally, but even when I mentioned the research I was conducting, I never asked individuals directly if they would volunteer to participate. In one of the meetings I presented myself and introduced my research. I talked to people who stated their interest in participating, considering the sampling design and the time schedules available to both of us.

Furthermore, I asked infectious disease specialists (IDSs) in eight hospitals in Ankara and in İstanbul to pass my contact details and information about the research to potential participants and provided them with copies of information and consent forms. However, I could only reach two participants through the infection clinics. I talked to one person who was in the clinic at the moment when I arrived there and another person whom the doctor called and invited for the research. Another person whom I reached through a doctor agreed on participating but later stated that he did not have enough time. I could not get detailed feedback from the doctors about why their patients did not contact me. At the time when I introduce my research to them and asked their help, some doctors stated that they would 'mention about, but not specifically recommend' their patients to participate; some stated that their patients are not 'educated enough to understand' this research; and some stated that the patients are generally reluctant to speak to anyone about their disease.

Considering that reaching participants through gatekeepers has limitations in terms of reaching only a population benefitting from access to health and social support, I also sought to reach other PLHIV using a snowball sampling technique. For this reason I asked every participant whether they knew other PLHIV who would volunteer to participate in this research. However, most of the participants whom I reached through the NGO did not know any other PLHIV who are not in contact with the NGO; the participants I met through an infection clinic did not have any contact with other PLHIV; and the ones who knew a couple of other PLHIV stated that these individuals are hiding their status and do not want to talk to anyone, including other HIV-positive people, about this issue.

Apart from the participants reached through gatekeepers, I interviewed five PLHIV with whom I had personal contact prior to the fieldwork. These five people were also connected with the NGO. Although I have reached most of the participants through the NGO, not all of them were their clients, as I explain in detail in the next chapters. With this overall sample, I was able to generate data about the lives and experiences of PLHIV who did not receive peer-support, had relatively small access to care and support mechanisms and did not have contact with other PLHIV. That allowed me to make comparisons within the sample. Moreover, my observations, informal conversations with other PLHIV throughout the years, and data gathered from the KIs provided important insights into the lives and experiences of PLHIV who are not represented in this sample. Yet, the major limitation of the sample is the inability to include female sex workers (other than transsexuals) and the individuals who withdraw themselves from social contact and perhaps seeking healthcare, which is an indication of the higher fear of stigma they experience.

With a view to gain a deep understanding of the lives and identities of PLHIV, biographical narrative methods are used. I preferred to generate data on the entire life story of each participant, instead of focusing on illness narratives. While illness narratives offer accounts of meanings constructed and practices that occurred in the face of illness (Kleinman, 1988; Bell, 2000), the biographical narrative method I used was aimed at understanding PLHIV's experiences and changes in their lives and identities, not only relating to their HIV status, but also to their other experiences and broader social inequalities. Especially considering the intersectional approach of this research, this is regarded as an appropriate interview method.

The methods for generating biographical narratives took insights from the framework of Biographical Narrative Interview Method (BNIM) (Wengraf, 2006), with the aim of collecting unstructured and rich narratives. The BNIM interview procedure is primarily based on a single question aimed at generating an “uninterrupted”, “free-form” of narrative (Wengraf, 2009), and therefore considered useful to elicit research participants’ self-defined perspectives on their lives and identities.

The main focus in this approach is on facilitating the expression and identification of ‘implicit and often suppressed perspectives and practices in the present as well as the expression and detection of perspectives, practices and counter-narratives at various moments in the past’ (Wengraf, 2009, p.34). In other words it aims to elicit narratives of the past experience, as lived and felt in the past by the respondent, as much as possible, rather than generating assertions about a remembered situation in the past, from the respondent’s present point of view. Thus, this approach is concerned to ‘clarify both (evolving) situations and (evolving) subjectivities by exploring locally-historically ‘situated subjectivities’’ (ibid, p.33). With this aim, the interview method of BNIM is organised around questions seeking ‘particular incident narratives’ (PINs) (Wengraf, 2006; 2009). I briefly outline the BNIM interview procedure below, based on Wengraf (2009). After that I explain how I conducted my interviews, with some modifications.

There are two sub-sessions during an interview, separated by a short break. The first sub-session begins with asking a “single question aimed at inducing narrative” (SQUIN). This question is carefully designed to start the interviewee off in telling their story. In the interviews, this question is asked as designed, without any change in its content or wording. The interviewer listen to the ‘whole story’, without any interruption, intervening, or asking any question, until the respondent explicitly expresses that they have finished. During this process the interviewer makes notes of around three to five words for each ‘cue-phrases’ that the respondent used as they told their story. It is important to note the exact words used by the respondent and not to change them. These ‘cue-phrases’ are then used in the second sub-session’ to generate PIN-seeking questions.

When the respondent explicitly states that they have finished telling their story, the interviewer asks for a short break (five to ten minutes) and privately chooses some items that were noted during the first sub-session to be probed in the second sub-

session. It is important that the selected items include the very first item that the respondent brought up and the last one. Apart from these, the interviewer select other items that are seen as important for the research topic and also the ones that are more suitable for facilitating PINs.

In the second sub-session, the interviewer asks questions, based on the 'cue-phrases', using a particular 'formula', such as 'You said [cue-phrase]. Can you remember a particular [moment, day etc.] ... how it all happened?' It is important to follow the 'formula' and not to ask 'how'/'why' questions, in terms of not interrupting the flow of ideas and feelings in the respondent's mind. During their response, the interview continues as in the previous sub-session. If the initial response does not generate a PIN, the formula is used again, based on the 'cue-phrases' used in the response. Again, it is important not to combine the items or interpret their responses when asking questions. This process continues until the interviewer obtains a rich PIN or a clear refusal. The second sub-session ends with the last PIN (or refusal) raised in relation to the last item that the respondent originally mentioned at the end of the first sub-session. In the BNIM interview method, an additional sub-session can be conducted, at least three or four weeks after the initial sub-sessions, for asking further questions if necessary.

Prior to the fieldwork, I have participated in '5-Day Intensive BNIM Research Interview Training', I conducted a pilot interview and received feed-back from Tom Wengraf and my supervisors on the pilot interview. For my interviews with PLHIV, the introductory words are formulated following the BNIM formulation (Wengraf, 2009), as shown below:

'As you know, my research aims to understand the lives and experiences of HIV-positive individuals living in Turkey. So, I would like you to tell me the story of your life. By 'the story of your life' I mean all that is important for you, personally. You can start from whatever point you like and end wherever you want. I will just listen and I will not interrupt. I will take some notes in case I have any questions for after you have finished. You can take your time before you start. So, please tell me the story of your life'

I have prepared a guide and a form for myself as a reminder and a facilitator for taking notes during the interviews. The guide for the formulation questions aimed at generating PINs are provided in the Appendix 1. When selecting the 'cue-phrases' used in the second sub-session I took into consideration:

- a) what seemed important for the participant, personally,
- b) the phrases/topics that are closer to give me PINs,
- c) my research questions (for example their health-related and stigma-related experiences, the points that had a potential of revealing their questioning of gender norms and medical knowledge, their social and economic resources, their religiosity etc.)

While I followed the rule of BNIM in not interrupting participants' narratives and not asking how/why questions, the interviews were more interactive than it is suggested by the formal BNIM interview procedure. Taking into consideration the cultural setting of the research and the aimed relationship between the researcher and the research subjects I considered this as rather beneficial. At the end of the second sub-session, the conversations mostly turned into an informal chat by itself and this continued for a short while. I observed that this also helped the participants gradually digress from the highly emotional state that the interview created. After that, I also asked some extra questions about the topics not mentioned during the BNIM sessions. These included questions related to their professional and educational experiences, their connection with other PLHIV, their involvement in activism, and question about illness perceptions. I also noted interviewee's gestures and other indicators of their emotional situation, our conversations before and after the interviews and during the breaks.

Generally, the participants stated that they enjoyed this style of telling their life stories. Only two participants stated that they had difficulty with telling their stories without questions and that they would prefer a more structured interview style.

Except one, all interviews were conducted face to face, mostly in a private room allocated to us in the NGO that helped me in recruiting the participants. Three interviews were conducted in public places like a coffee shop or a shopping-mall. These places were chosen by the participants. They were crowded and noisy places, where other people could not hear our conversation; but this did not cause disturbance for our interview. Two interviews were conducted in a private room in a hospital, allocated by the doctor who introduced me to the participant. In other cases, I conducted one interview in the home of the participant and one in a private room in another NGO. One interview was conducted on the phone, since the

participant lived in a town far from the city, did not have time to travel and did not want me pay a visit to this town, because of the fear to attract attention and disclosure of identity. However, I initially met this participant face to face and had an informal chat before the interview. While a phone-interview has disadvantages in terms of not getting non-verbal forms of expression, I still aimed at generating narratives, using the BNIM interview procedure.

In face-to-face interviews, I noted the participants' gestures and other indicators of their emotional situation, as well as our conversations before and after the interviews and during the breaks. In most cases, we had the opportunity to chat before and after the interview. Except for four interviews, I used a tape recorder. The exceptions were the phone-interview and other three interviews in which the participants did not want me to use a recorder. Among them, there were only two participants who had no formal education and lived in rural areas. All three were people who did not have any regular contact with another PLHIV or any institutional social support.

The average time of an interview was two hours, the shortest one being 45 minutes and the longest one four and a half hours. Including the introduction, informal chats before and after the interview and the breaks, the average time spent for one interview was three to four hours. Except for four interviews, the first and second BNIM sub-sessions were done in the same day.

I have transcribed the tape-recorded interviews verbatim, including repetitions, self-interruptions, fillers, interjections, variations in pronunciation and speaking modes, my speech and contextual sounds. The average length of a transcribed interview was 12.000 words. A detailed transcription conventions and an explanation about the display of the verbatim quotes used in this thesis are provided in the Appendix 2. The thematic and narrative analysis techniques I employed are explained in the next subsection. During the analysis process, I did not translate the interviews from Turkish to English, unless I use a passage as a quote in the first drafts of this thesis. All quotes from the participants presented in this thesis are translated by me and proof-read by a professional Turkish-English translator.

4.2. Semi-structured interviews with key informants

The key informants were selected based on their positions in key institutions as I explained in the above section on research design. I conducted the interviews mostly in the second half of the fieldwork. This is because during the fieldwork I had a better idea about the persons and institutions that are in key positions. I identified a list of around 40 people and tried to narrow it down. I approached the KIs face to face during meetings or via e-mail or phone and submitted an informed consent form (see Appendix 4). With few exceptions, all replied positively. I conducted interviews in the offices of the KIs. An average interview lasted an hour. I tape-recorded the interviews, with the exemption of two people in critical positions who did not wish to be recorded. I did not have to obtain official permission from any of the institutions, since such a mechanism did not exist. However, one person wanted to see a copy of the ethical clearance form prior to the interview.

The interviews were semi-structured, although I prepared a detailed interview guide for myself as a reminder of the possible topics to discuss. The topics covered, broadly, their views on the general situation of the epidemic in the country, on HIV/AIDS related policies and activities, on the social perception of HIV/AIDS and their opinions and experiences related to stigmatisation of PLHIV. Additional questions were also prepared, relevant to the specific working area of the participant. The interview guide is provided in the Appendix 5.

4.3. Review of key documents and statements

The main policy documents and oral statements of official institutions and other key organizations are reviewed in order to generate additional data on the discursive construction of HIV-related stigma and its institutional setting. These included:

- Country situation and evaluation reports written by the MOH and sent to the Global Fund, WHO and UN,
- Project reports of NGOs,
- Brochures and leaflets prepared by state and civil society organisations for HIV/AIDS related campaigns,
- Policy documents released by the MOH which include sexual and reproductive health (SRH),

- MOH legislation and regulations concerning the delivery of SRH services and testing and treatment of HIV/AIDS, and
- Oral statements of key actors (including MOH representatives) as published in the media.

In addition to collecting the above documents from available sources, I also asked KIs, at the end of each interview, whether they could provide me with any relevant document that they may have. This is because of the difficulties in reaching data, policy documents and project reports, which are not always open to public access in Turkey.

4.4. Participant observation and informal interactions

During the fieldwork I participated in several meetings as a volunteer helping for the preparation of the meeting or as audience requesting permission for making observations. These meeting included PLHIV networking meetings or training, seminars given by a person living with HIV to small groups, LGBT conferences where HIV/AIDS is discussed and other meetings which involved participation of infectious disease specialists (IDSs). I also participated in a number of other meetings, which I considered confidential and did not use any information acquired from them in this thesis.

Spending a long time in a support centre enabled me to have informal conversations with many persons living with HIV. Furthermore, I have spent with some of them a considerable amount of social time, such as going for a walk, to see a movie, birthday parties, pubs and diners. It allowed me to observe and participate in their daily life. We became friends with some of them and talked about our personal lives, shared feelings, called each other when we were sick or in trouble.

5. Data analysis

I have used a combination of thematic and narrative analysis techniques for the analysis of the data generated in PLHIV interviews. The thematic analysis was composed of three steps, namely: data expansion, data reduction and data display. I summarise these steps below, based on Grbich (1999), Mason (2002), Richards (2006) and Holliday (2007). The analysis of the data generated from the KI interviews were carried out following the second and third steps described below.

To analyse the narratives of PLHIV, I first read the transcripts and related notes from the fieldwork and wrote a brief summary narrative for each participant. Doing this I also identified particular passages that I found interesting in terms of the research questions or in terms of raising a different question. In the second step, data reduction, I generated 'topic nodes' and 'analytical nodes' using a data management software. The initial topic nodes were created based on the research questions, the theoretical framework and the themes preliminary emerged during the fieldwork. These included health related experiences, beliefs and behaviours, self-expressed changes in life, social relationships, reflections on self and gender related topics, along with sub-topics that emerged under each one. In addition, three other topics (thoughts on other social problems / inequalities, family related issues and enjoying life) emerged during the coding process as big portions of narratives. The analytical nodes are created to link the emerging themes under each topic to their meanings and relevancies to the conceptual framework. When coding passages from the interviews under related topics, I also noted how a particular passage is expressed by the participant, in order not to lose the link between the told story and the context which affect the telling of the story. This also helped with the narrative analysis. At the end of this step I identified regularities, similarities, variations and singularities in passages coded under a category and looked for correlations between the topic codes and analytical codes. I assembled the nodes and their relationships in diagrams and displayed differences among the participants in tables.

The coding process described above was not carried out using the software for all of the cases. About half of the narratives were analysed manually, since I found that I was quicker and more comfortable working on the data on paper. This is partially because I was already very familiar with each of the narratives, having carried out the interviews, transcribed them personally, read and summarised them again during the data expansion process; thus I was able to move across parts of the interview and link them together easily on paper. Also, instead of first coding the data for the thematic analysis and then looking at individual interviews from a narrative analysis approach, I started to carry out both processes simultaneously. I found it more comfortable to identify different use of language and segments of speech on paper.

As Riessman (2000) states, there is considerable variation in the assumptions beyond narrative analysis and the strategies employed accordingly. In this thesis,

narratives are considered as 'meaning-making unites of discourse' (ibid). 'Narrative reconstruction is an attempt to reconstitute and repair ruptures between body, self, and world by linking-up and interpreting different aspects of biography in order to realign present and past and self with society' (Williams 1984, p.197-198).

Despite differences, a common understanding in narrative analysis is to identify ordering and sequencing in the narrative, to pay attention to the 'telling' of the story (ibid; Grbich, 2007). Accordingly, all narratives were analysed not only by looking at the expressed experiences, events and feelings but also focusing on the ways in which they were expressed. I did not employ techniques to investigate the linguistic features of the speech in detail, since it required considerable amount of time for the analysis of each case. Instead, I followed simple steps (Grbich, 2007) to understand the telling of the story, in each of the particular topics that I identified through the above explained thematic analysis procedure. First, I identified the boundaries of the narrative segments in the interview transcript. The topics were already identified through the thematic analysis; here, I identified the ways of expression (for example making comparisons between HIV and other illnesses). Secondly I looked at the content (what feelings, emotions, ideas are displayed with this particular way of expression) and context (the background information) of the story. I then looked at how participants' differed in telling the stories that are grouped under the same topic.

6. Ethical considerations

Ethical approval for this research has been granted by the University of East Anglia, International Development Ethics Committee on 24/12/2009. Since there has been no formal requirement or procedure in place for getting a research permit or ethical clearance applicable to this research in Turkey, I have not sought in-country research permissions.³

³ There has been no formal system or guidelines for ethical governance and monitoring of social research conducted by individuals in Turkey, unless the researcher is a member of or the research is funded by an institution in which ethical clearance procedures are established. Formal permission may also be required when the research is conducted within the settings governed under state institutions. Some NGOs require that researchers fill an application form as a proof of approval of the research to be conducted with the assistance of the NGO. I have obtained verbal permission from the NGO that acted as a gatekeeper in this research. No unpredicted research permit or ethical clearance requirement emerged during the fieldwork. In only one case, a copy of the ethical clearance from UEA was provided to a key informant who wanted to see it.

Considering the high stigma attached to HIV/AIDS and the limited number of individual and institutional actors related to HIV/AIDS in the research setting, I have taken utmost care for prevention of disclosure risks. Confidentiality and anonymity of all research participants (PLHIV, key informants and gatekeepers) have been managed through strict adherence to the procedures of safe data storage and anonymity, during and after the fieldwork, when collecting, analysing and presenting the data. I also constantly evaluated my impact and the impact of my research on the field during the whole process. I considered keeping my research diary as a beneficial tool for reflecting on my research practice (Hughes, 2000) and to provide a better understanding of the trustworthiness of the data and the general integrity in the research process (Nadin & Cassell, 2006). Furthermore, I understood research ethics as not only about responsibilities to the research participants but also to “those who read, re-interpret and take seriously the claims that we make” (Doucet & Mauthner, 2005, p.125). In this sense, I considered being as clear as possible about my interpretation of the data as my ethical responsibility. I regularly reflected on the ethical considerations outlined in this section during the fieldwork, data analysis and writing up processes.

I kept the electronic data under folders protected by password and stored all hard copy documents, including consent forms, field notes, research diaries and audio recordings, in my personal lockers in my family homes in Ankara and İstanbul. Both the data and the files linking real names (of the participants, institutions, places, other actors) and pseudonyms have been accessible only to me. Data were anonymised once collected. Real names of the participants and other names that can allow identification of the participants or institutions did not appear in transcriptions, field notes, or in research diary. Gatekeepers’ names, institutions and positions have also been kept confidential. Key informants are referred in this thesis with numbers. PLHIV were asked to choose pseudonyms for themselves. Some did, while some other did not have a particular choice. In these cases I used an online name generator web-page to assign pseudonyms for the participants. Doing this, I wanted to avoid any personal bias in assigning pseudonyms.

I also considered important to maintain anonymity of the KIs, gatekeepers and any other institutions since there are a limited number of actors specialised in the area of HIV/AIDS in Turkey and their names, institutions and other affiliations are well known to each other. Therefore I made every effort to protect their identity and did

not refer to the specific institutions nor gave details about the KIs while presenting the data.

Participation to the research was voluntary and based on informed consent obtained from all participants at the beginning of the interview. When I asked gatekeepers to pass on my details and consent forms, they demonstrated sensitivity of the issue and showed appropriate understanding of the importance of voluntary participation to ensure that potential participants do not come under pressure to get involved in the study.

Two different consent forms (one for participants living with HIV and one for the key informants) were used. Their English translations are attached as Appendix 3 and 4. The forms explained the aim of the research, the risks and benefits of participating to the research, how the confidentiality and anonymity are maintained, the interview procedure, financial source and the anticipated dissemination of the research, the right to refuse to answer questions, refuse the interview to be tape-recorded, remove information provided, withdraw from the study at any time and to renegotiate consent during the research process. The form did not directly state or confirm the participants' sero-status.

All participants living with HIV read the consent forms, except one participant who was illiterate and to whom I read the form. Participants were given enough time to think about whether or not to take part in the research. The forms included my contact details and also the details of a local university professor assigned as the contact person for questions or concerns about the research and the researcher. Participants were free to keep a copy of the informed consent form, but approximately one third of PLHIV did not want to keep the form.

I obtained signed consent from the KIs. However, consent from the participants living with HIV was obtained verbally (tape-recorded). This has several reasons. Asking signature for obtaining consent is considered to be problematic in some research topics, situations and in some cultures. For example, 'individuals who identify themselves as a socially excluded or belonging to a marginalized group, are unlikely to formally consent in writing to participation on a study' (Miller & Bell, 2005, p.54). In addition, participants who are involved in illegal behaviour (such as unregistered sex work in the case of this research), may fear that signed consent forms may put them at risk (Wiles et al., 2007). I also considered that asking for

signature may 'challenge the trust relationship that is aimed to be built between the interviewee and the researcher' (Miller & Bell, 2005, p.65) and may 'compromise principles of confidentiality and anonymity' (SRA, 2003, p.30). Also, in some cultures, signing a document as the proof of consent may be seen as offensive by respondents because it may imply that one's word is not believed. People may also be reluctant due to perceived linkage between signing papers and negative consequences, because of the events experienced in the country's history (Ginsberg & Mertens, 2009, p.600). Finally, I anticipated that participants who cannot write would feel uncomfortable. All of the above mentioned points were considered relevant to the subjects and the setting of this research.

I sought to prevent participants from physical and emotional discomfort. Participants were reminded that they were free to refuse to answer any questions, cease the interview, change the topic or withdraw from the research at any time. During two interviews, when the participants felt deep emotional stress, I proposed to cease the interview, but they said that they were content to have an opportunity to pour out their feelings and they wanted to continue. The interviews were carried out in places of the respondents' choice, in order to minimise any distress that research subjects may feel and the risk of disclosure. I also avoided conducting interviews with people in more vulnerable situations. Although they volunteered I did not conduct BNIM interview and only had informal chats with a person who was in poor health and another with a serious psychological health condition.

Due to the fact that the opportunities to receive social and/or financial support are very limited, I anticipated that participants would have expectations from me. In a few cases where the participant sought psychological advice or expressed serious emotional problem, I reminded that I was not trained for providing such counselling and mentioned the ways of getting information and support. However, I sought to comfort them, without giving a particular advice. Even if the participant did not raise any particular need, I informed them at the end of the interview about the available institutions and networks that they were not aware of. I considered this as my responsibility and a possible benefit for them in participating in this research.

No payments or incentives were given to any of the participants. I planned to offer refreshments and cover any costs occurred during the interviews such as lunch or dinner. In cases where the interviews were conducted at the NGO environment, I could provide these. However, when I met the participants outside, they did not

allow me to pay, due to the cultural rules, in which it is neither acceptable nor polite that the younger person pays for the older one, as well as for a woman to pay for a man.

Because of my involvement in many activities before and during the fieldwork, I mostly felt 'at home'. At the same time, I paid very much attention to constantly reflect on my positionality as a researcher. For example, I stayed away from some discussions concerning institutional matters, I purposely tried not to learn details, not to be seen as taking side and not to affect important decisions.

However, I have been more than an observer when sharing scientific information and contributing to some work with my professional skills (as a person from a social science background). I continued to do several voluntary jobs that I was involved in before the start of the fieldwork. For example, I reviewed previous research on different topics, translated documents from English, interpreted data and contributed to writing up project reports for the NGO. In addition, I was asked to give speeches on the current situation of HIV/AIDS in the world and in Turkey to the Health Commission of the Grand National Assembly of Turkey (GNAT) and in a national radio show as a guest speaker. I considered these both as my ethical responsibility to share scientific information and as outreaching activities.

Chapter Four: HIV/AIDS in Turkey

1. Introduction

This chapter presents background information on HIV/AIDS in Turkey and the country response to it. I present the available data on HIV/AIDS, overview Turkey's response to HIV/AIDS, including state and civil society institutions and projects related to prevention, treatment, care and support. These will be explained briefly since I present an extensive analysis on the country response in relation to cultural and social-political features of the country in the next chapter. This chapter also overviews the level of knowledge and attitudes towards HIV/AIDS and PLHIV among the general public and presents previous research findings on HIV-related stigma.

2. HIV prevalence and data

According to the latest data that the Ministry of Health of Turkey (MOH) released in December 2011 (see Appendix 6), since the first reported case of HIV infection in 1985, a total of 5,224 cases have been identified in Turkey; 921 diagnosed with AIDS and 4,303 diagnosed as HIV-positive. In addition, a MOH representative verbally announced that 596 people were diagnosed with HIV or AIDS in the first half of 2012 (Özlu, 2012). The available data do not specify the number of people currently living with HIV, but data submitted by MOH to WHO (2008a) report that from 1985 to 2006, 140 individuals died of AIDS-related illness.

Considering the overall population of the country and the rise in new infections in the geographical region in which Turkey belongs, these figures are considered an underestimation. Turkey had a population of 74.7 million at the end of 2011 (women: 37.1 million; men: 37.5 million) (TSI, 2012). Turkey is classified by UNAIDS in the region of Eastern Europe and Central Asia, which is the only region in the world where the rate of new infections continue rising, despite the global decline (UNAIDS, 2012). The number of officially reported cases is considered underestimation mainly because of the low level of HIV testing and the inadequacy of surveillance and registration systems (Ay & Karabey, 2006; Tümer, 2009). As I explain in detail in the next chapter, data on HIV/AIDS in Turkey are very limited. The available data on HIV/AIDS in Turkey are summarised in Table 5:

Table 5: Summary Data on HIV/AIDS in Turkey

Estimated prevalence (at the end of 2007)	Less than 0.2 per cent
Reported cases of HIV/AIDS (since 1985)	5.224 (921 AIDS, 4.303 HIV positive) (3.729 men, 1.495 women)
Recorded deaths from AIDS-related illnesses (between 1985-2006)	140
The maximum number of new infections within a year (in 2011)	619
Routes of transmission	59.3% heterosexual intercourse 8.6% "homosexual/bisexual intercourse" 3.9% "IV drug addiction" 23.9% "unknown"
Most affected age groups	men between 40-49, 30-34, 35-39 women between 25-29 and 20-24
Country of origin of infected people	80.8% Turkish, 17.8% "Others"
City of origin	49,1% İstanbul 14,7% Ankara 11,7% İzmir 2,4% Antalya 22,1% in 62 cities
Number of PLHIV receiving HAART	685 in 2006 (75 % men, 25 % women) 800 (estimated) in 2007 50% (estimated) in 2010

Reports by WHO (2008) and UNAIDS/WHO (2008) state that Turkey has had low and stable rates of HIV/AIDS incidence and prevalence, with an estimated prevalence of less than 0.2 at the end of 2007. To compare the situation in Turkey with that of the regions in which it is located, both the geographical location and the cultural characteristics of the country necessitate looking at two different: Eastern Europe and Central Asia, and Middle East and Northern Africa (MENA). According to UNAIDS' (2011) global report, prevalence in Eastern Europe and Central Asia is 0.7 and the HIV prevalence clearly remains on the rise. Prevalence in Middle East

and Northern Africa, on the other hand, is 0.2. At the country level, all of Turkey's neighbours (Georgia, Armenia, Iran, Iraq, Syria and Greece, but not including Bulgaria, for which data were unavailable) have estimated prevalence rates of less than 0.2 (UNAIDS/WHO, 2008).

The most affected age group in Turkey is the 25-49 group; half of the population of Turkey is under the age of 29.7 (TSI, 2012). There is an apparent difference between men and women in terms of the most affected age groups. Men aged 30-49, and women of 24-29 are most affected. In total, 69.7% of the 3,370 people affected by HIV/AIDS are men and 30.3% are women. However, the number of women under the age of 25 is higher than that of men, with 61% of women and 39% of men in the age group 15-19, and 52.4% of women and 47.6% of men in the age group 20-24 (MOH, 2011).

The main route of transmission is heterosexual intercourse (59.3% of the total). Other modes of transmission are 'homosexual/bisexual intercourse' (8.6%) and 'IV drug addiction' (3.9%). (original wording used in MOH data, see Appendix 6). Levels of infection through blood transfusion and mother-to-child transmission remain low. However, the data indicate that in 23.9% of cases, the second largest percentage in the data, the route of transmission is 'not known' (MOH, 2011). WHO (2008) comments that 'the present epidemiological stage of HIV in the country and the low level of injecting drug use, make it reasonable to assume that commercial sex work is the main driver of the epidemic'. In Eastern Europe and Central Asia, where the most significant route of transmission was once IV drug injection, the epidemic is increasingly characterised by sexual transmission (UNAIDS, 2009). In the Middle East and North Africa, on the other hand, according to UNAIDS (2009), at least two patterns are contributing to transmission: transmission among 'key populations' (IDUs, men who have sex with men, sex workers and their clients), and second, 'many people in the region are contracting HIV while living abroad, often exposing their sexual partners to infection upon their return to their home country' (UNAIDS, 2009, p.71). Data about the country of origin of infected individuals leads to the assumption that female sex workers coming to Turkey from former Soviet Union (FSU) countries and their clients play an important role in transmission, an assumption that is often used by government authorities to explain 'the cause' of the epidemic in Turkey. I return to this point and discuss in detail in the next chapter.

Data suggest that 80.8% of the infected individuals were citizens of Turkey, while 17.8% were 'others' and 1.3%, 'unknown' (Bal, 2009). The countries that constitute 'others' are not stated, and data about the proportion of women and men in the categories 'Turkish' and 'others' are not available. The identified cases between 1985 and 2006 were reported mostly in Istanbul (1250), Ankara (374) and Izmir (299). However, data about the cities where these individuals lived show that most people diagnosed in those cities were living in Istanbul and that the second highest group of people were living 'abroad' (MOH, 2006). Detail about the 'abroad' category is again unavailable. The data are limited to reported cases by year, age, sex, country of origin, the city where the case was identified and the city of residence of the infected individual. There are no data available from either MOH or international organisations (IO) such as UNAIDS or WHO about the proportion of infected people in rural and urban areas.

The limitation of the available data will be discussed in the next chapter in relation to the power and use of medical profession and the dominant discourses around HIV/AIDS in Turkey. To briefly note here, the MOH released the above mentioned data in the statistical yearbooks until 2006 but, as I explain in the next chapter, removed HIV/AIDS statistics from the published material and made simpler data sheets available on demand. An example of this data sheet is provided in Appendix 6.

3. Test and treatment

The majority of the people diagnosed with HIV in Turkey are identified during compulsory tests carried out when blood is donated and before medical surgery (Bal, 2009; Özlü, 2012). Many women find out their HIV status during pregnancy, and because of the low take-up of voluntary testing and reluctance to seek healthcare after being diagnosed, the majority of people make their first visit to a doctor in an advanced stage of AIDS.⁴ The MOH representatives have officially announced that there are eleven voluntary testing and counselling centres in four cities across Turkey: Ankara, Istanbul, Izmir and Trabzon. However, according to Positive Living Association (PYD) (2010), only six of these centres actually worked and the others are closed. There are ten centres in the country where confirmatory

⁴ Dr. Deniz Gökengin, oral statement in 'HIV in South East Europe - An HIV Medical Training for Turkish Doctors and Patient Advocates', organised by HIVTRI and PYD, 24/09/08, Istanbul.

HIV tests (Western Blot tests) can be performed (Özlu, 2012). A coding system has been utilised by MOH since 1994 to keep its records anonymous (MOH, 2006).

Treatment is offered in infectious diseases clinics in the hospitals. There are not specific HIV/AIDS-clinics or HIV-specialists. PLHIV are treated by infectious disease specialists (IDSs). PLHIV can receive treatment and medication free as long as they are registered with the social security system. However, because of deep-rooted problems in the social security system, which has recently been changed, many people are not registered.⁵ According to information provided by PYD, 30% of the people who receive counselling from this NHO do not have social security. Some hospitals informally donate medication to such people.⁶ WHO (2009) reports that during 2006, 787 PLHIV received medical care in Turkey. In 2004, 250 people were on ART while at the end of 2006, 685 people were on ART, which was offered at 25 facilities. Of the patients on ART, only 25% were women (WHO, 2009). According to UNAIDS (2010) ART coverage in Turkey is estimated to be 50 to 80 per cent.

Before January 2010, a referral from the workplace was required for public sector workers to access health institutions. In this situation, at least one person from the administrative departments of the workplace such as the accountant or the secretary would see the dispatch note on which the diagnosis or the names of the prescribed medicines were written. This created major problems for PLHIV; due to fear of their HIV status being disclosed in the workplace they were choosing to self-fund their ART or completely refusing treatment. This bureaucratic shortcoming of the social security system, threatening their right to privacy, has been reported in previous NGO reports (PYD, 2007; 2008; 2009). This referral procedure has been abolished during this research and considered by PLHIV advocates as an affirmative implementation in terms of the protection of confidentiality and accessing ART. However, it should be noted that this change was made as a part of a general renewal of the health system. The confidentiality of medical information was not the reason.

⁵ 'Turkey Report of the European Foundation for the Improvement of Living and Working Conditions' (Rose & Özcan 2007, p.33) shows that 35 % of adults are not members of a scheme providing social security and health insurance benefits.

⁶ Oral statement of Tekin Tutar, project manager in PYD, in 'HIV in South East Europe: An HIV Medical Training for Turkish Doctors and Patient Advocates', organised by HIVTRI and PYD, 24/09/08, Istanbul.

4. State structure for sexual and reproductive healthcare and the country response to HIV/AIDS

Since the early years of the Republic (founded in 1923), when there was a perceived need to increase fertility, policies related to sexual and reproductive health (SRH) have been formulated within the general framework of population policies. Since the 1960s, population growth control has played an important role in development policies of the country. A more liberal and comprehensive law on population planning, which also legalised abortion, was passed in 1985 (HUIPS, 2009). Turkey's participation in the 1994 Cairo Conference (International Conference on Population and Development) led to the development of a National Action Plan on Women's Health and Family Planning, which introduced the terms 'reproductive health' and 'women's health' into the agenda. Finally, the term 'sexual and reproductive health' was adopted in the latest action plan covering the period from 2005 to 2015. The plan indicates a decision to shift from the family planning approach to an SRH-based approach in relation to gender, population and development (MCHFP, 2005). The related document setting the standards of SRH services (MCHFP, 2007) reflects a rights-based approach stressing individual rights and needs.

Overall, the results of the related implementations demonstrate important achievements, mainly in the field of maternal and child health, where services are free of charge and widely accessible. However, it is not possible to state that the regulations made on SRH in the last two decades have been fully carried into practice. To date, 'sexual health' is not mentioned in any of the MOH's organisational charts or legislative documents. The most recent regulations published for the 'Family Medicine Program' (Official Gazette, 25 May 2010/27591) specifies that one of the duties of the family doctor is to provide 'mother and child health and family planning services'. Because STDs are dealt with by another unit in the Ministry, and due of the persisting view of sex and reproduction as mainly associated with fertility and motherhood, reproductive health services have not been mobilised in a way that meets individuals' sexual and reproductive needs. Sexuality remains unspoken about and sex is perceived to be an act between married couples for the purpose of reproduction. Consequently, as demonstrated by research (CETAD, 2006; HUIPS, 2009), access to correct information, materials and communication about sexuality is limited, especially for unmarried and young

women; the male condom is generally known as a means of contraception and its use is very low.

Currently, two different directorships (the General Directorship of Mother-Child Health and Family Planning (MCHFP) and the General Directorate of Primary Healthcare Services (GDPHC)) are responsible for HIV/AIDS prevention, diagnosis, counselling and treatment. Çokar (2008) states that communication and cooperation between the two directorships has been poor and this led to the emergence of a multi-axial and uncoordinated response.

A National AIDS Commission (NAC) was founded in 1996, with the effect of the advocacy activities of the reproductive health associations that I mention in the next subsection. The Commission involved both governmental and non-governmental organisations; it was convened by the Prime Minister and chaired by the MOH. In 1997 the NAC adopted a National AIDS Program and prepared action plans for the periods 2003-2005 and 2006-2010. However, as explained in the next chapter the NAC did not hold regular meetings and the plans could not be implemented as intended. The action plans and outcomes were not made public. Yet, the action framework can be learned from UNGASS National Composite Policy Index (UNAIDS 2008a). It addresses all of the topics that are in the agenda of UNAIDS, except from poverty and gender equality. A new action plan for the future has not yet been announced.

5. Civil society response to HIV/AIDS

Civil society work on HIV/AIDS with a focus on protecting, advocating and protecting the rights of PLHIV, and the most at-risk populations (MARP) are relatively new and small in number in Turkey. NGOs working in the HIV/AIDS field can be categorised into five groups. Associations working in reproductive health, founded as part of the population and development programmes of the 1960s, constitute the first group, which works primarily on women's and child's health and family planning. They were involved in HIV/AIDS-related advocacy, prevention and other programs on MARP after Cairo Conference with large funds from UN and EU. The second group is STD-related associations founded by health professionals, generally in universities or venereal disease clinics. The third group is composed of three organisations that were specifically established to work on HIV/AIDS prevention in the early 1990s. AIDS ile Mücadele Derneği (The AIDS Prevention

Association) and AIDS Savaşım Derneği (the Association for Fighting with AIDS) were founded in 1991 and 1992 respectively by health professionals. In 1997, the Hacettepe University HIV/AIDS Treatment and Research Centre (HATAM) was established, and it still plays an important role in education campaigns, prevention policies and the NAC. The common points of these AIDS-NGOs were strong leaders with backgrounds in medicine; working at high capacity with limited financial resources; and they had political power because of their leaders' presence in scientific comities of the MOH (Çokar, 2008). In the fourth group are LGBT organisations which were involved in several projects related to HIV prevention among sexual minorities and sex workers.

Finally, there are two NGOs founded mainly by PLHIV, their friends and relatives. To distinguish this group of NGOs from others mentioned above I refer to them as PLHIV-NGOs throughout the thesis. PLHIV were not able to organise at institutions in the early years of the epidemic because their total number was low and because of the requirement of identity disclosure in the Association Law (Çokar, 2008). The first and last two NGOs founded by PLHIV were established within a national programme funded by the Global Fund (GF) in 2005. One of these, which aimed at providing home-based care to PLHIV, was closed at the end of the programme and was in the process of being re-established towards the end of my fieldwork period. The other was founded with the aim of building a PLHIV network providing physical, psychological and social support, raising public awareness and 'carrying out advocacy activities in case of violation of legal rights' (PYD, 2005).

The NGO conducts projects aimed at identifying human rights violations of PLHIVs and providing legal consultancy to its clients, PLHIV and their relatives. The consultancy process involves providing information about basic rights, patients' rights, non-discrimination, defendants' rights, disadvantaged peoples' rights and legal issues, providing lawyers with support for criminal and legal trials. It also holds awareness-raising meetings aimed at informing different populations about HIV/AIDS and human rights. The target groups include doctors, medical students, lawyers, the media and other NGOs. Most recently, advocacy activities have been directed at governmental organisations and members of Parliament, and there is an attempt to introduce the human rights of PLHIVs into the parliamentary agenda via lobbying and legislative mechanisms such as the first national draft laws on discrimination and on the right to privacy.

In 2007, an NGO Platform for HIV/AIDS was established with the contribution of eleven NGOs but did not become effective. At the time of my fieldwork the field was predominantly led by the only PLHIV-NGO that maintained rights-based advocacy and support activities. However, the NGO was effective in only one city and had limited financial and human resources.

The years 2008 and 2009 were important in Turkey, with large-scale street demonstrations on World AIDS Day for the first time, although these were limited to three major cities. Again, for the first time, several public figures declared their support for HIV prevention campaigns. Women's organisations and NGOs working in different areas organised some activities taking HIV/AIDS on their agendas. The reluctance of LGBT organisations to participate is a remarkable element of NGOs' involvement in AIDS activism, which is discussed in the next chapter.

6. The role of international organisations and state-civil society relations in shaping the country response

The cultural and political environment that affect the formation of HIV-related discourses are discussed in the next chapter. However, as background information, the effects of the international organisations (IO) and the overarching state-civil society relations should be explained here.

The limits of civil society and the role of the state in monitoring, supervising and directing society have always been topics of debate in Turkey. In general, the sphere outside the governance of the state is limited. The institutionalisation of civil society has been informal to a great extent. Organisations that correspond to western-type NGOs that are recognised by the state are not common (Çokar, 2008).

The weakness of Turkey's civil society until recently is seen to be related to the 1980 military coup. Turkey's political history can be considered as marked with military coups.⁷ The 1980 military coup happened at the end of a decade when there were deathful conflicts between left-wing and right-wing political groups. The major effect of the coup was that the society had been frightened, suppressed, and thus depoliticized. Another important effect of the coup was the changes in the economic regime. The one-party governance after the coup made major changes in

⁷ Military coups of 1960, 1971, 1980 and the memorandum of Turkish Military Forces in 1997, also called "the post-modern coup".

order to liberalize the economic system. Therefore, the first diagnosis of AIDS coincided with that period in Turkey, when both the idea and the legal article that defends that state is responsible for protecting the health of its citizens was abandoned. The state's responsibility was declared as "monitoring" the health system. Also in this period, prevention programs that were once effective (in terms of fighting with malaria and syphilis) had lost its place in the agenda (Özçelik-Adak, 2002). Accordingly, HIV/AIDS had never been an issue within the demands from the state on the basis of 'equal rights to health for all'.

Civil society started to regain power in the late 1990s. The EU candidacy process was an important factor influencing its development; membership of the EU has been on the political agenda since 1963. In 1999 Turkey was accepted as a candidate country, and in 2005 membership negotiations started. In the process, funds were given to NGOs with the direct aim of improving human rights in the country. This process has mobilised and legitimised efforts to defend the rights of, for instance, women, children and Kurds. In terms of health-related civil society activities, IOs have been giving funds to Turkey for health improvements since the 1950s, but it is with the EU candidacy process that these funds have started to have a right-based content.

Since the 1990s, UNICEF and UNFPA have contributed to projects on SRH conducted by both the MOH and NGOs. In 2001, the MOH prepared a country situation report as part of a reproductive health programme funded by the EU (Kaplan, 2008). The majority of NGO activities on HIV/AIDS were carried out after 2003, when two large-scale health programmes, funded by the EU and the GF, were started. The EU-funded Turkey Reproductive Health Programme was conducted from 2003 to 2007 by the MOH General Directorate of Mother and Child Health and Family Planning, with one of the highest budgets for reproductive health (55m Euros) ever allocated worldwide. Forty-eight NGOs, most of which had never worked with HIV before, conducted projects directed mainly at youth and the general public. From 2005 to 2008 the Turkey HIV/AIDS Prevention and Support Programme, funded by the GF, was conducted by the MOH General Directorate of Primary Healthcare Services. Within this programme, 16 projects run by 14 NGOs aiming at prevention among MARP were conducted. For the first time in Turkey, support and home-care services to PLHIV were provided; voluntary counselling and test centres were opened and stigma and discrimination issues were addressed.

Work related to HIV and human rights was also conducted within this programme (Çokar, 2008).

According to my interviews with twelve professionals working in the area⁸, the positive outcome of these projects has been the start of HIV/AIDS-related activism in Turkey; the projects have reached a large number of sex workers and homosexual men for the first time; health workers who were unaware of the issue have been educated; and PLHIV and the 'positive examples' have started to become visible. On the other hand, the projects have been criticised for prioritising profit over the human aspects of the issue and for focusing on a limited geographical area (four cities). In addition, some of the program's aims could not be achieved for two main reasons; the first is related to the shortcomings of the general health system in Turkey and its lack of personnel, time, and financial resources; the second, to state policy based on concepts such as 'the general morality and socio-cultural structure of the Turkish society', which obstructed some of the prevention programs (Öktem, 2008).

According to Çokar (2008), those programmes could not fulfil expectations in terms of strengthening the country's response to HIV. The institutional capacity of the NGOs working in this area has developed, but the majority of the projects they have started could not be sustained due to lack of both finance and interest in the issue. Many people who were trained on this field had to work in other areas. Besides, the projects did not have the anticipated effect at state level because of the factors discussed in later chapters of this thesis.

7. Public knowledge of HIV/AIDS and the stigmatisation of PLHIV

Research on the public knowledge of HIV/AIDS in Turkey showed contradicting results. For example, according to the Demographic Health Survey conducted in 2003 (MOH, 2006), 88% of ever-married women had heard about HIV/AIDS and two-thirds believed that there is a way of avoiding it. The proportion knowing about HIV/AIDS is less than 80% only for the youngest age group of ever-married women (77 %); close to 90% of all other age groups knew about HIV/AIDS. The first large-scale survey on HIV/AIDS-related knowledge in Turkey was conducted in 2008

⁸ Research conducted in 2008, prior to my enrolment in the PhD programme at UEA. It consisted of qualitative interviews with 12 individuals working in key institutions and programmes. Presented as a conference paper (Öktem, 2008).

(GFK/PYD, 2008) and found that among 1,303 people from 16 cities, 54% (61% women, 51% men) had not heard of HIV; 79% of the sample did not know about HIV testing and 60% of women and 46% of men did not know how to protect themselves from it.

Social research on HIV/AIDS in general and HIV-related stigma in particular is limited in Turkey. Studies, mostly surveys, have focused mainly on levels of knowledge and negative attitudes towards PLHIV, and demonstrate ignorance and misconceptions about HIV/AIDS and associated negative attitudes towards the PLHIV among various study populations such as health workers (Okan & İrgil, 1993; Ünsal et al., 1999; Şahin et al., 2000; Duyan et al., 2001), medical school students (Ekuklu et al., 2004; Oğuzkaya et al., 2006), and university and college students (Çok et al., 2001; Mağden et al., 2003). For example, in a study conducted with university students, 76.8% agreed with 'AIDS patients and people with HIV must be isolated from their family and children'; 59.4% with the statement 'PLHIV must be enrolled in separate educational institutions' and 43.5% with 'there must be separate accommodation facilities' for PLHIV. Similarly, 20% of medical school students agreed with 'PLHIV should not be married', more than half with 'they should not have children,' and 77.7% did not want to be in the same classroom as a person living with HIV (Ekuklu, 2004). In another study, 36% of students in their third year at medical school would not want to shake hands with a person with HIV. Moreover, 35% would not operate on a person with HIV when they become surgeons (Bozkaya, 1993). In another study on the attitudes of health professionals, 56.2% of the sample stated that they would not want to be in the same physical environment as a person living with HIV (Okan & İrgil, 1993).

Very few studies have been carried out with a focus on the experiences and perceptions of PLHIV. Duyan and Yıldırım (2004) point out the consequences of stigmatisation for PLHIV such as withdrawal from family and friends and from social gatherings, loss of work and home, and internalised guilt. Namal (2003) documents discriminatory attitudes experienced by a person living with HIV and his acquaintances in a hospital.

To date, two studies have been conducted from a sociological perspective linking stigma to gender norms in Turkey. Aşar-Brown's (2007) study concludes that gender identity norms influence both discriminatory attitudes towards PLHIV and the experiences of PLHIV. The study shows that 'men's sexual freedom' and

‘women’s sexuality within wedlock’ are important norms that influence the formation and experiences of HIV-related stigma in Turkey. Based on interviews with 16 PLHIV, Kasapoğlu and Kuş (2008) state that heterosexual women’s position shows a duality (married women are tolerated better than single women) and that transgendered people are blamed and oppressed the most.

Reports prepared by PYD (2007; 2008a; 2008b) present data on the forms and frequency of HIV-related stigma in Turkey. According to its 2007 report, PLHIV most frequently complain about violation of their privacy and right to medical care. The report also shows that 62.3% of discrimination towards PLHIV is experienced in health institutions. The NGO has also prepared a report: ‘Evaluation of the Vulnerability Assessment of People Living with HIV in Turkey’ (PYD, 2008a) with the support of UNDP. The report emphasises the invisibility of PLHIV in Turkey. The bureaucratic shortcomings in the insurance system which threaten the right to privacy are mentioned as one of the main problems. PYD’s ‘Human Rights Violations of HIV Positive People’ report (2008b) resembles the reports previously mentioned; it contains 51 cases of human rights violations reported between July 2007 and July 2008, mostly occurring in health institutions.

Turkey signed the United Nations General Assembly Special Session’s Declaration on HIV/AIDS (UNGASS) However, to date there has been no specific legislation to enable PLHIV to exercise their rights. There are no health institutions or government department providing care and support exclusively to PLHIV; no specific regulations in law such as employment law or a civil code; and there is no act to prohibit any kind of discrimination such as gender, sexual orientation, sexual identity or ethnicity in Turkey.

8. Conclusion

The brief overview of the situation of HIV/AIDS in Turkey provided in this chapter draws attention to the limitations of the country response. The limitations of HIV/AIDS data and the lack of legislation, finance and more importantly, willingness to improve the country response at the state level that are discussed in this chapter are linked with the discursive power relations behind the formation of social construction of HIV/AIDS in the country in the next chapter, drawing on the data I collected.

The role of medical profession in this context of absence of epidemiological data is a major discussion topic, which I relate to the contextual framework about the use of medical discourse as means of social control. The taboos related to female sexuality and homosexuality, as control mechanisms of patriarchy, together with the conservative/nationalist political climate in which these taboos are reproduced are also discussed in the next chapter as factors contributing to the state inaction.

On the other hand, I demonstrate how the consideration of HIV as a human rights issue, with the effect of the involvement of IOs, challenges the dominant discourse. NGOs are advocating the human rights approach to the issue, which is increasingly gaining effectiveness, partially due to its relevance to the expectations from Turkey in the EU candidacy process. The contradiction between these approaches to HIV/AIDS is seen as related to the discrepancy between the dominant conservative ideology in contemporary Turkey and the country's objectives in the process of modernization.

In the subsequent chapters in which I focus on PLHIV's experiences and stigma management strategies, the effects of the lack of mechanisms to provide care and support to PLHIV and to enable them to exercise their rights will be shown as represented in their narratives.

Chapter Five

The social construction of HIV/AIDS: Contesting discourses and their implications for framing policies and public perspectives

1. Introduction

In this chapter I identify the key discourses framing the social construction and policy of HIV/AIDS in Turkey. I argue that the main driver of the state's response is a discourse of 'cultural immunity', while rights-based discourses are represented in recently-developing civil society responses. I explore the components of these discourses and the resulting policies and discuss how they are negotiated with regard to the power relations between the state and civil society. The overarching research question to be answered by looking at the sources of those key discourses in this chapter is: 'What are the roles of the medical and patriarchal discourses in shaping HIV-related stigma?'

This chapter is mainly based on the semi-structured interviews with key informants (KIs) as the primary data source, the review of documents and the main actors' oral statements in the field, as described in the previous chapter. The key themes of the KI interviews covered here are the place of HIV/AIDS in health policy, the role of civil society in HIV/AIDS-related policies and activities, the general situation of the epidemic in the country and stigma-related experiences of PLHIV.

As explained in the conceptual framework of the research, analysis of the formation of HIV-related discourses was informed by the social constructionist approach to health and illness and related constructions of disease as a means of social control and discipline. According to Joffe (1999), we can trace HIV-related discourses in explanations about the origins of HIV/AIDS, the ways it is spread and the groups that are perceived to be most affected. These explanations are motivated by the need to 'find security and order' and to provide protection from the impacts of the perceived crisis (*ibid*) Besides this, in accordance with the main research questions I trace the origins of these discourses in the overarching patriarchal and medical discourses.

Accordingly, I first explain the ‘cultural immunity’ discourse by pointing to its two main components: the exclusionary representation of HIV/AIDS as a disease originating from ‘foreign’ sources and the denial of behaviours such as socially-disapproved sexualities and drug use that can lead to HIV transmission among ‘Turkish society’. I explain the state’s restrictive measures and inaction as examples of outcomes of this cultural immunity discourse. Second, I identify rights-based discourses. On the one hand there is a call for the acknowledgement of PLHIV’s and MARPs’ human rights; on the other, the right to health is seen as a more acceptable discourse by rights activists in Turkey approaching HIV/AIDS from a rights-based standpoint. I explain how ideas about rights are being negotiated by different actors and discuss calls for the visibility and ‘normalisation’ of HIV. In the following subsections, I investigate the role of the medical profession and the patriarchy in the formation of the above-mentioned discourses which I discuss in relation to the socio-political context of Turkey that has shaped social perceptions about sexuality and health-related interventions, namely the modernisation project and the current rise of political Islam. I investigate the effects of the discursive formation around HIV/AIDS on the lives of PLHIV and their self-management in the following chapters, and merely introduce them here.

2. ‘Not our disease’: the cultural immunity discourse and public perception of HIV/AIDS

The ‘cultural immunity’ discourse is dominant discourse articulated in government statements and KIs’ opinions of state ideology. It is based on the assumptions that behaviours, especially sexual behaviours, related to HIV/AIDS are not intrinsic to ‘Turkish society’⁹ and that the preservation of social values is playing an important role in keeping HIV prevalence in Turkey low. Representations of these assumptions can be seen in official and non-official government statements. For example, the Ministry of Health’s report to UNAIDS in 2006 expresses the view that HIV/AIDS is a disease of foreign origin. According to the report, ‘sex workers who come to Turkey from Eastern Europe and newly independent states (NIS)’ are seen as the main drivers of the epidemic. Besides this, ‘another large contingent comes

⁹ I use the term ‘Turkish’ in quotation marks throughout the thesis (for example in ‘Turkish society’ or ‘Turkish men’. This has two reasons. First, because the term ‘Turkish’ not only describes citizenship but also has ethnic connotations important to the current political debates in the country. Thus, this is my political preference to emphasise that this is not a value-free word and that I am critical to its use in a nationalist, assimilating ideology. Secondly, concepts like ‘Turkish family structure’ are poorly defined and imply that conservative values are intrinsic to the whole of society.

from the 3.5 million Turkish nationals residing in Western Europe and regularly visiting Turkey, who bring with them their newly acquired Western European ways and standards' (MOH, 2006, p.5).

Statements given at the press conference on World AIDS Day 2008 also offer important insights into the unwritten perspective of state authorities who argue that HIV/AIDS is associated with the integration of foreign and 'immoral' elements into 'Turkish society', threatening traditional values. The Head of the Health Commission of the Grand National Assembly of Turkey (GNAT) stated¹⁰:

"(...) this disease, which is originated in other countries, unfortunately came to Turkey (...) Our country is a society to which people from different countries such as Ukraine, Africa (*sic*), China and Western countries are coming, for the purposes of business and tourism (...) After the collapse of the Eastern Block, AIDS patients who came to our country provoked the disease in Turkey (...) The family structure and [male] circumcision have preventing functions (...) It is known that this disease is a result of adulterine relationships (...) We need to encourage monogamous relationships."

This statement refers to the view that AIDS originated in a foreign country or continent; a view that is considered one of the components of exclusionary discourses about HIV/AIDS (Joffe, 1997, p.138). The response to the foreign threat is encouragement to preserve patriarchal and conservative values. The 'cultural immunity' discourse implies that the 'Turkish family structure' is conservative, thus monogamous; that sex outside marriage is uncommon; and that male circumcision is a religious practice that also helps to prevent HIV (Erdöl, 2008).

Abu-Raddad et al. (2010) state that 'polemical debate' on 'cultural immunity' in the Middle East and North Africa (MENA) region is fuelled by the absence of strategic information about the epidemic in the region.¹¹ While some argue that MENA's cultural fabric acts as a 'moral prophylaxis', others view cultural traditions as the cause of the failure to combat the disease in the region. Abu-Raddad et al.'s (2010) description of the cultural immunity thesis includes 'strong prohibitions against premarital and extramarital sex, homosexuality, and alcohol and drug use' in MENA

¹⁰ Verbatim quotes from my notes from the speech of Cevdet Erdöl (a medical doctor and Member of the Parliament (MP), and Head of the Health Commission of the GNAT) at a press conference in 01/12/2008 in Ankara.

¹¹ The relationship between the absence of strategic epidemiological information and the formation of discourses in Turkey is discussed in more detail in the next subsection on medical discourses.

countries, while in Turkey not the prohibition but the very absence of those behaviours in the social fabric is at the heart of the discourse, as explained below.

The cultural immunity discourse represented at the state level in Turkey has two components: the representation of the origin of the disease as a foreign element, and the 'othering' or denial of behaviours and groups that are perceived as related to HIV. This contrasts with official Ministry of Health documents that define MARP. 'Commercial sex workers, men having sex with men, IDUs, prisoners, refugees and asylum seekers' are officially accepted as target populations by the National AIDS Commission. However, as mentioned both by the Ministry itself and most of the key informants involved in prevention projects, working with these groups is difficult, due to state agency resistance. Some prevention programs directed at these groups could not be implemented because of decisions by the authorities. Examples of this are explained in a UNAIDS country report (2008):

Condom distribution to people below eighteen might cause a penalty. The National Authority for Prevention of Drug Use does not accept harm reduction strategies as a priority which prevents civil society organisations to work with IDUs. The police accept condoms as evidence of crime for illegal sex work when they found out during police search, although they were distributed to MSMs as a part of a prevention initiative. The authorities allow provision of information on HIV/AIDS to prison inmates but do not permit condom and sterile needle distribution as a part of a prevention initiative. (UNAIDS, 2008, p.16)

These problems were seen by most KIs involved in projects with MARP as an outcome of the state's denial of the existence and refusal to be associated with these populations. Some stated that, for example, sex education in schools and condom distribution to prisons were not permitted by the ministries, because the Ministry of Education argues that young people in Turkey do not have sex before marriage and the Ministry of Justice argues that there is no homosexuality in male prisons. As Joffe (1997, p.132) states, exclusionary discourses around HIV/AIDS often serve to 'protect the positive identity of the in-group'. In this case, it can be argued that state-level discourse is shaped around concern for preserving the idea of a 'decent' society free of 'immoral' elements. Another view among the KIs was that the existence of those populations and behaviours was accepted but state institutions did not want to be seen as accepting and therefore 'promoting' them.

The cultural immunity discourse does not necessarily lead to the argument that the culture provides full protection against HIV. Turkey's observed social change and developing relationships with neighbouring countries are creating anticipation of an increase in prevalence. As also stated by the KIs, including MOH officials, the current success of the tourism sector and the lifting of visa regimes with certain countries are 'frightening' officials. The General Director of Primary Health Care Services of the Ministry of Health stated:

"In the globalised world, the increase in tourism and the number of people coming to our country increase the importance of our country for this disease. In addition to successful prevention programmes, our social habits have positive influence for protection; but our habits can change. So we need to take precautions."¹²

The 'precautions' mentioned are the preservation of 'cultural values' rather than the promotion of safe sex, harm reduction or HIV-related improvements to the health system. Monogamy, as seen in the quote from the Ministry of Health below, is suggested as a means of protection. Monogamy is considered to contribute to Turkey's advantageous position:

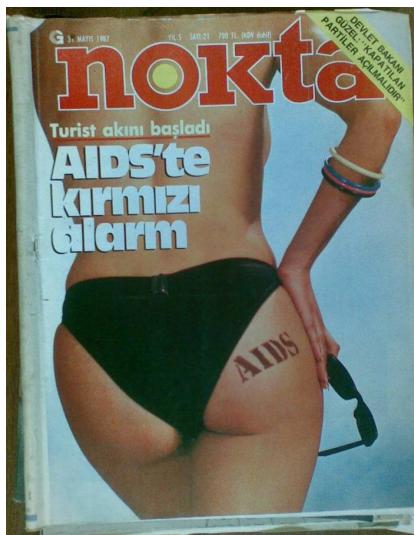
"Monogamy is encouraged in all European and developed countries. Adultery is something that is outside monogamy and has adverse effects both in terms of sexually transmitted diseases and in terms of one's sexual life in a mental sense. In Turkey the number of our registered AIDS cases at the moment [2004] is below two thousand. We are in a good situation in comparison to European countries. This does not mean that the AIDS virus would not be transmitted to our people. We should be very careful. Monogamy is very important. One should control their sexual life in this sense and should not put themselves in danger. In terms of the health system, we are improving towards the point where EU countries have reached. We are even more advanced in some points in terms of the system."¹³

The perception of HIV/AIDS as coming from abroad, mainly from the West and FSU countries, has also been put forward by the press since the early appearance of HIV/AIDS in the media in Turkey. For example, the magazine cover (below left) from 1987 warns the reader that: 'Tourists are coming: Red alarm on AIDS'; the

¹² Verbatim quotes from my notes of the speech of Turan Buzgun (General Director of Primary Health Care Services of Ministry of Health) at the press conference in 01/12/2008, Ankara

¹³ Recep Akdağ, Minister of Health, 11/09/2004 Vatan Gazetesi

article on the right reads 'Don't fear Communism: fear AIDS', explaining that AIDS is the new threat from FSU countries.¹⁴



Nokta, national weekly magazine
(31/05/1987)



Aksiyon, national weekly magazine
(5/1/2004)

A common assumption in both media coverage of HIV/AIDS and state officials' statements exemplified above is that HIV is brought to Turkey by foreign women. Foreign men, or men in Turkey who have sex with foreign women either in Turkey or abroad, are not situated at the centre of the argument. The other side of the commercial sex sector, male customers of sex workers, is not mentioned at all.¹⁵ As Witson (1997) states, this represents the gendered nature of the construction of HIV/AIDS. Women's subordination to men is reflected and reinforced through representations of HIV/AIDS that show women as the transmitters of the disease.

Below I discuss the policy implications of the cultural immunity discourse and the reflections of this discourse in the public perception of HIV/AIDS.

The ideological perception of HIV/AIDS was articulated by most of the KIs as the basis of their criticism of the state response. The government's response to and understanding of the epidemic have been criticised, especially for its lack of a comprehensive response, poor coordination and collaboration and for creating barriers to other actors' HIV-related interventions. Restrictive measures and

¹⁴ The text and the face of an HIV-positive woman displayed in the news article were concealed by me.

¹⁵ However the state level discourse and public opinions about the contribution of men to the spread of the disease differ, as I explain later in this chapter.

frightening discourses in the prevention area were also seen as resulting from the cultural immunity discourse.

One of the main aims of the interviews with KIs was to reveal which actors were perceived as having the greatest role and power in shaping HIV/AIDS-related policy. However, the general perception among the KIs was that there is no HIV/AIDS policy, mainly due to lack of political commitment. In the KIs' narratives, the general picture of the current actors working directly or indirectly in the field of HIV/AIDS, their activities and their views were seen as 'sporadic', disconnected from one another and not part of a 'master plan'. The state's principal role was seen as coordinating these activities within a comprehensive plan. However, the exclusionary discourse on the epidemic has resulted in inaction. The respondents who took part in the National AIDS Commission (NAC) exemplified this inaction, stating that NAC neither held regular meetings nor implemented plans; a new action plan for the future had not yet been announced and financial and human resources allocated to HIV/AIDS at state level were still very limited.

According to a respondent with experience of working in collaboration with the MOH, the worldview of the government manifests in the state's obstruction of HIV-related interventions with 'hidden obstacles'. The idea, presented by this KI and shared by a couple of others, is that the MOH is reluctant to be involved in such programmes because of the moral implications, but instead of overtly verbalising its moral stance it presents other excuses or offers no excuse at all. For example, 'the MOH did not want to extend the projects funded by the GF and sent the money back, presenting logistical reasons' such as insufficient technical and human resources. However, according to the KI the real reason was that 'the MOH realised that those projects involving sex workers and IDUs were damaging the Ministry's reputation in the eyes of the public'. A review of related documents¹⁶ shows that the MOH refunded the unspent USD 437,000 and closed the GF grant, although 'the performance of the grant in both programmatic and financial terms ... in [its] extension phase ... has reached satisfactory levels', according to the Global Fund (2008). The reason for the return of the unspent money was explained neither in GF nor MOH documents. However, the KI stated, the GF projects were affecting the reputation of the MOH. Some conservative newspapers and political party

¹⁶ Global Fund, Turkey Grant Performance Report, TUR-405-G01-H, 30 June 2008; Global Fund, Grant Closure Letter to the Minister of Health, 3 December 2008).

websites that share the same voter base as the ruling party published articles criticising the MOH for offering ‘prostitution training’, ‘encouraging adultery’ and ‘causing moral collapse’ in the name of AIDS prevention.¹⁷

Another, similar thesis about the MOH’s ‘hidden obstacles’ suggested by KIs is that the General Directorate of Mother-Child Health and Family Planning, which is part of the MOH, ‘is being held back from involvement in HIV-related interventions because it has a more ‘liberal’ view [compared to the dominant, more conservative view in the MOH] on sexual and reproductive health’. The National Action Plan on Sexual and Reproductive Health, which it has developed, represents clear opposition to the cultural immunity discourse. It states that instead of providing protection against HIV, the social structure of Turkey contributes to its spread. The patriarchal family structure limits women’s relationships outside marriage while giving more freedom to men, so men have sex with commercial sex workers (MCHFP, 2005). However, no similar consideration of culture and HIV/AIDS is seen in other documents or oral statements by state authorities. These two contrasting discourses, representing two different state agencies, can also be seen as the outcome of the ‘uncoordinated structure’ of the state response to HIV (Çokar, 2008).

The effect of these contradictory discourses is also seen in HIV/AIDS-related projects undertaken by IOs in Turkey. As their representatives explained, they were having problems implementing their programmes ‘within the boundaries set by the government’. At the IO level, priority is given to key populations. However, their approach to these populations, which is based on empowerment and the enhancement of their human rights, contradicts state-level discourses. IO representatives stated that the insufficient cooperation between NGOs and their weakness in relation to the state creates important problems with implementing their programmes. In order to be able to work with (or in spite of) the government, NGOs in Turkey, not only in the field of HIV/AIDS but also in general, have to be very careful of being critical. Any careless step that might create conflict between the NGO and a state actor or institution could lead to being banned from certain working areas as a result of the overarching relationship between the state and civil society explained in Chapter 4. Some KIs from IOs and NGOs recommended that a

¹⁷ <http://www.saadet.org.tr/haber/bu-ne-rezillik>,
<http://www.milligazete.com.tr/index.php?action=show&type=news&id=44820>

platform of several NGOs should be established, which would be more powerful than a single NGO, allowing demands and criticism of the state to be expressed with greater volume and courage without fear of being banned, abolished or stonewalled by the state.

KIs working in the civil society sector and in IOs stated that the unequal power relations between the state and civil society have resulted in the dominance of state ideology, which prioritises restrictive interventions in the area of prevention. The implications of the cultural immunity discourse for approaches to prevention was criticised for being based on frightening and victimization discourses, instead of the principles of normalisation and activism (Öktem, 2008). As previously mentioned, the fear of new infection from foreign sources is visible in state actors' statements, including those of some of my respondents. However, in response to the lack of priority given to HIV/AIDS in health policies, some of the civil society actor and doctor respondents also vocalised this frightening discourse. The assumption that HIV/AIDS is not prioritised by MOH because of the rarity of reported cases leads to a strategy of emphasising the 'real' extent or 'danger' that 'we are (or will be) facing'. KIs who argued that 'this is just the tip of the iceberg' referred to international organisations' recommendations. A commonly-repeated argument was that 'WHO and UNAIDS recommend that we should multiply the officially reported numbers by at least ten to get the real number in countries without a well-established surveillance system'.

Another main argument used to emphasise the size and urgency of the problem was that 'Turkey belongs to the only region in the world where HIV prevalence clearly remains on the rise'. In this case, considering that Turkey is now lifting visa regimes with its neighbour countries, there might be a boom in the rise of the epidemic due to an expected increase in the numbers of illegal sex workers and IDUs. This argument relates to the state-level discourse that sees the origin of HIV as foreign. Although civil society discourse is against the representation of HIV as a foreign disease, KIs from civil society used this argument with the specific aim of emphasising the importance of HIV/AIDS as a current or potential problem. It should be noted, however, that the civil society respondents who expressed this argument added that they do not mean to promote xenophobia or the stigmatisation of foreign nationals. Three respondents who played important roles in HIV-related interventions and education suggested that the general view in recent years about a global decrease in the epidemic is particularly 'dangerous' for Turkey. According

to them, the idea that HIV/AIDS is not a big threat any more can undermine efforts to raise awareness about HIV in a context where HIV/AIDS has been given little attention in the first place.

Some KIs explained the high stigma attached to HIV in Turkey, not mainly with regard to moral prejudices but more related to the lack 'familiarity' with the disease and with people living with it. According to a KI, 'discrimination [is about] getting used to the idea'. HIV/AIDS is 'a very distant concept' in society; mainly because people do not know or see HIV-positive individuals around them. Herek (1999) states that having personal contact with PLHIV is related to lower levels of HIV stigma. Echoing this idea, a respondent stated that the stigma is lower in countries that are badly affected by the epidemic because 'people have to live with it. They have felt obliged to get used to it'. Another respondent said that because Turkey has not experienced an 'AIDS shock', there is no clear idea about HIV/AIDS; people just do not know how to react to PLHIV and are not even sure why they discriminate against them:

"(...) there is no idea in the minds of lay people whether this is a problem. If they had at least an idea about this, then they would have had perceived this as a problem, they would have got a reason to refuse an HIV-positive person. If [this is] not [perceived as a problem], then they would have communicated with them. But since they don't know whether this is a problem, they would say 'let's not talk to this person who got AIDS'." (KI18)

Sharing the same argument that the main basis of stigmatisation in Turkey is the lack of knowledge, another respondent also stated that if the public is well informed, people would not discriminate against PLHIV, mainly because stigmatisation 'is not in the texture of this society':

"Because it is impolite. For us, it is impolite to ostracise. They [public] would not ostracise, just because it is impolite to do so. But they would label. They would label, but they won't ostracise. I think we can make use of this point. (...) then they will need to learn not to label. They will see [that HIV positive people are not like they were scared of]. What is labelling? We label what we don't know, what we fear of. But once we take them in, we will not fear anymore." (KI13)

When asked about the variation in public perceptions and knowledge of HIV/AIDS, most respondents from all sectors first stated that there is no difference at all between the opinions of general public and those of healthcare providers. Discriminatory attitudes and low levels of knowledge among health professionals as well as the general public have been found by other studies, as discussed in

Chapter 4. However, there is a lack of research into variation between other populations or different geographic regions. Based on their own experience, the respondents mentioned that there is no higher awareness or better attitude in other sections of society or in professional groups that could be considered highly educated. For instance, they talked of 'a public prosecutor who thinks HIV is something like rabies'; MPs who are not aware of ART; and, 'the intelligentsia's "dangerously conservative" approach. In terms of geographical differences, a few respondents with first-hand experience of eastern parts of the country and the smaller cities stated that in those regions perceptions of HIV/AIDS are more like 'those we saw in the late '80s and early '90s', meaning that HIV/AIDS is still seen as a non-treatable and fatal disease. The respondents explained this difference in terms of the unequal distribution of services and financial resources in the country, with the west benefiting from both governmental and civil society services more than eastern regions.

In this context of low awareness and familiarity with HIV/AIDS, public perceptions are shaped by the dominant discourse of cultural immunity. A large-scale survey demonstrated that most people explained the rise of the epidemic in Turkey in terms of 'Turkish men's tendency to have an affair and polygamous relationships, the huge number of prostitutes, the huge number of foreign women and changes in moral attitudes in recent times' (GFK/PYD, 2008, p.21). Foreign sex workers are perceived as the source of the disease and the preservation of moral values as a potential method of protection. However, unlike the state-level statements, the role of 'Turkish men' in the transmission of HIV was verbalised by the respondents of the above mentioned survey. The consequences of the cultural immunity discourse and related public perceptions of PLHIV are demonstrated and discussed in the following chapters in detail.

3. Rights-based approaches to HIV/AIDS: claiming individual rights for the sake of public health

Discourses that frame HIV/AIDS as a human rights issue position PLHIV within the broader struggle for access to healthcare, non-discrimination and a rights-based approach to HIV prevention, treatment and care (Seidel, 1993). While a rights-based discourse on sexual and reproductive health was introduced in Turkey's health policies in the period following the Cairo Conference (International Conference on Population and Development), its entry into Turkey's HIV/AIDS agenda for the first time was between 2005-2008, during the country's HIV/AIDS

Prevention and Support Programme (THPSP)¹⁸ funded by the GF and directed by the MOH (Çokar, 2008). As mentioned in the previous chapter, civil organisations working on HIV/AIDS, with a specific focus on protecting and advocating the rights of PLHIV and MARPs, are relatively new and small in number in Turkey. At the time of my fieldwork, the civil society field on HIV/AIDS was predominantly led by one PLHIV organisation which prioritised rights-based advocacy and support activities. Consequently, while relatively new and with limited institutional resources, rights-based approaches to HIV have had a certain degree of effectiveness in shaping the agenda.¹⁹

In line with current global HIV activism (International AIDS Society, 2010), the main NGO discourse on rights states that PLHIV and MARP's enjoyment of all human rights is the most effective way of preventing HIV/AIDS (PYD, 2009). The concept of 'positive health, dignity and prevention', which locates the human rights framework at the heart of prevention approaches, was developed by the Global Network of PLHIV and UNAIDS (Allen et al., 2011). NGOs argue that the enhancement of human rights could secure an environment where all citizens – regardless of whether they are part of a sexual minority, a young woman, a child, impoverished, immigrant, disabled or a prisoner – can access sexual and reproductive health-related information, materials and treatment. As voluntary HIV testing is not common in Turkey because of the fear of discrimination and the violation of rights (SIT, 2011), effective ways of protecting and promoting the right of PLHIV and of vulnerable and susceptible populations to health and non-discrimination will, the NGOs argue, increase the accessibility of both HIV testing and treatment. Besides, according to the 'positive prevention' approach, PLHIV who become aware of their rights can defend themselves, educate those in their close social environment and increase the visibility of PLHIV and awareness of HIV in society.

As mentioned earlier, there are two interconnected approaches in rights-based discourse; one emphasises acknowledgement of PLHIV and MARP's human rights and the other, the right to health. The construction and interpretation of these approaches by different agencies is demonstrated below in relation to perceptions

¹⁸ For details of the Programme, see the previous chapter.

¹⁹ Yet this NGO was based only in one city and had a small number of members and workers.

of the general notion of human rights in Turkey and the power relations between the actors in the field.

According to the respondents in the civil society sector, PLHIV's rights advocacy finds a legitimate basis to press upon the government because HIV-related interventions are dependent on international funds, which are mostly given to projects working to improve human rights. The development of human rights ideas in Turkey is closely related to the country's EU candidacy. Since the foundation of the Republic, the country's political ideology has been defined as oriented to 'European standards'. The current government declares this orientation to be a major goal. EU and other international organisations' progress reports on Turkey constantly emphasise the need to improve the country's human rights record, and therefore the protection and promotion of human rights have an important place on the political agenda.

In terms of the legal framework on the rights of PLHIV, the MOH (2008) states that 'people living with HIV have the same rights as other people in the country'. Turkey has signed the Declaration of United Nations General Assembly Special Session on HIV/AIDS (UNGASS); accordingly it has committed to 'improve human rights for the fight against AIDS, prevent discrimination and stigmatisation against PLHIV, continue to offer full access to medical treatment, support and care' (MOH, 2006). However, to date there is no specific legislation to enable PLHIV to exercise their rights.

State representatives' speeches contain sometimes implicit and sometimes explicit messages about their understanding of the rights of PLHIV. For example, Aydın, an MP who brought the HIV/AIDS issue up in parliament for the first time in Turkey on December 1, 2009, stated that 'these people must be protected from social isolation' and that 'we should permit these people to live among us as normal Turkish citizens' (Aydın, 2009). This statement can be read as a representation of the view that separates 'normal us' from 'others'. The former Minister of Health (1999-2002), Osman Durmuş, stated that 'it is not nice to treat people with HIV/AIDS as bad people or leprous', adding: 'People who consume alcohol want everybody to propose a toast with them; people who smoke want everybody to become addicted, and HIV-positive people want more people to become like them

so they won't be isolated'.²⁰ The above statements, while supposedly aimed at delivering an inclusionary message to the public, represent prejudices against PLHIV as a 'group'. Categorising PLHIV as an out-group with assumed stereotypical behaviour, they exemplify pejorative judgements about PLHIV. These prejudices, as attitudinal components of stigmatisation (Phelan et al., 2008) against PLHIV, affect the ideological framework in which PLHIV's rights are interpreted and negotiated at the state level.

Perceptions about rights in Turkey are shaped by conservative cultural and political ideology. In this context where collective rights and responsibilities are prioritised over individual rights and responsibilities, the rights-based approach to HIV/AIDS creates a discourse of claiming individual rights for the sake of public health. It can be argued that this resonates with the current government's maxim about human rights and its health transformation programme: '*Let the man live so that the state lives*' (Recep Tayyip Erdoğan in MOH 2010; Kapusuz 2011). HIV-related rights can also be advocated by NGOs within the general framework of health-related rights, which is much more acceptable than that of sexual rights. NGO respondents stated that in the face of the state's resistance, PLHIV rights advocates sometimes feel the need to rephrase or alter the tone of their discourse in order to achieve their goals. For example, my observations showed that at the level of civil society there is discussion about whether it is better to keep the rights of sex workers and homosexuals in the background and feature the 'general public' and basic health-related rights in order not to further marginalise the issue. This enables common ground to be found when conflict between NGOs and the state is difficult to resolve.

To understand the different interpretations of rights ideas in Turkey, the political connotations of the concept of rights and perceptions of a hierarchy of rights should also be mentioned. As some of the respondents expressed, the ideas of rights, discrimination and equality are interpreted mainly as matters of culture, ethnicity and nationality. In the current political climate of the country, the notion of human rights connotes advocating Kurds' rights, since 'the Kurdish question [has dominated] the agenda of the human rights associations' in Turkey since the 1990s (Casier, 2009, p.4). This understanding of human rights created an 'antagonistic' relationship between the human rights NGOs and the state actors; the state

²⁰ 1/12/2010, GNAT, special meeting of the Commission of Health.

challenging the NGOs ‘for authority over the “truth” concerning human rights in Turkey, especially regarding the Kurdish question’ (Casier, 2009, p.2).

In this context, women’s human rights remained a rather ‘marginal’ issue, not only at the governmental level but also among human rights organisations (İlkkaracan & Erçevik Amado, 2005). Rights related to private life and sexuality and the rights of populations connected with HIV/AIDS such as young women, sexual minorities and sex workers remain invisible or are not prioritised. As in some developing countries (Plummer, 2006), sexual rights and gay rights claims are seen as Western-originated values that are being imposed by international agents such as the EU.

Sexual and reproductive rights are given less priority than other categories of human rights by not only the state but also civil society. NGOs working with the general concept of human rights in Turkey are more concerned with ethnicity and freedom of expression. There is reluctance among NGOs, including LGBT, feminist and health-related organisations, to advocate PLHIV and MARP’s rights, partly because of the idea of a ‘hierarchy of rights’ and partly because of the identification of HIV with socially-disapproved sexuality.

A remarkable point about NGOs’ involvement in AIDS activism is the reluctance of LGBT organisations to adopt a proactive stance on HIV-related rights advocacy. Statements from LGBT communities imply that HIV is seen as a ‘heterosexual’ disease among the gay community. The western history of AIDS activism shows that the gay movement made a major contribution to AIDS activism by mobilising its institutional and human resources, and that in turn, AIDS activism strengthened the gay movement (Seidman, 1988; Epstein, 1995; Silversides, 2003). In Turkey, the homosexual community has not experienced an AIDS crisis. The negative results of the perception of AIDS as a gay disease are well-known by the LGBT community, and they do not want to be seen as salient actors in AIDS activism in case it reproduces this perception in Turkey. Another reason for not taking a lead role in AIDS activism was explained by a respondent in terms of the different perceptions of HIV/AIDS and homosexuality at the state level. It is easier for an HIV-positive person to claim their rights before the state, as it is related to health. However, if they seek their rights through an LGBT organisation they are likely to be rejected.

The same applies to sex workers, as explained by one respondent:

"[Being HIV-positive alone] is a little bit more acceptable [than being a sex worker]; because it is a disease (...) you can come to a degree of acceptance about your own disease, or your neighbours', or your mother's or father's or co-worker's disease after a while. Of course there are prejudices, but these prejudices can be broken down with certain interventions and training." (KI17)

Here, the participant distinguishes between prejudices motivated by 'disease avoidance' (Phelan et al., 2008, p.363) and pre-existing prejudices against sex-workers, which serves 'the function of norm enforcement' (*ibid*, p.362). The above quote implies that the specific kind of prejudice rooted in the perceived threat of infectious disease (Schaller & Neuberg, 2012) is easier to be reduced than the deep-rooted prejudices against sex-workers, rooted in perceived moral threats. The implication of this, as the participant added, is that advocacy of human rights in relation with HIV/AIDS could not be discussed through advocacy of sex workers' rights.

According to some of the respondents who were actively involved in rights advocacy, the conservative ideology interferes with the interpretation of law, making it difficult to act against human rights violations. Although human rights are protected on paper, ways of claiming individual rights and/or fighting legally against their violation are blocked by the 'mentality' embedded in institutions. For example, where a violation of rights occurs in a public institution, the law concerning the trial of civil servants requires permission to investigate from the administration, which is often not granted. Because of this constraint, to date no court case on discrimination on the grounds of HIV status could have been opened. Four cases have been taken to the European Court on Human Rights due to the exhaustion of domestic remedies.

PLHIV rights advocates offered different strategies to secure PLHIV's rights. One point of view emphasised the urgent need for specific HIV/AIDS legislation. Respondents who were aware of or involved in the process discussed an NGO project to draft an HIV-specific bill that was being put forward during my fieldwork period. The main axis of discussion was whether cultural change or law enforcement should be prioritised. According to some participants, the history of the powerful women's rights movement in Turkey and its achievements in the previous decade have confirmed that changes in the law have a strong potential to change the mentality of the general public. Accordingly, they suggested, more didactical, coercive and binding regulations in both national and international legislation.

Another view on the enhancement of PLHIV's human rights was that 'the problem is not specific to HIV/AIDS', since there is a 'general intolerance to all kinds of differences in our society'. By 'differences', the respondents meant the ethnic and religious minority issues and lifestyle differences that are currently occupying a major place in the political agenda of the country. Recent surveys (Toprak, 2009a; 2009b, Esmer, 2011) confirm high levels of intolerance among the general public regarding people who are considered 'different' in terms of sexual identity, lifestyle, ethnicity and faith. According to some respondents, the concepts of tolerance of difference and respect for human rights are not established in Turkey; mainly due its '[low] level of development' or 'primitiveness'. Accordingly, extensive cultural change to prevent discrimination on all grounds of social inequalities was considered the priority.

Other strategies expressed by the KIs who have taken a rights-based approach to HIV were based on calls for the 'normalisation' and 'visibility' of PLHIV. Normalisation was the KIs most frequent suggestion for reducing stigma. The key idea in normalisation was explained as the perception of HIV as like any other chronic or infectious disease, or at least any other STD. By the need for normalisation, doctors mostly meant the need to treat HIV-positive patients like other patients, without extra precautions and/or fear. In the narratives of KIs from civil society, the call for normalisation was explained in terms of emphasising how any 'normal' person can have HIV and that PLHIV can look and live like other people. Normalisation as a strategy was not enough for some KIs in the civil society sector, however, and is not the correct way to reduce the stigma: 'Messages like "we are human beings like you" are, of course, correct, but they are not enough'. More comprehensive and wider education is necessary. It cannot happen with 'half-hour [training that shows] that people living with HIV do exist, that they aren't monsters, you can shake their hands, share a plate...'

"(...) 'we are walking on the same places on the same pavements like you; we are swearing like you; shouting and surviving like you..' This is for establishing empathy and this is 'one method' of stigma reduction. Another method is to 'play with the edges of the society', meaning subverting the clichés, such as saying to the media: 'Yes we have searched for and found an AIDS patient for you: here is this child'." (KI9)

This method of 'subverting the clichés' was problematic for some respondents, who see presenting 'innocent' PLHIV as the face of PLHIV in Turkey or using 'good' examples to normalise HIV/AIDS as having the potential to reproduce the

stigmatisation and make it even harder for MSM, IDUs and sex workers to disclose their HIV-positive identities and claim their rights.

Considering that the HIV-related stigma is linked to the public's lack of familiarity with HIV and based on the positive prevention approach, some KIs advocated that PLHIV should become more 'visible'; in other words, more should disclose their HIV status publicly. However, it was also noted that in the current context, where non-discrimination cannot be guaranteed by the legal system, this call for visibility might not be realistic. Furthermore, as one of the KIs working in LGBT activism pointed out, the real danger of visibility is:

“(...) conservatives, Islamists are being organised against homosexuality; but soon HIV-positives are going to be the second target, for sure. Because HIV-positives are also saying [as homosexuals] 'I can sustain my social life'. In most senses, being HIV-positive is like being homosexual. When constructing their identities they say 'it's not an extra sphere of life for me; it's like a "normal", in inverted commas, disease like "diabetes" or whatever'. In that sense and also because [HIV] can be transmitted through homosexual intercourse soon they will be in the line of fire, as we [homosexuals] are now. In response to our [struggle for] legitimacy, the voice against our legitimacy is also rising. Before, there were less people who wrote [in the press] that 'we should throw homosexuals away from social life; that they are sinful and bad' comparing to people who wrote these in the last couple of years, people weren't writing that sort of thing five years ago. This [sort of attack] is something that increases as the [homosexual] movement progresses and people start to be visible. So this should also be taken into consideration.” (KI5)

PLHIV's perceptions and claims about their rights and how ideas about normalisation and visibility resonate in their perception are discussed throughout the following chapters. As a brief introduction, the level of awareness of human rights is limited among PLHIV as well as the general public. The results and fieldwork experiences of Turkey's People Living with HIV Stigma Index (2010)²¹ show that PLHIV do not perceive their experiences as a violation of their rights.

²¹ The People Living with HIV Stigma Index was developed by a joint initiative of organisations (The Global Network of People Living with HIV/AIDS (GNP+), The International Community of Women Living with HIV/AIDS (ICW), The International Planned Parenthood Federation (IPPF) and UNAIDS). The Stigma Index Turkey (SIT) survey was conducted by Positive Living Association (PYD) in 2010. The data have been analysed and interpreted by a group of people, including myself. The results have been presented in several conferences (GNP+ & PYD, 2010; Karataş, 2011; Sprague, 2011; Erkaymaz, 2011; Öktem, 2011) but not yet been published (Gökengin et al., forthcoming). Throughout this thesis, when referring to Stigma Index Turkey results, I do not only refer to the above mentioned papers but also to the raw data (on SPSS) which I have been given permission to access by GNP+ and PYD. For this reason, the survey results are cited in this thesis as 'Stigma Index Turkey (SIT), 2010'.

Due to the internalised stigma, many of the reported cases of discrimination were perceived by the person living with HIV as justifiable differential treatment. KIs working in PLHIV-support activities stated that with awareness-raising meetings, more PLHIV have started to defend their rights both in their personal setting and on a broader level. However, this is only valid for people with access to institutional support. A key result of the analysis of the interviews with PLHIV, as discussed in following chapters, is that the right that the participants mentioned most was the right to a private life and confidential medical data. Since the current situation does not provide a safe environment in which PLHIV can disclose their identities, one important effect of human rights training is that PLHIV seek to justify and defend their rights to conceal their HIV status.

4. Social perception of sexuality

When commenting on a country with a majority of Muslims in the population, attempts are commonly made to explain the perception of sexual rights on the basis of religion. However, as İlkkaracan and Ronge (2008) state, social perceptions around sexuality cannot be understood without looking at the broader political conflicts related to democracy and development. 'The Turkish trajectory confirms that far beyond being a private matter, sexuality has always been a site of political struggles' (ibid, p.240). As explained in the previous chapter, the construction of femininity and female sexuality in Turkey is seen as linked to the country's process of westernisation. The rights granted to women by the founders of the Republic were intended to 'destroy links to the Ottoman Empire and to strike at the foundations of the religious hegemony rather than promoting the actual liberation of women' (ibid). The idealised 'modern Turkish woman' was 'emancipated and active in the founding of the new republic as mother, teacher and political activist, yet at the same time modest, chaste and asexual'. While the republicans presented women as the face of the new society, the Islamists saw them as the symbolic protectors of traditional values.

Consequently, although the views of modernists and Islamists were completely opposed, their construct of a 'patriarchal ideal of female sexuality' were the same (İlkkaracan & Ronge, 2008, p.229) in terms of ascribing to women symbolic roles for the representation and continuation of an idealised nation, denying and controlling their sexuality. Also with regard to homosexuality, which was visible in the Ottoman Empire, all gender-non-conforming people, including homosexual,

bisexual and transgender individuals, have been regarded as threatening or throwing into question the key tenets of modern Turkish society (Öktem, 2008).

Issues related to the sexuality and sexual liberation of women were questioned by the feminist movement in Turkey after the military coup of 1980. However, with the shift of political power to the religious right in the second half of the 1990s, demands for sexual rights and the questioning of heterosexism lost its importance on the agenda because many women 'perceived the rise of political Islam as a major threat to their existing rights in the public sphere' (İlkkaracan & Ronge, 2008, p.230). The feminist movement in Turkey has been very powerful and has fostered major changes in the patriarchal perspective embedded in legal documents.²² Due to the movement's successful advocacy, important steps such as the ratification of the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) (1985, and its optional protocol in 2002) and major reforms to the Civil Code (2001) and Penal Code (2005), have been made in terms of considering women's sexuality from the perspective of equality. İlkkaracan and Ronge (ibid, p.239) argue that the Penal Code reform, which was 'achieved despite Turkey's ruling religious conservative government, radically transformed the state's conception of sexuality in Turkey and the code's underlying philosophy'. However, the controversial issues debated during the campaign for Penal Code reform reveal the prevailing norms about sexuality in society. As İlkkaracan and Ronge (ibid, p.240) note, the demands of the women's platform during the campaign were all accepted except for demands to '[designate] honour crimes as aggravated homicide, [criminalise] virginity tests, [remove] an article penalising consensual sexual relations between youths aged fifteen to eighteen, and [penalise] discrimination based on sexual orientation – issues related to sexuality outside the framework of marriage'.

The current conservative, religious and nationalist political climate reproduces taboos about female sexuality and homosexuality. Coşar and Yeğenoğlu (2011, p.555) argue that the AKP's (Justice and Development Party – Adalet ve Kalkınma

²² Some of the major amendments in the new Penal Code include classifying sexual offences under the section 'crimes against individuals/crimes against the inviolability of sexual integrity' instead of 'crimes against society/crimes against public morality and family'; patriarchal concepts such as chastity, honour, public morality, public custom, shame and decency have been eliminated; marital rape has been criminalized; and discrimination between virgin, non-virgin, married and unmarried women has been abolished (Gönüllü, 2005).

Partisi) period in government since 2002 'has been marked by the emergence of a new mode of patriarchy' in Turkey. This 'neoliberal-conservative' mode of patriarchy 'represents a tactful integration of seemingly contradictory structural assets, which can be observed in the party's liberal approach to the civil societal actors while preserving its anti-feminist stance' (ibid, 567). While there is a call for women's participation in the labour market, this mode of patriarchy 'warns' that this actually risks the 'integrity of family and, eventually, social integrity' (ibid, 568). Women's organisations and some IOs have voiced concern about this government's policies causing a backlash and affecting women's status. The current government is criticised for gradually restraining individual rights and freedoms and for its indifference to gender-related issues (Human Rights Watch, 2011; 2012).

Statements by the Prime Minister (PM) and other ministers represent their views of sexuality, reproduction and private life. For example, the Minister of State Responsible for Women and Family argued that homosexuality is a disease, and was not reprimanded by the authorities despite national and international protests (see e.g. Amnesty International, 2011). During discussions between the political parties in the process of the recent elections in June 2011, the PM stated that 'private life' means the relationship between married couples and that any other lifestyle that threatens the traditional family structure cannot be considered private (Erdoğan, 4/5/2001); and he accused the main oppositional party of supporting family planning policies within marriage (CNNTürk, 16/05/2011). In June 2011, just before the elections, the Ministry Responsible for Women and Family was abolished and restructured as the Family and Social Policies Ministry. In response to strong protest, the PM stated that the basic unit of a nation is the family and that women will be considered within family (KADER, 2011). Also, while research shows that women ideally wish for two children, the PM repeatedly calls for women to give birth to at least three children to ensure that Turkey does not lose its political power in the world. Finally, in May 2012, the PM declared his government's pro-natalist policy once more, saying that he is not only against abortion but also against Caesarean sections, which 'prevent women from having more than two children'. According to him, abortion is 'murder' and Caesarean section is 'nothing other than a program to prohibit the growth of Turkey's population' (ntvmsnbc, 29/05/2012; Independent, 30/05/2012).

The view of reproduction and women's bodies as a means of achieving demographic and political targets is openly defended at the state level, as

exemplified above. This is not to say that it is produced against the will of the general public. In fact, these norms and values are also internalised at the individual and community levels. However, as stated by the critics and this study's respondents, a single statement from a top-level state authority has the power to create a backlash against all efforts to improve the related rights, especially in a country where respect for the state is an important element of the culture.

Aşar-Brown (2007, p. 89-90) puts forward a four-level framework, from the individual level to the state level, for understanding the different mechanisms that operate to control women's sexuality in Turkey. At the individual level, women mostly internalise sexual norms that dictate the importance of virginity and honour. At the family level they face positive and negative reinforcements regarding conforming to the sexual norms. Protection from the father and/or husband is a positive reinforcement to keep norms and values in place. Violence, on the other hand, functions as a negative reinforcement of conformity to sexual norms. At the community level, social exclusion and discrimination act as sanctions for women who do not conform to sexual norms; and at the fourth level, governmental legislation allowing virginity tests and the dismissal of girls from school upon disclosure of their engagement in sexual behaviour give the authorities power to control women's sexuality.

The taboo on female sexuality outside marriage, which is maintained by the state ideology, can be seen in the reluctance of the state to implement HIV/AIDS prevention policies that involve sex education for young people. Accounts by authorities about the 'cultural immunity' of Turkey to HIV/AIDS and their call to protect the family structure as a prevention method can be seen as representing the conservative government's perspective on women's sexuality. The idea of the 'modest Turkish woman' held by both secularists and conservatives makes women invisible in the HIV/AIDS issue, with the exception of foreign women.

While most of the respondents stated that HIV-positive women are having more difficulty in living with HIV compared to men, because of the general social and economic restrictions that they already experience, some respondents pointed out that at least in terms of being labelled, women are in a more favourable position.²³

²³ See the section on experiences of stigma in the family in Chapter 6 for discussion of this argument.

However, HIV-positive female and transgender sex workers are experiencing the highest level of discrimination. Discrimination against HIV-positive women from FSU countries is even greater, regardless of whether they are sex workers or not. According to a respondent, this is because 'they are not seen as an HIV-positive person but as the very person who is responsible for the existence of the disease'. One possible reason that sex workers who are Turkish nationals are not blamed as much as foreign ones might be that 'registered'²⁴ sex workers are perceived as 'clean', as explained by a client: 'These women are healthy, the government checks them and we trust them'.²⁵

As mentioned earlier, while sex workers are seen as transmitters of the disease, men's contribution to the HIV/AIDS epidemic as sex industry clients is not questioned. Neither the sexuality of men who are clients of the sex industry nor that of heterosexual men in general is questioned in the cultural immunity discourse, which simply assumes that monogamy is intrinsic to the 'Turkish family structure'. However, sexual performance and experience are considered the bases of manhood in Turkey's patriarchal system. For men, sexuality before marriage is encouraged; their first sexual intercourse often takes place in a state-run brothel and/or with the 'help' of an 'older brother'.²⁶ Men's extramarital affairs are socially acceptable, as evidenced by various Turkish sayings.²⁷ In some cases, extramarital affairs are even socially legalised through the institution of polygyny (İlkkaracan, 1998). 'Illicit co-habitation' or regular sexual contact with sex workers during a marriage or long-term relationship is acceptable, since men consider some sex acts inappropriate for their 'sacred' wives within the 'sacred' institution of marriage (Zengin, 2011). Therefore, according to Aşar-Brown (2007, p.5), in Turkey men's 'sexual promiscuity' is more than accepted; the demonstration of manhood through sexual promiscuity is the constructed male sexuality norm.

While this norm is invisible in the cultural immunity discourse, it was mentioned by the KIs. When talking about 'Turkish men's perception of HIV/AIDS a couple of the respondents referred to well-known Turkish phrases such as *Atın ölümü arpadan*

²⁴ Only Turkish citizens can be a 'registered' sex worker; foreign sex workers work illegally.

²⁵ 'Dimming the Red Lights in Turkey', New York Times, 19/08/2011

²⁶ An experienced person, not necessarily a relative, who facilitates the encounter with a woman available for sex.

²⁷ For example: *erkeğin elinin kiri* (being a playboy is only a bit of dirt on a man's hand); *erkeğin elinin kınası kahpenin yüzü karası* (henna on a man's hand, black mark on a prostitute's face), both indicating that men's sexual enjoyment does not permanently mark him and disappears like dirt washed off his hand (Aşar-Brown, 2007, p.6).

olsun (literally, 'let the horse die from eating barley', meaning 'let's throw caution to the wind', implying that they practice unprotected sex because they like it so much); and *Türk'e bir şey olmaz* (nothing would ever happen to Turks). Referring to these phrases, the respondents implied that even if men had full knowledge of the disease this cultural idea of manhood causes people to see HIV/AIDS as unimportant and creates resistance to protection.

These social perceptions around sexuality are not necessarily linked to Islam, according to the respondents, none of whom mentioned Islam directly (unless specifically asked) as a factor shaping prejudices about PLHIV. One respondent specifically said that Islam cannot play an important role in shaping perceptions because Turkey is a secular country. Some said that homosexuality and premarital sex are considered sinful not only in Islam but also in other religions. As some of the respondents said, prejudice and discriminatory attitudes do not necessarily come from religious people. In fact, 'we experienced some positive situations as well, with Turkey being a Muslim country. For example, the only source of help experienced by one particular person who was being discriminated against was a former *imam* (Muslim religious leader in a mosque) (KI1). One respondent suggested that '[Islamists'] belief system might have a role in making them more tolerant', referring to the common understanding of Islam as 'the religion of tolerance and peace'.

5. Medical discourse: production of disease through epidemiology

Epidemiological data are important as they enable policy makers, planners and healthcare managers to make informed, rational decisions about the use of resources and preferential areas for action (Whiteside et al., 2003). Medical knowledge can be used to manipulate and control populations, distorting epidemiological data according to 'political sensitivities'. Scientific assessments of the epidemic may result in the over-medicalisation and stigmatisation of the disease, as seen in the early years of the epidemic. However, in Turkey the recurrent theme about the epidemiology of HIV/AIDS was the 'lack and ambiguity of data'. Whether or not HIV-related information is easy to obtain and what it does and does not say has implications for how we interpret the political sensitivity of HIV (*ibid*). The absence of adequate and reliable data is interpreted below as a discourse of 'informational silence' which acts as a barrier to the medical

profession's obtaining and interpreting epidemiological data, thus participating in the construction of public perceptions and policies around HIV/AIDS.

From its foundation, the Republic has been engaged in the systematic collection of health information even in the most remote parts of the country, and has 'assigned doctors to various provinces as directors of public health to work as intermediaries between state and society' (Evered & Evered 2012). The new republic's extensive commitment to public health and its prioritisation of population growth 'resonate with Foucault's observation that in modern Western states, population comes to appear above all else as the ultimate end of government' (*ibid*, p.470). For example, the fight against malaria was closely related to the 'early Kemalist state's nation-building project' because this was the first big health issue by which the emerging republic could prove its success in establishing a public health infrastructure, and because Atatürk's main goal was to maintain and increase the population (*ibid*, p.476). To this end, the new ministry encouraged the gathering of health-related information, the engagement of various actors such as the military in the combat against malaria and the application of malaria-related laws even before it passed its first Public Health Protection Law in 1930 to 'broaden and deepen the state's presence in societal and economic affairs' (*ibid*, p.478).

The regulation of sex work and the control of sexually transmitted diseases were linked even before the foundation of the republic. 'The first attempt began with the introduction of the Venereal Disease Ordinance in 1884' (Özbek, 2010, p.555). As stated by the KIs in the sexual and reproductive health sector, state interventions to gather data and to secure the public access to mother-and-child healthcare services were as successful as its fight with malaria. However, when it comes to information on HIV/AIDS, all the KIs emphasised the absence of adequate and reliable data.

The lack or unreliability of data may have two important consequences. The first is that 'the scientific assessment of the scope and impact of the pandemic is thwarted'; secondly, this may facilitate the state's continuing 'denial about the scope and seriousness' of HIV (Whiteside et al., 2003, p.74-75). The KIs discussed these issues with regard to the government's political commitment. As Whiteside et al. (*ibid*, p.50) state, unreliable data can be considered 'a problem with significant moral dimensions and ramifications' in terms of the political responsibilities of governments and scientists. The main question brought up by most KIs was

whether the lack and ambiguity of available data is a cause or a result of the deprioritisation of HIV/AIDS in health policies. From one point of view the reported numbers of HIV/AIDS cases are low, as the lack of priority given to HIV/AIDS results in a lack of surveillance and a monitoring system. In turn, the low figures create a basis for the government to justify the limited actions it takes. Trajectories of the state's response in some countries (Judge, 2005) show that insufficient or unreliable data on the epidemic have resulted in a lack of political commitment and leadership, and have even been used as an 'excuse for continued denial and obfuscation'. Inaccurate data can also be seen as an indicator of underestimation of the problem (*ibid*).

All the KIs were asked to evaluate the HIV/AIDS situation in Turkey. However, within the limits of the available data²⁸ and the lack of any established national model for epidemiological estimations or impact analysis, they were reluctant to make firm comments about the scale and scope of the epidemic. Strikingly, all groups of KIs were reluctant to present an opinion about the national trends of the epidemic, as their opinions were based on first-hand experience only. The common theme was that they could rely on only very few data points, 'basically on an Excel sheet', which should be treated with caution. While the main concern of NGO workers was that they 'do not want to make generalisations about individual people living with HIV'; doctors stated that any claim in the context of a lack of data would not be scientific or valid but would be very subjective and dogmatic.

For instance, the argument mentioned previously, that 'the officially announced numbers of HIV/AIDS cases in Turkey must be just the tip of the iceberg', was considered 'speculative' by some doctors, who challenged the commonly-mentioned UN recommendation to multiply the official numbers by ten, because advanced statistical models and multiple data sources are required for making this estimation (UNAIDS, 2010). In the absence of those scientific methods and data sources, arguments based on general UN recommendations remain speculation. A couple of respondents challenged the idea that HIV/AIDS prevalence rise in Turkey, since Turkey is in the only region in the world (Eastern Europe and Central Asia) where the rise continues. According to them, regional reports that include Turkey are not necessarily valid reference points. Depending on the institution that

²⁸ The content of the available data on HIV/AIDS and the procedures of collection and dissemination were explained in the previous chapter.

prepares the reports, Turkey is included in either 'Eastern Europe and Central Asia' or 'Middle East and Northern Africa'. Turkey differs considerably from the countries of both regions in terms of its cultural/religious practices and the main drivers of the epidemic.

The debate on the actual figures was also linked to issues around HIV-testing practice and procedures in the country. Available data indicate that voluntary testing in response to 'awareness' or 'perceived personal responsibility' is uncommon.²⁹ The results also raise some ethical questions about compulsory and without-consent testing. However, when a desperate need for more data is the major concern, the unlawful and unethical aspects of the testing procedures remained an insignificant topic during the interviews, and were not even mentioned by most respondents.

Another questionable point about the available data, according to the KIs, was the transmission routes of HIV. A very significant gap in the available data is the high number of 'unknown' cases in terms of the routes of transmission.³⁰ A point of consensus among the participants was that transmission through unprotected homosexual intercourse is more common than is shown in the data.³¹ The powerful stigma attached to homosexuality, according to the participants, results in misreported routes of transmission. Because the Case Report Form is generally filled in by the doctor at the first face-to-face encounter with the patient when the latter is given their HIV diagnosis, people could find it very difficult to disclose their same-sex relations. Married men in particular might feel the need to give the doctor another cause such as sex with a female sex worker, which is perceived as more legitimate and justifiable. As some doctors mentioned, if a closer, trust-based relationship between doctor and patient can be established later the doctor may learn of the patient's practice of same-sex intercourse, but cannot make any alterations to the Case Report Form, which has been sent off already.

Considering the general difficulties in understanding HIV/AIDS trends through statistics, opinions about the unreliability of the data may seem uninteresting. Especially in countries where well-developed voluntary testing schemes are not in

²⁹ Testing procedures and the results of Stigma Index Turkey on compulsory and without-consent testing are discussed in the previous chapter.

³⁰ See Appendix 6.

³¹ Different findings on HIV prevalence among male homosexuals and transgender individuals are discussed in the previous chapter.

place, national totals of reported HIV and AIDS cases are rarely considered useful (Whiteside et al., 2003). However, the salient point in nearly all KIs' narratives is the link between the absence of data and the state's reluctance to gather and share data, rather than technical inadequacy. The main theme of the 'lack and ambiguity of data' is not limited to statistics related to HIV/AIDS; it includes problems with obtaining available data and information on what is being done at the state level.

Until 2007, HIV/AIDS statistics were announced in the standard MOH annual reports but they were removed from these reports after 2007 on the 'instruction of the Minister', according to a participant. The reason for this instruction was that some of the figures announced by the relevant units of the Ministry and figures disseminated to IOs had been inconsistent, which had created serious problems (no further details were given by the respondent). Data are not 'hidden' from the public but have become difficult to reach. In this situation, some doctors who participated in the research stated that they learn the new figures from newspapers or have to send an official request to the Ministry.

Some research participants expressed problems with obtaining information on several issues such as the budget allocated to HIV-related interventions, meetings of the National AIDS Commission, the number and situation of the Voluntary Test and Counselling Centres and the output of the HIV/AIDS Prevention and Support Programme funded by the GF. For instance, some of the doctors and NGO workers who are personally involved in NAC said that they are not informed about when the Commission meeting was held and what issues were discussed, and some participants mentioned the lack of a transparent communication system by which they can be informed of the outcomes of the projects in which they were involved. I sought some strategic information about the above-mentioned points myself from people responsible for such matters, without success. A written parliamentary question was submitted by an MP to the Minister of Health³² asking for the most recent data on HIV and information about state-level interventions, but it remained unanswered.

The difficulty in obtaining and interpreting epidemiological data provides open ground for the construction of several, sometimes conflicting, discourses. One of

³² Accessible online from GNAT

http://www.tbmm.gov.tr/develop/owa/yazili_soru_sd.sorgu_yonlendirme

the main expressions across all KIs' narratives was that 'Turkey is somehow lucky'. In the absence of data, this 'luck' factor can be explained in different ways such as the 'advantages of the Turkish family structure', as seen in the cultural immunity discourse. The 'luck' factor can also be left unexplained, as some of the KIs in important positions at the MOH and in IOs do. The gaps in the data also offer opportunities for different interpretations. The relatively high proportion of 'non-Turkish' infected people, for instance, facilitates the association of HIV with foreign sex workers (MOH, 2008a). Opposing actors can defend their arguments with equal strength since it is equally easy, or difficult, to demonstrate valid evidence. As one doctor said, 'Maybe it is better this way; at least we can focus on whatever we want'.

The recurrent theme of Turkey being 'somehow lucky' is important, as it points out the idea that low prevalence is not explained by successful management of the disease. It is striking that none of the participants, including MOH representatives, introduced tangible examples or facts to state that the reason for the low figures could be successful management of the disease.

To sum up, in the context of the state's reluctance to obtain and share data, medical discourse does not seem to be contributing to the state's lack of action. The state does not draw upon medical discourse to justify its inaction. On the contrary, the medical profession is powerless in the face of the state's inaction. The state's deprioritisation of HIV obstructs the medical profession from putting a medicalised discourse in place for proper management of the disease. It is also notable that not only doctors, but none of the actors, such as the Ministry, the NGOs, health professionals or IOs claimed that they have a decisive role in shaping the patterns/trends of the epidemic.

Even though overmedicalisation is not seen as a major problem in HIV-related interventions, due to the resistance of the state, the effects of medical discourse can be seen in other areas, especially the relationships between doctors, patients and patient activists.³³ The bias in the sample should be considered here. Most of the doctors in the sample refrained from imposing personal opinions that are not

³³ Although doctors and NGO workers could be allies in terms of their criticism of the state's response, resistance to lay expertise acts as a barrier to such collaboration. Lay expertise and doctor-patient relationships are discussed in Chapter 6 and 7 in relation to PLHIV's own experiences.

based on evidence. However, the majority were infectious disease specialists (IDSs) who are among the most knowledgeable and experienced individuals in the field and are involved in civil society activities to varying degrees. Therefore it is possible to say that they would be more sensitive about the issue, especially in terms of seeing the gaps and opposing viewpoints in the field. In this sense the sample does not reflect 'general medical discourse' on HIV/AIDS in society at large. The general (low) level of knowledge and the prejudices of other health professionals, which have had a tremendous effect on the illness perceptions of PLHIV and the general public, were expressed in the narratives of both KIs and PLHIV, as discussed in the next chapters. It can be argued that in a context where medical professionals who specialise in HIV/AIDS cannot actively participate in the construction of HIV-related discourses, the medical discourse continues to reflect the cultural immunity discourse in the views and attitudes of other health professionals who share the same uninformed and biased ideas about PLHIV as the rest of the public.

6. Conclusion

The construction of HIV/AIDS as represented in the statements of health-related state representatives has two components: the attribution of the epidemic to foreign sources and the neglect of HIV-related populations and behaviours in the country. This leads to the cultural immunity discourse and results in deprioritisation of the epidemic. While there is not complete denial or silence because of the perceived necessity of improving human rights and health services in the process of modernisation, in the current political environment, rights-based approaches are interpreted in a framework that sustains patriarchy, religious values, communitarianism and xenophobia and leads to a controlling discourse that prioritises restrictive measures over the promotion of individual rights and freedoms. In this context, rights-based approaches to HIV/AIDS need to be reframed in a way that emphasises the 'normality' of HIV-positive individuals and their right to health for the sake of public health. The implications of this for NGOs' stigma-reduction policies is to focus on 'good', 'positive', 'innocent' examples of HIV-positive individuals. Because the state ideology was seen as responsible for (or a source of, and reproducing) stigmatising discourses, the participants did not see stigma reduction as its responsibility. An umbrella organisation of NGOs is needed both to facilitate stigma-reduction interventions and to strengthen the voice of civil society against the barriers set up by the state. The state's resistance and the relative weakness of civil

society to create change explained in the previous chapter are also important in understanding the contestation of discourses described here.

This chapter has explored the formation of the cultural immunity and rights-based discourses and the effects of patriarchy and medical knowledge in the social construction of HIV/AIDS within those discourses. In Turkey's political trajectory, sexuality has always been a site of struggle in building national and/or religious identities. Secularists' and Islamists' perceptions of gender both reproduce patriarchy in different forms. While, as an Islamist party, the current government engages in ideological moderation in all spheres, it also 'reconstructs femininity as pertaining to family by making references to religious texts, custom and tradition' (Çavdar, 2010, p.341). Epidemiological information and the medical profession have been used as a major means of controlling the population, and especially its sexuality, since the early republican period in Turkey. The current lack and ambiguity of epidemiological data and the inaction of the state might be interpreted as the state's reluctance to confront the populations and behaviours that it wants to deny. As a PLHIV activist stated, if the state identifies such populations and their behaviour, it must first confess that they have existed all this time, and next it must take action. There is then the dilemma that from its standpoint, such populations are marginal, sinful or dangerous, but in a democratic, modern and secular country they need to be protected and served. In these circumstances, deprioritisation seems to be the solution.

As stated by Strebler (1993, cited in Judge, 2005), discourses of silence facilitate denialism and apathy in response to HIV/AIDS and drive the epidemic underground, exacerbating vulnerability to infection and reinforcing the stigmatisation of both the disease and those living with it. As opposed to the cultural immunity discourse, it can be argued that the official figures for PLHIV are low in Turkey, not because of the cultural immunity, but because of the 'theory of cultural immunity' that contributes to the stigmatization and therefore to the invisibility of the disease.

Chapter Six

Family and healthcare as institutions shaping the initial meanings attributed to a life with HIV

1. Introduction

This chapter investigates how the process of stigmatisation is perceived and experienced by PLHIV, with a specific focus on the family and health institutions. Considering the main assumption of the thesis, that the management of HIV and its stigma involves the construction and transformation of identities, this chapter demonstrates the main processes by which HIV is given meaning and initially integrated into the identity. Healthcare and family are discussed as the main institutions in which perceptions about the illness itself and the anticipated stigma by society begin to form.

Both the narratives of the participants and the secondary data indicate that family and healthcare institutions are the two main areas for detailed investigation if we are to understand the context-specific characteristics of HIV-related stigma in Turkey. The investigation of these two institutions is also important because they are the main areas in which the effects of patriarchal and medical discourses can be seen, in line with the main aim of the research. Stigmatisation by health institutions was one of the most problematic dimensions of HIV-related stigma for PLHIV, not only because health institutions are the most frequently-mentioned site of stigmatisation but also because this has a major effect on PLHIV's ability to fulfil health-related chronic illness self-management 'tasks'. The family, as an institution, has a fundamental role in identity formation and self-evaluation of identity, especially in a relatively less individualistic context like Turkey. It is the main context in which the social effects of living with HIV are made sense of and where they are felt most intensely by PLHIV.

Focusing on these two topics, this chapter answers the key research question: 'How is the process of stigmatisation experienced and perceived by PLHIV?' The related sub-questions are: 'In what forms and contexts do PLHIV experience

stigma?'; 'What are the factors that differentiate experienced stigma, particularly in relation to family and health institutions?'; 'How are the meanings attributed by PLHIV to HIV/AIDS constructed in these contexts?', and 'How is internalised stigma formed by and/or affecting experiences in family and health institutions?'

One of my main arguments in this thesis is that the management of HIV-related stigma is an identity construction process in which actors are constantly negotiating with the discursive power relations that exercise control over them. In the context of Turkey, the family plays a fundamental role in the construction of the individual's social identity, within the framework of social control, and is a main reference point for self-evaluation to locate oneself in broader society. While most participants' narratives showed patterns of support rather than rejection from families, I argue that family-related social expectations and desires are the main drivers of internalised and felt stigma because the effects of HIV are expressed in terms of perceived success or failure to fulfil family-related social roles. I also argue that the nature of PLHIV's relationships with doctors and other health professionals, in terms of trust and support, is an initial factor in shaping the ways in which HIV is integrated into the self, the meanings attributed to health-related behaviour by PLHIV and PLHIVs' expectations about how they will be treated by society.

This chapter mainly draws upon a thematic analysis of the life stories of 24 PLHIV, generated through a biographical narrative interviewing method. Unstructured interviews with four people living with HIV who were initially interviewed as KIs are also included in the analysis. Informal conversations and daily interactions with other people living with HIV, as logged in my field diary, provide additional primary data. In addition, related themes in KI interviews are used. Unpublished results of the Stigma Index Turkey survey (SIT, 2010), interviews with PLHIV that have appeared in the media, published testimonials of HIV-positive people and entries on websites and in blogs written by this study's participants or other PLHIV in Turkey are also used as secondary data.

The main point of departure for interpreting PLHIV's stigma-related experiences and perceptions is the theoretical framework presented in Chapter 2, which draws on stigma-management and chronic illness-self-management literature. Here I should mention that while the analysis was based on these conceptual models, I paid attention to capture the participants' own definitions about the processes they were going through. As explained in the Methodology chapter, the interview format

(for both PLHIV and KI interviews) was designed to bring forward the subjective perceptions and to refrain from 'forcing' a conceptual framework on the data. When talking about stigma-related perceptions and experiences, the mostly used terms by the participants were prejudice, discrimination and exclusion. 'Stigma' was used mostly by KIs with an academic background and by PLHIV involved in NGO work. Participants working in civil society also mentioned 'human rights violations' to refer to the stigma-related experiences of PLHIV.

As explained in Chapter 2, an intersectional approach to stigma is adopted with a view to interpreting differences in the participants' experiences and perceptions. At the end of the chapter, family and health-related experiences and perceptions are linked to the discursive structure explained in Chapter 5, referring to patriarchal and medical discourses respectively. Chapters 7 and 8 focus more on the categorisation of stigma management strategies and the internal and external resources used in stigma management. Descriptions of how people manage some situations are given here with the purpose of exemplifying their feelings and perceptions.

2. Stigma in healthcare settings

Stigmatisation in the healthcare setting was most frequently mentioned by PLHIV and KIs and in NGO reports. In this chapter I describe various forms of stigmatisation in healthcare settings including 'refusal of care/sub-optimal care', 'excessive precautions and physical distancing', 'humiliation and blaming' (Rahmati-Najarkolaei et al., 2010), breaches of confidentiality by healthcare providers and anticipated stigmatisation. I then discuss the effects of stigmatisation in healthcare settings on the internalisation of stigma, trust in health professionals and the health system, and health-seeking behaviour. First, I briefly explain the test and diagnosis process that the participants underwent.

'We have detected foreign matter in your blood' or 'Your blood is spoilt so you need to come and give blood again': for many PLHIV in Turkey, the story of getting acquainted with HIV starts with words like these from a healthcare provider, on the telephone or in person. Wondering about identity of the 'foreign matter' in their blood sample, people rarely think of HIV for two reasons. First, as explained in previous chapters, most HIV tests are carried out without the knowledge or consent of the patient. PLHIV learn of their sero-positivity when they are being examined for

other illnesses, during pregnancy or when giving blood for non-illness-related reasons. Because of the low level of awareness and knowledge about the disease, people have difficulty in making sense of their possible illness when they hear the above words from a healthcare provider. The table below shows how participants were tested for and diagnosed with HIV.

Table 6: Participants' reasons and consent for testing

Reasons for testing for HIV and whether the test was voluntary/compulsory/with consent	Number of people	Total
Voluntary test after suspicion (only 1 received pre-test counselling)	3	5
Voluntary test after being ill	2	
Pre-surgical test (without knowledge/consent)	3	
Unknown serious sickness (without knowledge/consent)	5	
Other disease-related test (without knowledge/consent)	1	
Test during pregnancy (without knowledge/consent)	1	10
Compulsory test for sex workers	1	
Compulsory test before going abroad	2	
Compulsory test before marriage	1	
Compulsory test after donating blood	1	
Tested when the spouse is diagnosed	3	3
Total	23	23

With regard to the level of knowledge about HIV/AIDS before being diagnosed, none of the female participants said they had 'sufficient' information about HIV before being diagnosed. Three women explained that they had not even heard of HIV/AIDS. The levels of heterosexual and homosexual men's knowledge of HIV/AIDS before diagnosis also differed. Homosexual men's knowledge appeared greater than that of heterosexual participants. Some said that they knew about HIV and how to protect themselves, but did not know about the treatment and the possibility of living a long time with HIV. Three homosexual participants reported that they had sufficient knowledge of HIV/AIDS, including the treatment, but none of the heterosexual participants did. Two heterosexual men stated that they knew nothing at all about HIV when they were diagnosed.

In a context where pre-test counselling is not offered and where patient consent is not even requested, for many PLHIV who have had no chance to think or learn

about it, the diagnosis is an extremely shocking experience. The story of Tahir (22, male), who went to see a doctor for a mild dermatological problem, exemplifies the uncertainties and concerns of PLHIV in the process of testing and diagnosis:

"[I thought] I was going to be treated and leave [the hospital], I mean I was going to stay for one or two days and go. About a week later they said 'you should stay'; then after 2 days they wanted tests of me. I was behaving as if everything was normal. Then I saw.. HIV there [written on a piece of paper that the nurse put aside]. I said [to my self] *Allah Allah?* [expression of surprise and curiosity] (...) I asked the nurse 'what does HIV test mean?'; because I didn't know what it was. I said 'what does HIV test mean?', ... I mean 'what kind of test is that you are doing to me?' S/he said something like 'speak to your doctor we are not entitled to give information'. And that [document] read "suspicious". Suspicious? ³⁴ (...) Some way or another you get worried. What test are they doing to me? ... Then in the hospital I walked around, asked people 'what does HIV test mean for God's sake!' (...) [they said] 'your doctor will come tomorrow, you'll ask him'. I asked him. 'What does HIV test mean? What does HIV mean for God's sake!'. And then he said 'it seems at the moment that you are HIV-positive' and I thought it's a good thing to be HIV-positive. I mean it's 'positive'. What does positive mean? And then the doctor said 'uhm, now, there is nothing to be afraid of, HIV-positive means, that you are carrying AIDS virus (sic)'. At that moment my world already came crashing down around me, for real." (Tahir, 22, male)

During the period when he was not given information about the tests and diagnosis, Tahir understood that the problem was serious; he thought that it might be cancer. He explained that he had heard of HIV/AIDS as a disease related to homosexuality and so did not think of it at all as he is heterosexual. The public perception of HIV/AIDS as 'not our disease', due to the cultural immunity discourse explained in the previous chapter contributes to the lack of perception of HIV risk and to the overwhelming shock of being diagnosed with HIV.

Post-diagnosis counselling is important at this stage. However, fewer than half of the participants had received counselling from a health professional immediately after their diagnosis. Here, 'counselling' means what the NHS defines as 'post-test discussion for individuals who test positive'. It includes giving the results face-to-face and explaining, simply and clearly, the disease, its stage, its treatment, ways of protecting oneself and others, possible physiological and social effects, a discussion about partner notification or, if the counselling is given by a non-specialist, information about the disease and referral to a specialist (WHO, 2007; St Georges Healthcare Guideline, 2011). Of the seven people who received

³⁴ This possibly means that the first HIV test is positive, so another one and an additional confirmation (Western Blot) test is needed.

counselling when they were being informed about their diagnosis, four stated that it was a 'good' experience in terms of being provided with correct knowledge and comfort by the health provider. Other participants were left alone with their positive test results; some received counselling when they later visited a specialist and some received their first and only counselling from an NGO.

2.1. Discriminatory attitudes of healthcare providers

Rahmati-Najarkolaei et al. (2010) categorise stigmatisation in the provision of healthcare services as 'refusal of care', 'sub-optimal care', 'excessive precautions and physical distancing' and 'humiliation and blaming'. Two other forms of stigmatisation are also discussed below. Anticipated stigmatisation from healthcare providers is mentioned first. Finally I discuss breach of confidentiality by healthcare providers, which was one of the main themes put forward by both PLHIV and KIs when describing experiences of stigmatisation.

Table 7 below demonstrates incidents of stigmatisation in healthcare settings as expressed in the biographical narratives of the participants. Explanations of those incidents are given below under related sub-headings. Table 7 demonstrates only the number of incidents that the respondents personally experienced and explained in the interview. Participants also put forward some more general evaluations or arguments about their own and other PLHIV's experiences of stigmatisation in healthcare settings without being specific.³⁵ Those are mentioned or quoted below, under relevant topics but are not included in the Table.

Table 7: Incidents of stigmatisation in healthcare settings expressed as narrative

Incidents of stigmatisation experienced in healthcare settings	Number of incidents
Refusal/sub-optimal care	8
Excessive precautions and/or physical distancing	7
Humiliation/blaming	8
Breach of confidentiality	5
Anticipated stigmatisation before seeking health-care	10

³⁵ For example, 'they don't feel comfortable when dealing with us', 'doctors should be educated', 'going to the hospital is a source of worry for PLHIV'.

Only two participants stated that they had never experienced any of those forms of stigma. One explained that he was discriminated against because of his sexual orientation and not his HIV status. The other participant, a male homosexual, explained that health professionals generally facilitated the provision of healthcare, 'because they felt pity for him'.

Stigmatisation is experienced in various settings such as the doctor's office, the dental practice, the ER, the waiting room, the test laboratory and the registration desk. Participants mentioned different actors as perpetrators of stigmatisation in healthcare settings, including not only doctors and nurses but also senior professors at teaching hospitals, pharmacists and other non-medical hospital staff such as secretaries, cleaners and security guards.³⁶

Anticipated stigma during the test, diagnosis and seeking health-care

Previous research shows that anticipated stigma in healthcare settings is one of the sources of concern before being tested for HIV, while waiting for test results and between being diagnosed and seeking healthcare from an institution. Concern about mistreatment and lack of confidentiality from healthcare workers are among the drivers of late testing and late treatment (Sprague, 2011). In a context where the majority of HIV tests are done without the knowledge or consent of a person already under treatment in the hospital, as exemplified above in Tahir's case, there is little space for anticipating stigmatisation during the test and diagnosis process. On the other hand, the few people who were tested voluntarily or who thought themselves at risk of HIV mentioned anticipated stigma from healthcare providers.

In this context, anticipated stigma is experienced after diagnosis, firstly in the period between the diagnosis and seeking healthcare, and later when attending hospital for any reason. Although many people were diagnosed with HIV at the hospital when examined or treated for another illness, some were not seen directly by an infectious disease specialist (IDS), especially when there was no specialist in that hospital. In such cases, or when they prefer to see an IDS in another hospital/city/neighbourhood for various reasons, concern about how they would be treated by the healthcare providers began. Mehmet, a 21 year-old man, who

³⁶ Although discriminatory attitudes from hospital staff in non-medical jobs are not the subject of this chapter, in Turkey, it is not uncommon for people in these jobs to be involved in delivery of care, for example in the forms of carrying a patient or giving medical advice.

reported having had no problems while receiving healthcare, explained his fears and how he had prepared himself for his first encounter with his doctor:

“I’m a person who cannot tolerate unfairness. And I always thought [after being diagnosed with HIV] that I was going to be subjected to prejudices in some way. The first day I went to the hospital.. Actually a day before going, at home, I kept talking to my self, er, like ‘this is what you need to do: Keep quiet, no matter what they say to you. And you certainly must do that, one way or another; because you need to live’. Because I was thinking that I was going to be subjected to prejudices, for sure. This was my first fear. I was trembling when I entered into the hospital. And I went there alone. My mother and father wanted to come but [I thought] if something happens to me there my mother and father would get very upset. Because I didn’t want them to be sad, I took the train from [the city where he studied] to [another city] by my self. Er and I talked to my self. ‘They will certainly yell at me, they will reprehend, despise me. But you have dreams, you have ideals. You must absolutely take the path of least resistance because you have to live.’ I said to myself ‘no matter what they say to you, just don’t say anything back at them.’ And this is how I entered the room.” (Mehmet, 21, male)

Experiences of other people that he knew and research on the Internet had convinced Mehmet that he was going to be verbally abused by medical staff. However, when he entered the room he ‘came across a very nice doctor. Everybody in the hospital, including the nurses, was very nice’.

Not all the participants were as lucky as Mehmet. Many were subjected to discriminatory attitudes from healthcare providers; sometimes their own doctors (IDS who care for PLHIV) but mostly other medical staff in non-HIV-related departments. Different forms of stigmatisation in the provision of healthcare are explained below, following Rahmati-Najarkolaei et al.’s (2010) categories of ‘refusal of/sub-optimal care’, ‘excessive precautions and physical distancing’ and ‘humiliation and blaming’.

Refusal of care/sub-optimal care

According to the narratives of both the PLHIV and KIs in the health sector, healthcare providers in general are reluctant to be in physical contact with PLHIV. Motivated by fear of contamination and/or moral judgement, this unwillingness sometimes results in sub-optimal care if not direct refusal to provide healthcare altogether. Although NGO reports (PYD, 2009; 2010) and KIs stated that direct rejection from hospitals on the basis of HIV status have decreased in recent years, PLHIV who revealed their HIV status to healthcare providers were refused care in different ways. Both they and KIs mentioned cases of sub-optimal care including

delays in treatment, being offered alternative treatments and insufficient attention to the patient.

Eight participants' narratives included cases of direct refusal of care or sub-optimal care. Among those, two were denied surgery; scheduled surgery being cancelled at the last minute when their HIV-positive status was revealed. Nurses refused to take blood or vaccinate three; two were kept waiting for excessive periods for an appointment, a test or medical screening. These delays were perceived as intentional due to the patients' HIV status.

Another participant, Aslıhan, was taken to the emergency service of a general hospital when she was at AIDS stage. She was kept in a bed at the emergency room (ER) for three days, since she was not accepted by the infection department. According to her, the reason was not that she was HIV-positive but that she was a transsexual. The official reason that the hospital gave was that she did not have social security. However, after three days her friends, all MTF transsexuals, threatened to burn the hospital down if their friend was not offered a place in the infection unit. In the next hour Aslıhan was taken to the infection unit and her ARV treatment started. According to her she would have died in ER if her friends had not done this. A similar case occurred during my fieldwork period; another MTF transsexual who was close to death was refused by two hospitals on the grounds that she had no social security. She was cared for by her friends in a hotel room until some LGBT and PLHIV activists made her case public and attracted the attention of the Ministry of Health.³⁷ The chief doctor of one of the hospitals that had rejected her stated: 'The patient voluntarily decided not to stay at the hospital because she was embarrassed' (KAOS GL, 26/08/2010).

PLHIV are experiencing refusal not only of HIV treatment but also, and more frequently, non-HIV-related healthcare. In August 2011, an HIV-positive man with a prosthesis in his knee explained to the media that his prosthesis had developed an infection and needed to be replaced, but that he had been refused by many doctors. For the last three years while trying to find a surgeon who would operate on him he had an infected knee and was unable to walk without crutches. When he revealed his HIV status doctors argued that they did not have a place, the

³⁷ This was a short-term and rare example of collaboration between LGBT and HIV/AIDS activists, who generally do not work together except for a few prevention projects, conferences and World AIDS Day activities.

equipment, the time or authorisation for surgery, or openly said that they could not operate on him because of his HIV status. He stated: 'I could have been operated on if I had not revealed my HIV status, but I did. I trusted the doctors and they ruined my life.' (*Medimagazin*, 08/08/2011). Similarly, Civa, a 32-year-old man, explained that doctors changed their minds about the treatment he needed after they learnt of his HIV status. They offered different treatment options that did not involve a surgical operation, even after his doctor (IDS) had provided an official letter stating that having an operation would not be bad for his health.

According to the participants and KIs, doctors who refuse to operate on HIV-positive people often claim that they involve special precautions, but in fact no additional measures are needed besides the universal precautions. They also stated that denial of treatment on the grounds of HIV sero-positivity is illegal, but there are bureaucratic and moral obstacles to winning such cases in the law courts. Infection specialists who defend their patient's rights to proper care have come into conflict with other doctors or the hospital administration. They do not always win their cases, and their patients continue to live with this unresolved, non-HIV-related medical problem. For example, I was introduced to a person who lived with a bullet in their head. While their doctor believed that surgery to remove the bullet had been denied because of their HIV status, both doctor and patient were convinced that there was no urgent need for surgery as the patient was 'just doing fine'.

Apart from refusing to perform surgery, other frequently-mentioned cases of refusal or sub-optimal care in non-HIV-related health clinics occurred in dental and obstetric services. A PLHIV activist explained that in recent years there have been more frequent cases of HIV-positive women were being denied delivery at the obstetric department, and NGOs have to intervene to persuade the hospital to take them, or find another for the delivery. Another frequently-mentioned problem was nurses in non-HIV-related health services refusing to provide care. According to the participants, they 'get nervous' when they need to take blood and 'one nurse hands it off to the other, that one hands it off to another'.

Excessive precautions and/or physical distancing

Seven participants stated that they perceived excessive precautions being taken and/or physical distancing as stigmatising. Wearing double layers of gloves, isolating the patient from other patients, labelling their files or beds 'HIV' and

refraining from touching things including blood tubes associated to the patient are some examples. Some participants had been kept waiting for hours in dental clinics because the dentists tend to wait until all their other patients are gone.

Two participants were kept in a quarantine ward for no clear medical reason. They were denied contact with both their families and other patients on the same floor. For days they saw only a couple of healthcare providers who visited them. The respondents considered this situation unnecessary, based on misinformation about HIV transmission and psychologically painful.³⁸

Isolation and physical distancing is experienced not only in the clinic environment but also in other settings in health institutions such as a laboratory or administrative offices where PLHIV take their test results or other paperwork. Two participants explained that they had been literally kept at a distance in an office, being told that they might 'spit or sneeze'.

Besides the participants' narratives I personally experienced an incident when I was accompanying an HIV-positive person just after surgery at the hospital and a nurse was reluctant to offer the required care and made me undertake some of the jobs that she would normally do. The nurse gave me instructions – including wearing a double layer of gloves and taking the utmost care to protect myself – and supervised me while I was doing the procedures, which included the patient's blood and other body fluids.

Humiliation and/or blame

The majority of the participants' narratives about stigmatisation in healthcare settings were about humiliation and blame from healthcare providers. Eight participants had experienced such verbal and/or non-verbal behaviour. Doctors' over-inquisitive attitudes, asking questions such as how the patient 'caught' HIV, giving advice about how to behave or live their life and even their facial expressions were perceived as discriminatory. Tahir described his first encounter with discrimination as follows:

³⁸ Another person was subjected to a similar physical isolation when he was in prison. He explained, in an HIV-related local conference, that he was kept in a one-man cell normally used for solitary confinement in prisons in Turkey, for weeks because the prison administration did not know what to do with an HIV-positive person.

"She (doctor) [said something] like 'don't get married, don't get into relationships', she behaved like that, I asked her something like 'is my sex life over now' and she said to me 'er, of course'. She said 'of course'. I said 'when you are protected, is there a probability of transmission?' She said 'even if it's 1 percent there still is'. Because of that, my orientation towards sex .. I became a bit more reluctant, I mean I'm scared now because, what if it is transmitted or so? (...) [She] said 'what do you do for living, are you in food business? Mind you don't.. be careful' she said 'food business is very risky business' she said, I mean she was like threatening me, I mean like 'you are in food business, I will report you because you contaminate people'. And she wasn't looking at my face when she was asking things. She was just filling my file. I experienced this kind of apathy. I mean, then I said, oh so there really is such a thing like discrimination." (Tahir, 22, male)

In some cases this can be more directly and explicitly expressed. For example, Tibethan's (31, male) doctor told him that he 'should have thought about all this before he [had unprotected sex]' and that he must suffer the consequences. In another case, witnessed by an infection specialist among the KIs, the doctor yelled at a patient, calling her a whore to her face in front of other patients waiting in the corridor.

Humiliation and blame from healthcare providers are based on their assumptions about PLHIV's 'immorality' and personal responsibility for acquiring HIV. Such assumptions have also been documented by Namal (2003) in a case study of an HIV-positive man and his acquaintances who were discriminated against in different hospitals. Namal (ibid) reports that a 35-year-old homosexual man, who was nearly in the final stages of AIDS and who eventually died in the hospital, was brought to an intensive care unit (ICU) after he attempted suicide. The unconscious man was discharged from the ICU and his friends and family experienced moral judgement. Namal (ibid, p.499) quotes the ICU chief and doctors saying:

Only their lives are important. They live in ways that give them AIDS and then they undermine the health of other people. We have just performed a tracheostomy. I have inserted an intravenous line without gloves and taken blood by sucking it with a pipette.

Namal (2003, p.499) also reports that other medical staff, including medical students and nurses, thought that they could simply 'throw him out whenever we want and not even touch him. We do not have to take care of an AIDS patient!'

Breaches of confidentiality

The PLHIV Stigma Index Turkey survey results (SIT, 2010) offer an idea about the confidentiality of medical records of PLHIV in health institutions. Of the 100 PLHIV who participated in the survey, 44 reported that their HIV status had been disclosed to third parties in a health institution without their consent; 30% were not sure if a health professional had disclosed their HIV status without consent; 30% were sure that their medical records were not being kept confidentially and 39% were not sure about this.

Participants' and KIs' narratives confirmed that confidentiality is breached in various ways in hospital including marking or labelling beds and files, revealing patients' status to other doctors for no medical reason, gossiping among nurses and other hospital staff such as secretaries and security guards, telling patients' friends and relatives the patient's HIV status without consent, and publicly announcing their status such as by calling them, 'Hey you, the woman with AIDS' in the waiting room. Two participants witnessed that their HIV status had been disclosed by healthcare providers to other healthcare providers in different services at the same hospital without a medical reason and without their consent; three others explained that healthcare providers talked about their condition with other patients, making them feel embarrassed and angry.

The idea of medical confidentiality or the confidentiality of personal information in the provision of public services in general is not well established in Turkey (Berk, 2009; Çokar, 2012), and some features of the health system facilitate the breach of confidentiality.³⁹ For example, the newly-adopted Family Medicine system (*Official Gazette*, 25 May 2010/27591), was considered by some participants to pose a major danger of unwanted disclosure for PLHIV. The main concern was that, in this system, HIV status of the person will be known by the family physician, who will be responsible for all members of a family and of a neighbourhood. According to some respondents, the HIV-positive status of individuals will now be spread around more easily and provide grounds for more stigmatisation, since the concept of confidentiality is not well-known or respected by health professionals in general. Although no participants mentioned a case of disclosure without consent occurring

³⁹ See Chapter 4 for the details of a former referral system that affected access to healthcare for PLHIV working in the public sector.

in this newly-adopted system, in this context of insecurity both KIs and PLHIV themselves expressed their fears about what will happen now:

"But I don't want these [the things we talked during our interview] to be heard by the family physician [practice], if they are heard, then I will blame you [the researcher, personally]. They [physicians] would search for us, they would laugh at us. In big cities, in here, it won't happen but in small towns [home town of the interviewee] it happens. .. As long as I can, I won't go to these places [family physician practices] .. Let these things [our interview] not be heard by our country (here, means 'my village)." (Adem, 60s, male)

Secondly, as mentioned by some respondents, the online MEDULA computerised system for organising and following information about patients, doctors, hospitals, diagnosis and treatment is creating a major threat to the confidentiality of medical information. The system is also used by pharmacists, who, along with anybody else with access to the system and who knows the national identity number of a person can see their whole medical history. According to the respondents, this creates a problem, particularly in small towns and neighbourhoods where people know each other. Some HIV-positive persons prefer to use a pharmacy as far as possible from their neighbourhood. I observed during my fieldwork that PLHIV learn the names of 'non-discriminatory', 'more conscious' pharmacists by word of mouth and prefer to use these:

"Here [at the NGO] they told us [me and my husband] that there is this pharmacy, that we can get [our medicines] from there. It's also close to the hospital, they behave very nicely, they are very concerned [with us], also, it's like as if everything is planned for us, everybody is so smiling, so nice, they are guarding [our] secret strongly [I told this to them as well] I say 'you also have a lot of effect upon us'. Because, I go into this place without any hesitation, as soon as they see me they say 'okay your medicines are ready' and they give them to me in a package. I mean, even if there is someone else with me, whom I know, I think, I feel comfortable, even if I am with someone I know, I know that they won't let on about it. This is why it's very good, it's very important." (Fidan, 27, female)

Breach of confidentiality of PLHIV's medical records in health institutions, which is considered one of the most important problems for PLHIV in Turkey, is not considered a major issue in the literature on discrimination against PLHIV in the provision of healthcare. Breach of confidentiality might not be seen as specific to PLHIV and thus might not be considered as 'discrimination based on HIV status', in a context where medical records of other patients are not protected either. Yet, the effects of these breaches are unequal and facilitate stigmatisation in terms of both

creating shame and worry for PLHIV and providing grounds for discriminatory attitudes in others.

To understand the importance of breaches of confidentiality, I look at the reasons behind them and PLHIV's perceptions of this situation. Respondents' narratives and my personal observations indicated that non-HIV-related healthcare providers and hospital personnel are more likely to disclose patients' HIV status than the health professionals specialising in HIV. The former group's reasons for disclosing a patient's HIV status are to 'protect' others (which represents misinformation about HIV transmission) and/or to 'share' 'interesting' information (in other words, to gossip). Both reasons point to fear- and value-based assumptions about PLHIV. Accordingly, PLHIV were faced with those assumptions when their status was disclosed to others without their consent. They not only perceived confidentiality as a 'special necessity' but also considered breaches of confidentiality ill-intentioned. A very important aspect of PLHIV's perceptions of confidentiality is that breach of confidentiality affects their expectations from and trust in medical professionals, and contributes to the feeling of insecurity mentioned in the following subsection.

Variations between healthcare providers/institutions in terms of discrimination

Both PLHIV and the KIs of this research stated that stigmatisation is lower in infection clinics, and higher and more frequent in other departments.⁴⁰ Diminished stigmatisation occurs in healthcare settings as an outcome of doctors' familiarity with HIV/AIDS cases. According to a key informant from civil society:

“(...) [It does not make sense] to expect that an orthopaedist is free of prejudices, when the doctors in infection departments have only recently started to face the issue, to gain experience and to break their prejudices. Because, s/he has not met [any HIV-positive person] so far; the only HIV-positive people they have seen are people in deathbed, what s/he knows as AIDS.” (KI18)

According to the KIs, in hospitals with well-established infection units and doctors experienced in HIV treatment, doctors in other departments are also 'getting used to the idea' and to PLHIV. There are cases in which PLHIV's doctors are important

⁴⁰ It should be noted that this might reflect a sample bias, since the majority of participants living with HIV had had some kind of peer advice about the 'best' and 'non-judgemental' hospitals and doctors.

actors resisting stigma and acting as intermediaries to solve problems between doctors resulting from HIV-related stigma. Problems of refusal or sub-optimal care in non-infection departments are generally resolved by the personal initiative and communication skills of PLHIV's doctors. One KI explained that because there is no proper system for dealing with patients' social problems and preventing violations of their rights, doctors sometimes 'embrace their patients as if they are from family, as if they are their siblings or relatives' and try to solve problems using their personal relationships with the people in those services. According to the respondent, this is a reflection of the general 'problem in our country, the problem of social injustice and [shortcomings] of the system. When a problem could not be solved within the system, doctors try to use personal relationships. [However] after a while this doctor is replaced by another and everything starts all over again from scratch.'

According to a KI who had visited healthcare providers in hospitals in different cities across the country as part of awareness and advocacy projects, there are geographical differences in doctors' perceptions about HIV patients. The differences are again related to the extent to which hospitals in a particular city have experience of HIV/AIDS patients. For example, in some 'exceptional' cities in the East where HIV/AIDS is 'normalised' and there are well-established infection clinics with good relationships with other departments, refusal or sub-optimal healthcare is less common. For instance, in the north-east of the country, 'because they had to face many cases [of HIV/AIDS] and they have a perception that they will have to face many more in the future, they have said "Okay, this is not going anywhere like this, we need to normalise [this disease]"'. However, in places where doctors have not met any PLHIV there is more discrimination based on fear of the unknown. Whether or not this lack of knowledge is the fault of the doctors is a question the KIs put forward. According to them, this should be seen as related to the amount of knowledge, training and equipment provided to the health institutions in those cities by the state and civil society, and it indicates the broader problem of the unequal distribution of financial and human resources in the country.

Stigmatisation by healthcare providers is related not only to fear of transmission based on lack of knowledge but also to value-based assumptions. Although Herek (1999, p.1110) makes a distinction between 'instrumental AIDS stigma' resulting from the communicability and lethality of HIV/AIDS and 'symbolic AIDS stigma' resulting from the social meanings attached to HIV/AIDS, we can see that those

two bases of stigma are intertwined. KIs in the health sector expressed observations about their colleagues' 'unbreakable' moral prejudices about PLHIV, regardless of how well-trained they are. I also observed cases where doctors perceived as specialists in HIV treatment expressed stereotypical views about sexual minorities. My research data are not sufficient to argue whether or not such moral judgements necessarily translate into differential healthcare treatment, but as demonstrated above, PLHIV narratives exemplify cases of both fear-based and value-based stigmatisation by healthcare providers. In this regard, some health professionals among the KIs emphasised the importance of training healthcare providers in ethical approaches to patients along with their medical training.

A participant living with HIV and working in peer-support, explained the differential treatment of patients according to their gender, sexuality, nationality and socio-economic status. The below quote exemplifies the situations in which being a woman, 'a foreigner', having low educational background and having no social or financial support can intersect and trigger discrimination:

"The reason that I haven't been [discriminated against by healthcare providers] was perhaps .. It's partially because of the way I talk. Or the doctors, they distinguish people right away. The first question they ask to people who come there is 'what is your financial situation?', 'what do you do for living?', 'Are you studying at a university?'. There is a huge difference between a person studying in university and a normal primary school graduate or a person who cannot easily express one self. I mean they are really being discriminated against. For instance, there are many things that I have witnessed. Doctors regard a woman who came from abroad as a "Nataša" (common name used for female sex workers from Russia and from FSU countries). This woman rejects treatment. For 12 years she is not receiving treatment. Another woman, she was told by the nurse 'you're not married and you're HIV-positive. Go get married to restore your honour. Then you can divorce'. I mean there are also people who face this kind of discrimination, psychologically."

There is a question as to whether or not mistreatment or low interpersonal quality of care in healthcare settings is particular to PLHIV, as pointed out by a couple of participants. One KI who has both a medical and an NGO background suggested that when interpreting PLHIV's problems in health institutions one should consider that in fact 'health institutions discriminate against everybody':

"It's not possible to say that a person with diabetes is free from discrimination and treated with honour in a hospital; while HIV-positives are facing discrimination. ... If they (PLHIV) knew, due to their other health conditions, that health institutions were already not very good in providing

services, behaving nicely with patients or validating [patients'] rights, then maybe, they wouldn't consider themselves as being discriminated against. It is already difficult to have surgery in a hospital. They do not want to perform surgery on HIV-positives either. In fact, we have also seen the opposite: because there are few people [living with HIV], with the help of doctors who pulled some strings, people have been able to undergo some operations which could not have been performed anywhere else." (KI17)

2.2. Effects of stigmatisation in healthcare settings on internalised stigma, trust in health professionals and health-seeking behaviour

Participants' narratives show that first encounters with healthcare providers, at diagnosis or a later stage when seeking HIV-related healthcare, are crucially important for the construction of PLHIV's knowledge and perceptions about HIV/AIDS, mainly because of the lack of other sources of information and because of initial trust in the medical profession. A few words from the mouth of the doctor in a limited amount of time is often the main source of information and hope in Turkey, where people are not equipped with HIV-related knowledge, pre- and post-test counselling is very rare and the numbers of HIV support groups are extremely limited.⁴¹ Also, stigmatisation in healthcare settings generates internalised and anticipated stigma, indicating to PLHIV how they will be treated in broader society if they disclose their HIV-positive status.

Discrimination in healthcare settings and internalised stigma

Being treated as a person who needs to keep away from others and whom others do not want to touch is, before anything else, degrading. Although none of the participants expressed the view that they deserved to be treated like this, this treatment can contribute to a picture of oneself as isolated and segregated from society. An interesting point from the observational data which was also mentioned by a couple of PLHIV and doctors is that even the physical locations of infection units in some hospitals, at the very edge of a hospital compound, infection services behind opaque locked doors and the doctors' offices at the far end of corridors, imply that HIV is something to be ashamed of and hidden.

⁴¹ How the knowledge and perceptions about HIV/AIDS are subject to change in the process of communication with other PLHIV and with NGOs is explained in the next chapter.

When going to the hospital to seek HIV- or non-HIV-related healthcare, PLHIV's beliefs in healthcare professionals as people who will provide them with what they need to get well were accompanied by the feeling that they should endure the stigma against them from healthcare providers. In other words, they sought care 'from' the healthcare providers 'in spite of' the healthcare providers, with a view to surviving. It is interesting to see that even some of the respondents with important roles in activism and advocacy sought 'to keep a low profile' in hospital. Some participants stated that they forced themselves to be uncharacteristically silent or obedient to get what they need and not hinder their treatment. When Adem went to hospital for a test he was told:

"Don't come close, stay away, don't come near.' They said 'I will leave your documents on the desk, you go and get them from there.' I said [to myself] 'My God, give me patience to leave this place without quarrel.' What could I do, I went off *boynumuz büük* [embarrassed, desperate and obedient]." (Adem, 60s, male)

Some participants said that they felt the need to change not only their behaviour but also their physical appearance when going to the hospital because of the anticipated stigmatisation. For example, when Sevgi (36, female) and I were having an informal chat, complimenting each other by praising each other's outfits, she said 'Oh yes, by the way, please write this in your thesis: I cannot wear this leopard-print dress, which I really like, when I go to the hospital because you know, it would trigger prejudice'. Objektif (31, male) said he told his female friend not to 'get dressed like that again' when attending the hospital, and not to wear her bracelets as they might make her look like a 'bad woman'.

Stigmatisation creates feelings of rage and anger. In some of the participants these feelings were accompanied by the inclination to take violent revenge, as also mentioned by Rahmati-Najarkolaei et al. (2010). Tutku (55, female) said:

"For instance, in the hospital (...), if they are to take blood (...) ... they take ten tubes of blood from me and they hand all ten tubes to me. Now, the blood, they are warm, excuse my language but they are disgusting. I'm hemophobic. ... Ohh! Sometimes, I have half a mind to open the lids and waw! [spew it out] like fireworks! Why on earth should I carry those bloods? You idiot, you are so disgusted by me that you hand the blood to me. Idiot. This is me [I am not a kind of person who would spill around the blood. But]. There are people who aren't like me. And I can also have a moment [of yielding to temptation]." (Tutku, 55, female)

Some respondents said that if they had not known that such treatment of them or refusal to treat them for whatever reason was illegal (information they received from other PLHIV) they would not have argued with the healthcare provider. They would have accepted that they are not entitled to and do not deserve proper care because of their illness. This indicates that even if poor behaviour from healthcare providers is not accepted as legitimate by PLHIV, some PLHIV might think that they have legitimate reasons for refusing them healthcare to protect themselves, which they have a legal right to do.

Lack of trust in the medical profession

The narratives of PLHIV indicated that healthcare providers' stigmatising attitudes trigger distrust in their medical knowledge and their personalities as carers.⁴² According to Brashers et al. (2006), the extent to which healthcare providers are seen as 'credible authorities' by patients is based on two main factors: their knowledge about HIV illness and treatment and their communication behaviour. The narratives of the research participants show that doctors and nurses were expected to be the most knowledgeable about routes of HIV transmission. However, fear-based refusal to care for them on the part of health professionals puts their knowledge into question in the minds of PLHIV, and their differential treatment of people on the basis of gender, sexuality or other social status diminishes the credibility of the idea of doctors being fair in accordance with the professional oath they swear. For instance, Zafer, a 40-year-old man, explained his feelings when denied a swine flu vaccination:

"They [media and PLHIV-NGOs] were talking about swine flu vaccination. 'All HIV-positives should be vaccinated. They shouldn't catch that flue. It's a terrible thing'. I went [to a hospital] to be vaccinated. [they asked] 'do you have a chronic disease? What are you?' 'HIV-positive'. 'Excuse us, we cannot vaccinate you'. .. It's a vaccination for god's sake! They need to wear gloves! (because of the expression of my face he adds:) Oh yes, don't get surprised, this is the reality we are facing with. And you know what I said? [HH] 'You, I said, you are working in health. You and your superiors. You .. do you get this job with some categories [in your minds]? Like, this person is one of us and this person is not one of us? You take an oath, for healing humans, for humans' health. I mean, why, it bothers you that much, while I want to breathe (to live)'. I said a couple of words like that. They said 'sorry I can't do that'. .. I got angry and I left." (Zafer, 40, male)

⁴² Distrust of health professionals and medical knowledge is one of the main themes discussed in the next chapter under self-management of HIV.

Another female participant stated that the doctors put a note on her file reading: 'Her "friendship" with [a particular person from a foreign country] is the reason she got HIV'. The participant explained that this indicates a moral evaluation of her and is unacceptable: 'If this [hospital] is a scientific institution they mustn't write this – they don't have the right to write this'

As Thom (2001, cited in Brashers et al., 2006) explains, trust in medical professionals is also influenced by behaviour that signals comforting and caring, among other skills. As seen from the narratives of PLHIV, in Turkey doctors are not only seen as healthcare providers but are also expected to give social support, since there are very few support mechanisms available for PLHIV. Considering that in many cases the doctor is one of the few people to whom PLHIV can talk, the person feels very alone in terms of receiving support and feeling comfort and security, and when healthcare providers engage in stigmatising behaviour, trust in them and their communication skills is affected.

A perception that there is no system for protecting PLHIV's rights in terms of both access to healthcare and equal treatment as humans adds to distrust of the medical profession and contributes to feelings of helplessness and desperation. Some participants expressed their lack of optimism about stigmatisation in health institutions being reduced or legally challenged. Some saw rejection from a nurse when giving blood as 'nothing': 'Much worse days are ahead of us'.

From this point about feeling insecure we can infer that stigmatisation in healthcare settings damages not only trust in the medical profession but also trust in the state in general as an institution that protects and serves its citizens. Both PLHIV's own experiences of being denied healthcare and subjected to poor behaviour and stories of other PLHIV that they heard convinced them that when care is refused there is nothing they can do to claim their rights without disclosing their HIV-positive status to many people. They have seen that court cases about these issues do not end up with positive outcomes. Consequently beliefs about protecting the rights of patients have weakened. Regardless of whether or not health institutions are equally problematic for people who are HIV-negative, in terms of rights to healthcare and confidentiality a perception has been constructed of PLHIV as second-class citizens in the eyes of the state.

The right to conceal one's HIV status and the confidentiality of medical records were prioritised in this context of hopelessness. Many people stated that they had 'the right' not to disclose their HIV status to healthcare providers every time they seek healthcare unless necessary, for example if there is a risk of infecting the health worker or of drug interaction for HIV treatment. As I discuss in the next chapter, the right to the confidentiality of medical records and the right to privacy were the main themes when participants were referring to their rights as people living with HIV.

Health-seeking behaviour

As mentioned earlier, stigmatisation in health institutions is an important factor affecting health-seeking behaviour. For example, a participant who went to the hospital for taking his verification [Western-Blot] test said:

"There was a Russian girl waiting there. I asked the nurse 'what's her illness?' [The nurse] said 'she's gonna kick the bucket she got AIDS'. I couldn't go [back there] to take my test results." (Objektif, 31, male)

Another participant who refused to have treatment at a hospital very close to his home explained why he was receiving treatment from a hospital which is two hours' distance from his home.

"(...) It costs me a lot of money and time but I am not receiving treatment from the other hospital. (...) In a way, it's also related to the health [policies] (...) related to the requirements who can or can not work in hospitals. (...) I mean if you put there these illiterate idiots, they call you 'hey you HIV guy' on the phone, the other stupid nurse says to you 'oh I generally understand when I see a gay but I couldn't guess you were' (...) I find it ridiculous that a guy who graduated from medical school can actually act like that. Unfortunately this is the situation and there is nothing one can do about it. (...) Why didn't I do anything? Because I don't have any trust in their profession, their career, their humanity. If they were people to whom I trusted, then I would've defended myself. But since I don't find them mature enough, I didn't think that it would be worth explaining something or that it would mean anything to them. That's why I didn't take it seriously, it's just a waste of time."

His account shows how not only discrimination itself, but also his distrust of and lack of hope that these people who discriminated against him can be changed, have affected his health-seeking behaviour. Instead of 'fighting a losing battle' he preferred to attend a different hospital.

Participants' health-seeking behaviour is discussed in Chapter 7.

3. Stigmatisation related to the institution of the family in Turkey

While PLHIV experience stigmatisation most frequently in healthcare settings, stigmatisation in relation to the family was perceived as most important. Family was a predominant theme in the participants' narratives. This is not surprising, considering that the research context is a relatively less individualistic society and that the interviews were in the form of life stories. The fundamental role of the family in framing perceptions and experiences of HIV-related stigma becomes evident when we consider the link between the stigma and the construction of self.

As explained in Chapter 2, an individual's self-definition is central to their perception and management of stigma; thus in the incorporation of the stigmatised identity into self (Link & Phelan, 2001). Stigmatisation is about a 'discrepancy between the "virtual" and "actual" social identities' of an individual (Goffman, 1963). In the perception of this discrepancy and its outcomes, comparison of the self with in- and out-groups is important (Crocker et al., 1998). Family was the main point of reference in the research participants' narratives, in their self-evaluation in general and when comparing themselves with others and giving meaning to living with HIV in particular. All the narratives indicated the importance of family in the construction of their social identity and their evaluation of their position in wider society, and led to the argument that even if family is not the main source of stigmatisation of PLHIV, it is one of the main frameworks that determines how the HIV-positive identity is incorporated into the self, how its consequences are perceived and how internal and external resources are mobilised to manage HIV.

To begin, a brief look at the participants' family situations is necessary to understand the importance of family status and relationships in living with HIV in Turkey. Three women were married, one with children. Two had HIV-positive husbands. The other woman's husband's HIV status was not known, since he refused to be tested. Two widows, both with children, had lost their husbands to AIDS. Two women were divorced and one had never married. An MTF transsexual was married to a woman and had fathered children before her transition. Among five unmarried women, two were in a long-term relationship with HIV-negative partners. One MTF transsexual was also in a long-term relationship. In total, five women had become infected through their husbands during their marriage.

Among the heterosexual men, four were married and four were never-married. All four of the former had been diagnosed with HIV since marrying their present wives; only one had an HIV-positive wife. Three homosexual men were divorced from their wives (two had children), one had been engaged to a woman, and three were in long-term relationships with HIV-positive partners and had been diagnosed with HIV while in this relationship. None mentioned problems about who had passed the virus to the other.

None of the single participants who were in a relationship with intimate partners (two women, three homosexual men and 1 transsexual) were cohabiting, reflecting the general social norm in the country. It is more desirable and acceptable for both men and women to live with their parents than with a partner outside marriage, regardless of age. Accordingly the concept of 'family' in the participants' narratives did not include intimate partners.

With regard to the participants' relationships with their parents, eleven participants, most aged over 30, were living with their own or their spouse's parents. Participants who lived with their parent(s) and another family member included single people, divorced women and men with children. Three women who were married or widowed were living with the parents or another family member of the husband.

These sample characteristics of relationships with parents point to one of the unique cultural features of Turkey. The literature on relationships between parents and their adult children living with HIV is limited (UNAIDS, 2001; Ukackis, 2007; Ssali, 2010), probably because the family structure and patterns explained above are not common in other cultures explored in the general HIV/AIDS literature. Since adults living with HIV have more distant relationships with their parents, disclosure to and support from parents are not major issues unless the parents become the primary care-givers to their adult children (UNAIDS, 2001; Ukackis, 2007; Ssali, 2010).

Table 8: Household structures of the participants

Members of the household	Number of participant
Wife and parent	2
Husband and husband's family member(s)	3
Parent(s) (and other family members)	6
Spouse (and children)	3
Other family member	2
Housemate(s)	4
Alone	4
Total	24

Below, I summarise different experiences of stigmatisation in the family and then discuss the role of family in the construction of self.

3.1. Experiences of stigmatisation in the family

In this subsection the reactions of spouses and parents, the difference between enacted and anticipated stigma by family members, and the conditions and motives behind family support are discussed.

Acceptance by both the parental and the formed family is an important factor of the nature of HIV-related stigma in Turkey, according to a KI in the civil society sector who has research and field experience with MARP and HIV-positive people.

“Family support is considerably high in Turkey. Discrimination against an HIV-positive family member must be different in Turkey while it is different abroad [while we do not really know; due to lack of data]. But since the beginning, we suggested that if it [HIV status] is heard by the family, it will necessarily be the end of the world.” (KI17)

According to the KI, family support in Turkey is one of the main factors that cannot be explained by adopting theories built on other countries' experiences. Some doctors among the KIs observed that compared to some years ago, fathers have started to accept their HIV-positive children and the wives of HIV-positive men generally empathise with their husbands. The results of Turkey's PLHIV Stigma

Index survey (SIT, 2010) supports the conclusion that one of PLHIV's most important fears is the fear of being rejected by family, whereas actual stigmatisation by the spouse, partner or other family members is considerably less than anticipated.

Participants in the Stigma Index (N=100) were asked about the fears and concerns they had had before being tested for HIV.⁴³ As in all countries in Eastern Europe, concern about relationships with spouses, partners, children and families were strong in all respondents (Sprague, 2011, p. 21). The most commonly-reported fear was that they would be 'shunned by family or friends' (61%). In Turkey, the second biggest fear among both women and men was of being 'left by their spouse or partner' (46%). Women more than men (52% and 45% respectively) were concerned about being left by their spouse or partner, and 23% were concerned that they would not be able to marry. Those who identified themselves as men who have sex with men or as sex workers were significantly more concerned about violence from their partner or spouse, other family members and community members (SIT, 2010; *ibid*, p.25).⁴⁴

However, when we look at enacted stigma, family members were supportive. A total of 75% described the reactions of their spouse/partner when they first learnt of their HIV status as 'supportive' or 'very supportive'; 63% reported that the reactions of 'other adult family members' were also 'supportive' or 'very supportive'. There is no significant difference between men and women or other subgroups with regard to family reactions.⁴⁵ Ninety per cent of the participants had not been excluded from family activities (e.g. cooking, eating together, sleeping in the same room). Almost 90% had not been subjected to psychological pressure or manipulation by their spouse or partner due to their HIV-positive status.

Yet the highest rates of self-stigma were found to be related to family. As an indicator of self-discrimination, participants were asked whether they had avoided

⁴³ Questions related to fears and concerns before testing are not included in the original Stigma Index but were added to the questionnaires adopted in Eastern European countries to measure the effects of stigma on late testing, diagnosis and treatment.

⁴⁴ The Stigma Index Turkey results regarding fears and concerns before testing for HIV should be viewed with caution. All participants were asked about their fears before testing; however, 55 % of participants were tested without their knowledge or consent, thus did not have the time or the opportunity to think about these issues before testing.

⁴⁵ However, data on the ratio of PLHIV who disclosed their HIV status to their family and spouse/partner are not clear in the Stigma Index Turkey results.

any social situations or opportunities for enriching their lives because of their HIV status: 20% reported that they had decided not to get married; 28% had decided not to have (any more) children because of their HIV status and 27% had isolated themselves from their families and friends.

The findings of the research parallel the above explained survey findings. Both married men and married women were 'accepted' and 'supported' by their spouses. No HIV-positive woman were blamed by their husbands or their husbands' families and expelled from their homes. In the narratives of heterosexual men, the most important people mentioned as a source of support was their wives, while single heterosexual men only mentioned their parents as a primary source of support. For homosexual men, the primary source of support was their partner or friends.

Six participants had not disclosed their HIV status to their parents; most of these had elderly parents who lived elsewhere. Among people who lived with their parents, only one was concealing their status and another had disclosed it to their mother only. All but three participants whose HIV status was known to their parents generally described their parents as supportive. Of the others, a single, female participant spoke of one of her parents and siblings trying to talk to her, meet her and help her, but she perceived their approach as judgemental and annoying. The reasons behind this perception were not clear in the narrative. This participant was one of the most self-isolated in the sample. Another female participant who did not receive support from her parents, was the only woman in the sample who was not wanted in her parents' home. However, her problems with them had started before she was diagnosed, due to her resistance to gender-related parental pressures, and she had already been thrown out. The other participant who was not supported by his family had also had problems with his parents prior to his diagnosis, due to his sexual identity.

Some of the participants' narratives described isolating themselves from their families because of the strong fear of rejection but then being surprised by their parents/partners/siblings' support and realising that 'this wasn't something to be so frightened of'. Many described their mothers and/or fathers as supportive or even closer and/or more understanding than before the diagnosis. In some cases, their relationships with their parents improved after being diagnosed with HIV because the parents became less authoritative or more indulgent, mostly because of their fear of losing their child.

Perceiving their child as sick, vulnerable and in need of help can lead to a protective reaction, as expressed by both the participants and some KIs working in support and counselling services. For example, İlker explained that he needed to live far away from his mother and aunts 'because they remind me of my disease all the time ... it makes me live, like, face-to-face with the disease'.

Fathers' acceptance of their heterosexual adult child had another dimension related to their acceptance (or even affirmation) of pre-marital sex for men as a sign of 'healthy manhood'. In this case, being infected by HIV is seen as a consequence of 'wrong' behaviour in terms of not practicing safe sex. It is not the nature of the sexual relationship but the negligence in taking the risk that is questioned, and this does not become a moral basis for judgement. However, in the case of homosexual men whose sexual identity is known by their families, the 'HIV virus could not get ahead of homosexuality, could not be seen as an illness', as İlker (40, male) explained. He thought that the situation he experienced in his family was a reproduction of the general discourse and lack of knowledge in the country:

"The only thing they [my family members] ever know, 'oh! AIDS, oh, it's a homosexual disease'. [They] are not interested in the illness part, they're interested in homosexuality. I mean, .. no matter what has been done up to this point (...) it is still being discussed in this country about whether or not homosexuality is a disease; whereas, on the other hand, there is HIV which is an illness and it's not discussed at all. It just remains like, 'oh it's faggots' disease'. While you need to find a solution for that, you discuss if homosexuality is a disease, if it can be cured. People's minds get.. These people are idiots anyway, and their minds get more confused." (İlker, 40, male)

On the other hand, lack of knowledge and ignorance about HIV/AIDS was seen by some of the respondents as positive and leading to acceptance without reservation. For example Pelin, whose husband and his family were illiterate, from a low socio-economic background and from an 'underdeveloped' region of Turkey, said:

"I got the diagnosis and my spouse took it as.. I don't know maybe out of ignorance but he said '*Allah verdi*' (it is from/by God) and he didn't leave [me]. I mean if it was somebody else he would've left right away but he didn't, he said 'if God gave this' he said 'we'll put up with it, together', he said." (Pelin)

However, her husband and his family did know that HIV is contagious and that her status had to be kept a secret. At the end of our interview, which took place on a stormy day in a place far from her neighbourhood, Pelin explained that before

coming here she had had a fight with her husband about her participation in this research: 'Even my family doesn't want me to go around talking about it like this. But me, if I don't tell I feel I'm going to burst at some point'. Even if her husband's family only 'feared from her disease', her own family had rejected her, not only for fear of being infected but also because of the moral stigma she brings to the family name.

"We have a falling out [with my brother]; he doesn't want me, because of all these affairs of mine (leaving home, being raped by strangers, married twice). In a way I acknowledge him to be right; but in a way I don't. At the end of the day, he's a man. He feels it beneath him [to take me back home or to help]." (Pelin)

Other women, infected by their husbands during their marriage, who participated in the research had different stories. They were not rejected by their parents or their new partners. Being infected within the institution of marriage 'protected' them from being considered immoral. While HIV-positive women are having more difficulty living with HIV because of the general social and economic restrictions that they already experience as women, as some of the KIs pointed out, women are in a more favourable position in terms of being labelled. The advantageous position of married HIV-positive women in Turkey is also demonstrated by Kasapoğlu and Kuş (2008). An activist female participant argued that this argument is questionable, since it reproduces the patriarchal norms ascribed to women:

"... if it's a woman, especially a woman who appears to conform to societal norms, then instead of discrimination, people immediately say 'what a pity for her!' (...) If it's a man, [he is labelled], without knowing anything about him. He might have got it from his wife; maybe he's 17, got it from his mother, got it abroad, through relationship - unprotected relationship, maybe he's homosexual, maybe he's a sex worker. This is more certain that we put many labels on him, without knowing anything about him. [But if it's a woman:] 'Oh but it's such a pity'. (...) And obviously, this is also discriminatory, in a strange way." (KI1)

The immediate feeling of pity for married women could be seen as a reflection of the internalisation of patriarchal values intrinsic to the cultural immunity discourse. The cultural understanding of married women as modest and sacred, whose infidelity is unthinkable, contributes to a presumption about HIV-positive women as 'victims' of their husbands. This is only valid, of course, if the married woman appears to conform to gender roles.

Women's forgiveness or toleration of their HIV-positive husbands can also be seen as related to the acceptance of patriarchal norms. These women support their husbands for different reasons, such as accepting men's extra-marital relationships as normal, holding valued social identity as a caring wife or sustaining economic status. But in some cases, where the source of the HIV is 'unknown' or thought to be 'something else', families' support and acceptance are based on trust:

"My son knows [my HIV status]. My wife knows. Here [at the hospital] *hoca* [here, the doctor] told me to tell my wife. And we [I] told it, in a proper way. Neither my son nor my wife gave any bad reaction, because they trust me. After all, there is no person in our family who goes out gallivanting. This is our family structure. This is how our family is like." (Adem, in his 60s, living in a rural village)

The participants who had not disclosed their HIV status to all their family members explained the reason they have not done so is not necessarily fear of stigmatisation. Especially people whose parents were elderly stated that they did not want their families to worry about them. For younger participants, the main motive behind the concealment of their status was to protect their families from gossip and rumour. In cases where the family is a well-known or 'fine' family, the PLHIV stated that they would not disclose their identities publicly even if their families were supportive, in order not to 'discredit the family name'. Two women participants with HIV-negative teenage children explained that their most important motivation for hiding their positive status from their children was to avoid being asked, 'Who did this to you?' They both stated that they did not want their children to feel hostility towards their fathers.

3.2. The attribution of meaning to HIV and the construction of its stigma within the family

In the narratives of PLHIV, the first starting point when describing one's life or identity was the family. Many participants' freely-formed life stories began with a statement about the kind of a family they were born into or had formed.⁴⁶ Some of the very first sentences of the interviews described a family situation – 'I'm a son of a rich family'; 'I eloped with my husband'; 'I'm a child of a well-educated family'; 'I'm

⁴⁶ Nearly half of the participants preferred to tell their life stories starting from the point when they were diagnosed with HIV. The other half, who started from other life events, first introduced their family as background information.

the only son of the household' (*bir evin bir oğlu*⁴⁷); 'I left my family home when I was 20'. Family-related explanations were also given as main background information – 'I grew up in an authoritarian family'; 'I maintain my normal family life' – or as the cause – 'I'm a "military brat"'; 'I'm a family guy' – of an important life event or situation.⁴⁸

Family-related social expectations and desires were recurrent themes throughout all the narratives, regardless of whether or not the issue under discussion was related to HIV. These expectations were not only evident in the stories told but were also articulated with great emphasis by the participants. That family-related social expectations are the most important thing in this society was expressed as 'fact' by all of the participants⁴⁹ from either an affirmative or a critical point of view. Enes, a 30 years old homosexual man, summarised a typical life plan tailored for middle-class men:

"At the end of the day, you are the only son of a household. This is what you have been taught: You will study, get your university degree, do your military service, establish your job, get married, have children, after getting children work forever to provide your children with a high quality of life, put <their> life in order, arrange the marriage for them, have grandchildren and die. I mean this is what has been taught to a person, to us, in Turkey, the plan from the very moment when we were born until the moment we die. The life plan for a man is this. If anything apart from that plan or any delays in between [the planned steps] occurs (...) then you will have to face oppression from peers and from society. Both you and your family." (Enes, 30, male)

Participants who described their families as educated, literate or modern also stated that in spite of this, traditional values were maintained and preserved by their families. Others stated that however individually-minded or strong they thought they were, it was very difficult to resist following the course of events within this life plan. For example, Enes said:

⁴⁷ A common phrase implying the importance and the privileges of the only male child in a household.

⁴⁸ An interesting example is the explanation of Evrin, an MTF transsexual, of the cause of her unsuccessful marriage to a woman before she came out as transsexual. She explained that she had problems in her marriage because she had grown up in a broken home and did not have a proper concept of what a family is.

⁴⁹ I observed that participants sometimes felt the need to explain Turkey's social context, thinking that the audience for this research would be 'English people' (when they glanced at the tape recorder and explained something well known by almost everybody in Turkey). The detailed argumentation and commentaries on family may also have arisen partly from this concern.

"We were in the process of getting married, the preparations started, but me, for some reason I just could not stop it. I mean, me, I'm a person with an awful lot of power of compulsion, power of sanction but no I just couldn't put the clamps on anything!" (Enes, 30, male)

The 'turning points' (before HIV)⁵⁰ in the lives of many participants manifested themselves as the changes that occurred as a result of ruptures or delays in this life plan. For example, young homosexual men explained that they had started a new life after leaving their family home because it had become very difficult to deal with their parents' expectations. One of the participants had decided to disclose his homosexual identity to his parents just before his arranged marriage to a woman. Sevgi said that for a long time she had had to resign herself to a dysfunctional and violent marriage arranged by her parents, and that only after the divorce had she discovered that a different life is possible. Pelin's life was thoroughly marked with stories of rejection and coercion by her parents. Her father threatened to kill her after he found out that she had had a relationship with a man before marriage. Afraid of him, she ran away from home and was raped by strangers. After being kept in a mental institution for a couple of months, her parents forced her into marriage to an older man.

The above points exemplify situations where the family comes into play in the construction of identity, regardless of HIV status. In this sense, the incorporation of HIV into the identity and whether being HIV-positive is perceived as a problem or not are related to how HIV-positive status influences the expected life course. HIV was perceived as a major obstacle to fulfilling family related expectations, which were seen as normal and desirable social functions, such as getting married, having children and earning money to maintain the family. Being diagnosed with HIV breaks the socially-expected life trajectory designed around the concept of family.

Heterosexual single men were mostly concerned about not being able to get married and with not being able to complete their compulsory military service, which is seen as a condition for marriage. As a form of self-isolation they had ended their romantic and/or sexual relationships and given up their plans to get married and to have a family.

⁵⁰ The extent to which being diagnosed with HIV is considered a turning point by the participants is discussed in Chapter 8.

The problem of not being able to marry is a dominant issue discussed in PLHIV Internet forums. The discussion is based on questions about whether it is possible to practice safe sex and have a healthy and happy marriage without 'violating the poor woman's *kul hakki*' ('rightful due': Islamic rule specifying protection of the rights people have with regard to each other), and whether it is possible to find a non-prejudiced partner. In addition, possible ways of overcoming community pressure to get married is discussed. A young heterosexual man whose long-term girlfriend left him after he disclosed his HIV status a few months after our interview, explained how he and his family had arranged the 'required marriage':

"There was this girl, who my mother really wanted, okay?, she [my mother] really wanted her very much, she was afraid of losing her. (...) At first, she fixed her up with me, by 'fixed her up' I mean she wanted her to become ours (to be married into our family). I never spoke to that girl (...) [my mother saw this girl in a women's gathering and thought:] she's very white and pure (chaste). And, I was of course very sad that I cannot be able to get married, I was so so sad and my mother didn't want to miss that girl and she was seeing that I was healthy, so she was thinking that I was normal, I mean ... 'what if.. what if you're not [sick]' she kept saying, 'while there is life there is hope, with the will of Allah' [she kept saying]. And I said, 'so, if you want this girl that badly (...) let my brother marry her'. [She said:] 'Are you saying this for real? Do you want to give your turn?' I said 'mom, is there anything else to do? No there isn't. What else have I got, except being a kind person? What can I do?' (...) So they sought my father's advice, asked my opinion again and then they said 'okay then let's ask for the girl's hand for [my brother].' (...) They [brother and his wife] are very happy now [and I console myself with it]."

Even if they knew about safe sex practices and about how PLHIV can have children, they stated that they did not want to risk causing physical or emotional harm, explaining this in terms of religious obligations related to not harming others.

"I would like to marry a negative [HIV-negative woman] and I would like to have a descent. But I wouldn't like to violate *kul hakki*. *Kul hakki* is not only about not to steal you know." (Objektif, 31, male)

Kul hakki and *vebal* were terms used by both married and single, heterosexual and homosexual men to explain their feelings of conscientious responsibility towards others. For example, one married respondent explained his main motivation for using condoms while having sex with sex workers in these terms. By *vebal* they meant that they did not want to 'shoulder the unworldly moral responsibility of an evil action', while *kul hakki* refers to the religious duty of not violating people's

rights. According to Islam, this is a sin that cannot be forgiven by Allah in the afterlife unless the affected person forgives.⁵¹

Some heterosexual men stated that they saw their HIV-positive status as a punishment that they must accept. Whether the sexual relationship was extramarital or not, their feeling of guilt and responsibility was related to 'disappointing' or 'betraying' their family. This is either about the perceived possibility of failure to fulfil family-related duties and functions or about putting their loved ones, including their children, at risk. For married men the fact that their wives were HIV-negative was expressed as a major source of relief amid all the negative feelings that came with HIV. Apart from one person who believed that he had not been infected through sexual contact, they all felt guilty for putting their families in danger. These men did not show patterns of non-acceptance such as self-isolation, high distress or non-adherence, probably because of the support they received from their wives.

Not only men, but also one woman, Sanem (late 30s, widowed) talked about her feeling of self-blame, even though she did not consider herself responsible:

"(...) When you have a child, when you have a family, you don't just think about yourself but you automatically start thinking on behalf of four-five people. And your worries are multiplied by five. (...) Because unavoidably, you blame your self. I mean, if something happens to them, it would be because of me. You yourself are living in this situation because of someone else, but still.. your thinking is focused only and solely on your child. Or maybe, this was my personal trauma at that time." (Sanem)

In relation to HIV self-management, fulfilling family-related expectations also has a role in the perception of 'normality' and order in life. The Turkish idiom 'establishing one's order' means getting married, having children and getting a regular job. In the narratives of the participants, their familial situations served as a criterion and a reference point for their self-evaluation. Their reflexive accounts of whether or not life is good, normal, ordinary or in order often included comparisons between their own and others' familial situations. For example, the unmarried compared their lives with those of married people; those who were married with no children compared themselves to people who have children. A sero-concordant couple

⁵¹ *Kul* means servants of Allah and *hak* means right, fairness or justice. *Kul hakki* as an everyday expression means the labor that people give each other, or people's rights with regard to each other, and is a concept that regulates people's relationships with each other in general (Murakami, 2011, pp.18-19).

explained that their main aim was to have a child to complete their family and satisfy their relatives, who are expecting a baby:

"We [me and my wife] have spoken to our infection doctor, who treats us and he frightened us at first. I'll call him idiot. He said 'you'll never have a baby'. Oh, we said, 'so, we will not have a baby then'. We were completely devastated. [We thought:] We'll stand alone, at home, by our selves, like two deadwoods. I mean.. you know, a child is required for a person, I mean a child is an important factor for a family, in my opinion. I mean this is one of the most important elements that make up a family. Er.. as you would suppose or you would know, the child is one of the most important elements, that brings joy to home.. that means the future, I mean it's important for the continuation of one's bloodline.."

A very clear example of how family status and roles serve to secure a sense of normality can be seen in Zafer's (40, homosexual man) accounts. His first sentences after he stated that he identified himself as homosexual at the beginning of his interview were: 'Er.. what can I tell you about my life story? Like every human, I too have a family. Like most people, I too was once married, I too have a child.' The last sentences of his uninterrupted life story (1st BNIM session) were:

"In conclusion, er.. I told that I was a father; that I also have a mother and father, that I am a son, a younger brother and an older brother as well. I told you I have a job, a family life and a social life as every other person. These are all related to my past and present, general things, but in sum, there is nothing else apart from these. Me being gay or being HIV patient er.. doesn't mean that I'm living in a different world." (Zafer, 40, male)

Considering the differences between younger and older HIV-positive people, this sense of normality was stronger in people diagnosed with HIV at a stage when they have already established 'order' in their lives. Also, it is important to note that, for openly gay men and for transsexuals the 'aim' or 'hope' of 'establishing the order' was not a question that had arisen after the diagnosis.

While discrimination in the workplace and health institutions is more frequently mentioned in previous research (PYD, 2007-2010) and by the KIs in this study, family rejection or acceptance remains the most important factor affecting PLHIV's self-management, according to both KIs and the PLHIVs themselves. Even when talking about an entirely different topic, family support as a social, economic and psychological resource was a recurrent theme, as exemplified in İlker's (40, male) account:

"As I said at the beginning of our talk, if you do not feel kind of a family support behind you, it means that you are very lonely. I mean, if you can still maintain your life in such a loneliness, I think this is called [SL] survival (in English)." (Ilker, 40, male)

According to a participant who also worked as a peer counsellor, when it comes to living with HIV the reactions of family are more important than those of any others and can literally be a matter of life or death:

"It hurts you much more; it hurts you enormously. I mean, someone whom I know for three days (expression meaning for a relatively short time) can discriminate against me, but so what? It won't affect me. It could affect me for a couple of days. It's like, when you break up with your boyfriend/girlfriend, with a person you love very much, you cry for a maximum of three months, you mourn for a while [but then it goes away]. But if your mother excludes you.. this is your mother! It's an indispensable part of yours. So, 'my mother doesn't love me; doesn't want me; it is already a bad illness; I deserved it; it's the curse of Allah and my family doesn't want me'. That's how you go get sucked in to a whirlpool. And after that.. I saw people who expedited their own death. I saw families facilitating death".

Comparing their problems caused by HIV and those caused by family-related issues in their lives, some respondents stated that 'HIV and so forth' are 'trifles' or 'just trivial' compared to current familial problems and that they can 'laugh away other things', such as discriminatory attitudes in health institutions. However, as I tried to explain in this subsection, those aspects of the life with HIV are intertwined.

4. Conclusion

Stigmatisation in healthcare settings, including anticipated stigma, refusal of care, sub-optimal care, excessive precautions, physical distancing, psychological abuse and breach of confidentiality, is the most frequently-experienced form of stigma. On the other hand, PLHIV perceive enacted and anticipated stigma in relation to familial roles and values as the most important aspect of HIV-related stigmatisation. Both forms of stigmatisation are discussed in this chapter in relation to the meaning they give to living with HIV. Both facilitate the internalisation of the stigma in terms of perceiving oneself as categorically excluded, a person not entitled to access certain health services open to others or who will not be able to create a family. Below, I point out some connections between stigma in healthcare and family with the previously-discussed discourses that shape HIV-related stigma and with the stigma management strategies that are the topic of the next chapters.

The effects of the cultural immunity discourse can be identified in both forms of stigmatisation. Healthcare providers are not exempt from the general public perception that sees HIV/AIDS as a 'marginal' disease. Besides, because this discourse is maintained by the state, which does not give priority to HIV/AIDS, it is not easy for healthcare providers to access accurate knowledge and to question their own behaviour in ethical terms. Also, healthcare providers who refuse to deliver care do not face enforcement in law because of the general lack of anti-discrimination legislation in the country and the bureaucratic and moral barriers to winning (or even bringing) such cases in court. For PLHIV, this situation creates a context for feelings of insecurity and distrust.

Anticipated stigma from family seems to be higher than enacted stigma. The results indicate the importance of the institution of the in the formation of internalised and felt stigma. The strong social and personal expectations formed around the cultural value attributed to 'the family' in the ideal life trajectory is an important basis for giving meaning by PLHIV to the consequences of being HIV-positive.

Women's forgiveness of their HIV-positive husbands, the acceptance of heterosexual male children and the immediate feeling of pity for married women affected by HIV/AIDS can be seen as reflections of the internalisation of patriarchal values intrinsic to the cultural immunity discourse. Interestingly, the lack of knowledge caused by the perception that HIV/AIDS is 'not our disease' may contribute to family members' unconditional support.

The limitations of HIV-related interventions as an outcome of the low priority given to HIV/AIDS in Turkey are seen in the lack of knowledge in both the general public and healthcare providers and the absence of counselling and support services. Health workers' lack of knowledge and skills means that PLHIV receive either no guidance at all about how to manage their social and sexual lives or morally-driven misinformation that leads to 'wrong' decisions that they regret or to the loss of hope about the future. The narratives of the participants show that PLHIV make many important decisions affecting their family life such as giving away their children due to the fear of infection or deciding not to marry following explicit or implicit suggestions by healthcare providers.

The effects of the low priority given to HIV/AIDS due to the view that it is 'not our disease' are also seen in the absence of counselling and support services. 77% of

PLHIV in Turkey do not receive any counselling either before or after being tested. Consequently, considering the low level of awareness and the public perception that HIV/AIDS is a 'foreign' disease, the moment of diagnosis is experienced as a shock, especially by people who have been tested without their consent or knowledge.

In relation to rights-based discourses on HIV/AIDS, stigmatisation in healthcare settings affects PLHIV's ideas of trust, justice, equity, citizenship and rights. Firstly, it contributes to the prioritisation of the right to 'privacy' or 'confidentiality' of one's health status. Although violations of the right to equal healthcare were also mentioned, PLHIV's right to conceal their HIV status remains at the forefront of their narratives for two main reasons. The disclosure of their status, either voluntarily or through a breach of confidentiality, facilitates further stigmatisation. Secondly, PLHIV's sense of insecurity and distrust in the medical profession and the health system in general foster strong feelings of hopelessness and disbelief in the possibility of securing their right to equal treatment. Lack of trust in the medical profession has important implications for HIV self-management. As I explain in the next chapter, it affects the tasks involved in managing physical health – seeking healthcare, following doctor's orders, adhering to treatment and managing uncertainty.

Another important point related to the rights discourse is that, in relation to both family and health institutions, there seem to be a felt dilemma between the 'right' to conceal one's HIV status versus the 'duty' (mostly in the moral, religious understanding of the word) to protect others. This manifests in the narratives of people who want to be married but refrain from emotional relationships because of the risk of causing harm, and in cases where people choose to be honest with the healthcare provider to protect them from infection. These feelings of conscientious responsibility, the need for honesty and to avoid stigmatisation by concealing HIV status are important psychological components of self-management that I discuss with disclosure strategies in the next chapter.

Chapter Seven

Management of health: Perceptions of illness and treatment experiences

1. Introduction

The previous chapter addressed the role of anticipated and enacted stigma in family and health institutions as the main domains through which the illness and its stigma are given meaning by PLHIV. This and the following chapters aim to answer the main research question: How do PLHIV react to, resist or challenge HIV-related stigma?, by focusing on the third key-question: 'What are the constraining and enabling factors for PLHIV to resist or challenge stigma'⁵² So far I have discussed the formation of stigma and of PLHIV's perceptions of it; the following chapters focus on the management of HIV and its stigma, including the reconstruction of their meanings by PLHIV.

Following Swendeman et al.'s (2009) categorisation, this research addresses the management of HIV and its stigma through investigation of three interlinked domains: physical health, social relations and identity.⁵³ This chapter looks at the management of physical health.⁵⁴ Therefore, the main sub-questions to be answered are 'What are the strategies developed by PLHIV to manage physical health? and What are the ways in which PLHIV assert agency in managing physical health?'

'Tasks' related to the management of physical health when living with HIV include developing a framework for understanding the illness, self-monitoring physical health, health-promoting behaviour, accessing treatment and health services, adherence to treatment and preventing transmission (Swendeman et al., 2009, pp.1326-1328).

In this chapter I discuss the development of a framework for understanding the illness through the model of 'illness perceptions'. Based on Leventhal's

⁵² See Research Questions diagram in Chapter 1.

⁵³ Swendeman et al.'s (2009) original wording for the last of these is 'psychological functioning'.

⁵⁴ The next chapter addresses the management of HIV in the other two domains.

conceptualisation (cited in Weinman et al., 1996; Broadbent et al., 2006; Figueiras & Alves, 2007), illness perceptions are defined as the patients' perceptions of the 'label and symptoms', 'cause', 'time-line', 'consequences' and 'cure and controllability' of their illness. I discuss perceptions of the label, symptoms, time-line (duration and nature of the disease as being chronic) and physical consequences of the disease in the first subsection, and the 'cure and controllability' component of illness perceptions in the following subsections.

I explore other treatment and self-care related components of health management in relation to the importance of uncertainties,⁵⁵ lack of trust in the medical profession and system-level problems in access to healthcare. I also introduce the concept of 'framing agents' in this chapter to examine the role of support groups in the management of physical health. As Watkins-Hayes et al. (2012, p.2028) state, "framing institutions" is a useful conceptualisation for understanding how stigmatized populations manage chronic illness'. The concept is used to explore institutional environments such as support and advocacy groups in which illness is given meaning and management strategies are developed.

As in the previous chapter, primary data from interviews and observations constitute the empirical basis of this chapter. I focus on PLHIV's narratives, coded under the overarching topic of 'health-related experiences, beliefs and behaviour'.⁵⁶ I aim to maintain a balance between identifying certain categories of experience and people and representing the 'complexity and uniqueness of each person's journey' in the process of self-management of HIV (Telford et al., 2006). The management of chronic illness is not a 'chronological process' during which people gradually develop deeper understanding and decide on certain illness meanings and self-management strategies. Rather, it can be considered a 'fluctuating process' in which people can face conflicting needs and individual changes in life (Audulv et al., 2012, p.333).

I discuss some of the components of managing physical health separately in the following chapter. Although safe sex, as a behaviour for promoting own health and preventing transmission, is a component of physical health management (Swendeman et al., 2009), I discuss it in relation to the management of social

⁵⁵ See Chapter 2 for the conceptualisation of uncertainty in illness experience.

⁵⁶ See Chapter 3 for the details of how analytical and topic-nodes were generated from PLHIV's narratives.

relations in the following chapter. Moss-Morris et al. (2002) suggest that 'emotional representations' are also important components of illness perceptions. Maintaining hope 'despite [an] uncertain or downward course of health' is an important part of health management (Miller, 1989). I also discuss these factors in the next chapter under the psychological aspects of identity management.

I mention the links between the self-management of HIV and discursive formations of stigma at relevant points in this chapter and emphasise and interpret them with regard to the broader theoretical framework in the last chapter.

2. Knowing and understanding the disease: The 'HIV-positive disease'

The initial reaction to being diagnosed with HIV is marked by shock and fear of imminent death, as explained in the previous chapter. This section focuses on how such perceptions about the disease change or are reframed in the post-diagnosis process.

Participants' narratives suggested that the reconstruction of illness perceptions differed according to the length of time since diagnosis and relatedly, to the level of access to peer-support. Nearly half of the research participants, 10 people (out of 24, excluding KIs living with HIV) were diagnosed with HIV more than five years ago, while nine were diagnosed in the last two years (see Table 9 below). The differences between the two groups reflect the role of peer-support, since the main PLHIV network in Turkey was institutionalised and became more accessible to PLHIV in 2005, five years before my interviews.

To provide a background to the discussions in the following subsections, some of the key themes and categories of experience are demonstrated in Table 9.

Table 9: Participants' perceptions of HIV and ART according to the length of time since diagnosis, health status and access to peer-support

Time since diagnosis	'Not yet' on ART	HIV-related health problem when starting ART	Near-death experience	counselling from NGO	Peer-support (regular contact)	'Positive' reconstruction of HIV through comparisons	'Negative' perception of ART	Total
Less than 2 years	4	0	0	5	7	6	2	9 ^a
2 to 5 years	1	1	0	3	2	1	1	5
More than 5 years	1	8	4	1	2	0	1	10 ^b
Total	6	9	4	9	11	7	4	24^c

^aFour were diagnosed in the previous year. The most recently-diagnosed participant learnt of his HIV status two months before our interview.

^bFour had been diagnosed more than ten years ago. The earliest diagnosis was twenty years ago.

^cTable does not include the four KIs living with HIV.

All of the participants who were diagnosed less than two years ago except two who lived in Ankara received peer-support very shortly after learning their HIV status, either from an NGO or personally from an individual living with HIV. Some had their very first post-counselling sessions from a person living with HIV. They have found readily-available tools and language to reframe the illness. Participants diagnosed over five years ago could not access peer-support or counselling so quickly or easily. Some were among those who had created and institutionalised a network for PLHIV motivated by their own need for communication and solidarity. This division among the participants creates one of the main points of differentiation in perceptions of HIV and ART, as I explain below.

The labels and names given to a health condition and its symptoms are considered components of the ‘illness identity’ through which patients represent and make sense of their illness (Weinman et al., 1996; Broadbent et al., 2006; Figueiras & Alves, 2007). Once a name is given, illness-related experiences are mediated or interpreted by that label. In illness narratives, labels act as linguistic devices to produce and represent meanings attributed by the patient to the health condition and to related social roles such as ‘the sick role’ or the ‘lay expert’.

To look at those labels in participants’ narratives, some clarifications of the translation are required. The difference between the terms ‘illness’ and ‘disease’ in the English language does not exist in Turkish. *Hastalık* (illness/disease/sickness) or *rahatsızlık* (discomfort/disease) are both used to refer to a particular disease or to being/feeling ill. *Hastalık* does not always refer to an abnormal or unwanted condition: for example, being fond of somebody or something and menstruating are also commonly expressed by this word in colloquial speech. Not all participants used these words to refer to their HIV-positive status. Some, mostly those who actively participated in peer-counselling or advocacy activities, preferred to say ‘my diagnosis’, ‘my status’ or ‘my condition’, which implies that they did not define themselves as ill. However, when other participants said ‘my *hastalık*’ or ‘*rahatsızlık*’ it was hard to interpret whether they were referring to HIV as a disease, to their status of being diagnosed with HIV, or to being ill. I have tried to interpret the

situation considering the context of the whole narrative and their other explanations of their health conditions.⁵⁷

As explained in the previous chapter, knowledge of the distinction between HIV and AIDS is minimal among the general public and the notion of AIDS is identified with the images of people on their deathbeds that appear in the media. For participants who had also had these ideas about AIDS and who did not experience serious illness before being diagnosed with HIV, the first step in accepting the illness seemed to be the realisation that they did not have AIDS and were 'only HIV-positive'. As Baumgartner (2012, p.3) states, 'learning that the availability of life-extending medications meant a person could live with the disease for an extended period' can be 'a turning point from the shock of being diagnosed with HIV/AIDS'. The idea of living with a chronic illness that requires lifelong treatment might be easier to adjust to than the idea of imminent death, as this young man's narrative suggests:

"I had books and magazine subscriptions, like National Geographic and some health magazines. I had a look at them. And amazingly.. I mean, I used to like reading them very much .. I had around 50 books and in around 10 of them HIV/AIDS were covered. But I realised that I have never read them. I didn't even think about it. So, I went through these books, that very first night. (...) And I have learnt that this is not a deadly disease, that this is a very different disease [than I thought]. The next day, I was so so much positive. ... I mean, I was relatively positive." (Mehmet, 21, male)

The analysis of the representation of HIV in participants' narratives suggested a sense of commonality among some participants who represented a 'positive' and 'optimistic' perception of HIV through comparisons of HIV with other illnesses. Table 9 shows the number of participants whose narratives represented this 'positive reconstruction through comparison'. I discuss the commonalities between these participants and the components of this positive reconstruction below. Other participants whose narratives were not representative of the positive reconstruction did not necessarily represent express HIV negatively.

Making comparisons between one's disease and other diseases is common in chronic illness self-management in general (van der Zee et al., 2000; Dibb &

⁵⁷ In the Turkish-English translation of the quotations from the narratives, the terms 'illness' and 'disease' are used depending on the context of the narrative.

Yardley, 2006) and in the self-management of HIV (Roura et al., 2009; Dibb & Kamalesh, 2011). Similarly, the stigma management literature shows that it is common to compare the 'in-group' with similar 'out-groups' (Crocker et al., 1998; Shih, 2004). Participants' comparisons between HIV and other diseases led to three meanings attributed to HIV: it is a 'manageable' chronic condition, a disease that 'can happen to anyone', and a 'not so dangerous' disease. The first has a function related to health management, creating hope and facilitating acceptance, while the latter are related to 'normalisation' and the destigmatisation of HIV, as I explain below.

Regarding the acceptance of HIV as a manageable chronic condition, a common theme, especially in the narratives of people who regularly received counselling and training from an NGO, was seeing HIV as 'just another chronic illness like diabetes or hypertension'. The emphasis in these narratives was that the person will live a long and healthy stable life without any experience of AIDS-related illness. Furthermore, some expressions used such as 'every bad has its worse' (*Beterin beteri vardır*) or 'the job of [patients with chronic dialysis] is even harder' reflected the idea that the management of HIV may be relatively easy, an idea which might facilitate acceptance. Here it is important to note that comparing oneself with others in a worse condition – downward comparison, in Wills' (1981) terms – is a common way of thinking within the religious necessity of 'being thankful to Allah', which is a part of everyday practice, also in secular contexts.

Perceptions of HIV as a 'disease that can happen to anyone' and 'not so dangerous' can be understood in terms of 'normalisation' and destigmatisation of HIV. Roura et al. (2009, p.310) demonstrate that many PLHIV on ART feel comforted that HIV has became a 'normal' disease (like malaria or fever in the context of rural Tanzania) and the realisation of HIV as a disease 'for everyone' made them feel 'normal'. Some participants compared HIV not only to other chronic diseases but also to a headache or a toothache, to emphasise that 'everybody' can have this disease. This reconstruction of HIV detached from moral meanings can offer comfort by providing relief from guilt and otherness. In addition to disassociating it from moral meanings, participants also represented HIV as 'less contagious' and 'less dangerous' than some other diseases. This representation is related to destigmatisation, since fear was perceived as an important cause of HIV-

related stigma in Turkey due to the low level of knowledge about means of transmission.

Both the observational data and a couple of participants' narratives point out an interesting use of language by the participants. Some people used the phrase 'the HIV-positive disease'. By inventing and using such a phrase they were making the point that they were aware of the distinction between HIV and AIDS and were not ill; they were just people diagnosed with HIV who have not experienced AIDS. Another salient usage of language among the participants, especially those who were more involved in NGO activities, was the removal of 'HIV' from the term 'HIV-positive'. The word *pozitifler* ('the positives', like the word 'poz' in English) was used to refer to people living with HIV and AIDS. This usage might be merely a type of abbreviation, but it might also indicate a preference for language with more positive connotations.

The positive language used by NGOs had problematic aspects according to one of the participants living with HIV. He complained that AIDS is never talked about, as if it does not exist. According to him, the 'total abandonment of AIDS' from the language is causing the misperception that HIV never kills anyone and neglects people who have or are dying of AIDS. I also witnessed the question: 'Is it true that no one dies of AIDS anymore?' being directed at a counsellor and to another person living with HIV. This suggests that communicating the information that HIV is a non-fatal disease might raise hope, but it also encourages denial.

It can be argued that the positive reconstruction of HIV through normalising and destigmatising meanings is important for successful health management, but its beneficial effect is constrained by the fact that the way PLHIV tried to reframe HIV in their minds does not correspond to the perception of HIV in healthcare settings. In other words, while PLHIV are motivated to accept HIV as a 'normal chronic health condition', the stigma that they faced in the healthcare settings was a constant reminder of the opposite. On one hand they were constructing 'normalising' meanings of HIV at the cognitive level while on the other they had to

construct strategies to hide their status.⁵⁸ The quote below represents the desire for 'normalisation'. Enes explained his 'only dream, only ideal':

"When I go to whichever department of whatever hospital because of my different illnesses, be it a dermatology or dental department, when they ask me if I have a chronic illness, I should be able to easily say 'yes I'm HIV positive'! Or in the society, I want to see a time when old people waiting in a bank queue or sitting on a bench having a chat are able to talk about their [HIV treatment], just like they talk about their diabetes and pills. This is my wish. Of course I would like this [HIV/AIDS] to be eradicated totally from the earth. But if we don't have this possibility for now, I want a life in which people could express themselves without hesitation, without fear. This is what I'm concerned with. When I go to the hospital (...) okay, write "immune deficiency syndrome" or HIV/AIDS on my prescription paper [instead of writing other things to protect privacy]; but the nurse should not be annoyed by me. I wouldn't have to do something to ensure that the nurse does not feel uneasy about me. Or [I wouldn't have to] tell the nurse to keep this prescription paper in a secure place because it's written HIV on it." (Enes, 30, male)

As seen in Table 9, positive representation of HIV was more salient in the narratives of people who have been more recently diagnosed, for a couple of reasons. First of all, they had never had AIDS-related health conditions. Other narratives of people who have reached the AIDS stage showed how comparing oneself with others might create a more negative perception of illness. For people who had been close to death such as Sevgi, comparisons of HIV with other non-terminal health conditions were not always in favour of HIV:

"When I was going back home [from the hospital], and I was still in the wheelchair then, [I thought 'look at these people'], how lucky they all are'. I mean, there is a blind person; there is a person with walking disability, so what? (that's nothing) They are not HIV-positive. I mean, we (PLHIV) sometimes have this psychological mood, thinking that their conditions are better. I don't know why we feel that way." (Sevgi, 36, female)

Secondly, it can be argued that the narratives were dominated by this reconstruction of HIV in this group which was still in the process of adaptation after the first shock of diagnosis; taking in and convincing themselves of the newly learned idea of a 'long and healthy life'. Finally, they received counselling and peer-support right after their diagnosis from the same support NGO. Thus the salient

⁵⁸ This dilemma will be mentioned again in the following chapter when discussing concealment and disclosure issues.

form of reconstruction of HIV in their narratives may be an outcome of their interactions with the NGO. I return to this effect of NGOs as 'framing agents' later in the chapter.

3. Perceptions about ART

Among the 28 participants of this study, including KIs who were living with HIV, 22 were on ART.⁵⁹ Previous research (Robins, 2005; Seeley & Russell, 2010; Baumgartner, 2012) has demonstrated that starting ART can be perceived as a positive turning point by people who have experienced serious AIDS-related illness in terms of a beginning of a new, healthy, 'normal' life. Turning points are defined as significant events that cause a major change in the life course, such as a change in the person's major social role, environment, and perspective on life or self-perception (Fiori et al., 2004). Ten participants had been diagnosed when having an AIDS-related health problem.⁶⁰ Among them, four women and two men reported a near-death experience.⁶¹ Only three of these mentioned that starting ART had made them feel reborn. Even if others might also have felt this, the turning-point effect of starting ART was not a visible theme in their narratives.

As shown in Table 9, six participants were not on ART at the time of the research. One was not seeing a specialist yet; two reported that they had not been recommended to start treatment by their doctors yet because they had high CD4 counts, and three had decided to start treatment later, although their doctors wanted them to begin. The narratives of these participants (except for the person who had not been seen by a doctor) and of one person who had recently started treatment suggested that ART can be seen as a negative turning-point for people without HIV-related health problems (see Table 9). The motivation expressed most in those narratives was to be able to put off commencing treatment for as long as possible.

"When I first went to the hospital, they told me to start treatment in the next three months. But honestly, I didn't want to start treatment when I was 17-18

⁵⁹ Among them, three started ART only very recently (a month ago, a week ago and just two days ago) and one participant described herself as 'on and off treatment'; she was on ART at the time of the research.

⁶⁰ See Table 6 in Chapter 6 for the test and diagnosis process.

⁶¹ Note that the numbers of people who had experienced these situations are different in Table 9 which does not include KIs living with HIV.

years old. (...) And I poured myself into books on diet and strengthening my immune system. (...) It's been 4 years now and I haven't started treatment and I hope I won't start in the next 3 or 4 years." (Mehmet, 21, male)

The need to start treatment can be perceived as medical 'evidence' that a person can no longer manage their health status by using only 'natural resources' such as healthy food, exercise, positive thinking and spiritual beliefs.

"I don't pay much attention, for instance when the doctor tells me about names of pills I don't listen at all. Because if I learn, I know my brain will tend towards taking it. I.. I don't think I will use pills for quite a while. (...) I feel it. ... (...) They laugh at me sometimes when I say this. But it pleases me when they do. For example [my former doctor] laughed at me when I first said that. They said 'we're going to start treatment in one year time'. ... 4 years went by and they said 'okay now do whatever you do, I am not suggesting anything'. I love myself. ... I'm not doing anything else. That's what I am trying to do. I am trying to love myself." (Tutku, 55, female)

Being able to manage their health without medical intervention comforted these participants because it made them feel that they were in control of their bodies. Starting treatment, on the other hand, meant losing control over their bodies, giving it to the hands of medicine. A participant was told by the doctor:

"I can keep you alive for 10 years [when you start treatment]. Then I will take you upstairs (to the clinic for inpatients), I have my nurses there, they'll take care of you and you'll pass away within 2 months".

Considering this trajectory pictured by the doctor, starting treatment can be considered by PLHIV as the start of this path. It can be perceived as a point where HIV actually starts to affect their health and a step towards succumbing to and 'actually' living with HIV. As Baumgartner and David (2009) also find, the first encounter with the need to start taking medicines may feel like 'the real slap in the face' (2009, p.1734), that makes PLHIV begin to make HIV part of themselves. Musheke et al. (2012, p.5) also demonstrate that taking pills can remind PLHIV of 'being "sick", having an incurable and fatal condition, and dependent on medication' and that this can cause PLHIV on ART to discontinue medication in order to feel 'normal' and 'healthy' again.

In addition to the motivation of managing health without medical intervention and thus delaying self-identification as a 'patient' there was also resistance to medical advice in these narratives. One of the possible causes of such resistance is the

mistrust in medical professionals discussed in the previous chapter. Both the participants' own negative experiences in interactions with their doctors and stories about wrong treatment practices heard from other PLHIV may be behind this mistrust.

[My doctor] "said your virus is slightly higher so we need to reduce it. I said 'what do you mean, it's so early! .. It's been only 7 months after diagnosis, how come my CD4s are that high, how come I should start the therapy that early!' I couldn't stand it and I cried. (...) And I immediately threw myself here [the NGO office]. I said 'do I need to start taking pills?' (...) [The doctor working in the NGO] said 'no my dear, you do not have to start treatment with these results. (...) You can go more than a year without using drugs.' And I said okay. (...) I trust the people in here a little bit more than I trust medicine, more than I trust our doctors. Because I become more enlightened and more conscious in here. At least, I feel happy here." (Murat, 23, male)

It is important to note that the above participant mentioned feeling happy while explaining his trust in the advice he got from the NGO. This indicates that trust is based not only on the sufficiency or level of expertise but also on the quality of communication and interaction in a non-stigmatising environment. The effect of mistrust on perceptions of ART was also seen in some accounts about the drugs' side-effects, as mentioned later in this chapter.

An important point about negative perceptions of ART is that they were not related to doubts about its potential success. As Schumaker and Bond (2008) explain, meanings attributed to the pills affect the perceptions and use of antiretrovirals. In this study, none of the participants' narratives reflected concern about the toxicity or efficacy of the pills. In other words, concerns about the treatment were related not to the medicines themselves but to the expertise of the medical professionals recommending a treatment regimen.

If starting ART is an important step towards the incorporation of HIV into the self, we must ask whether trying to postpone starting to use it is a sign of denial or rejection. None of the participants who postponed treatment against the advice of their doctors mentioned having HIV-related health problems. Their doctors had advised them to start treatment on the basis of their CD4 levels and when the patient refused they agreed to wait until the next CD4 count test. In rejecting ART these respondents did not give up monitoring their condition and made extra efforts

to maintain their good health. Thus resistance to ART in these cases can be seen as asserting agency in decisions about treatment. It is not possible, however, to predict whether they will continue resisting ART when their CD4 counts drop or they start having health problems.

Some of the participants who had recently started ART criticised others who considered that not needing to start it was a sign of success. According to them, ART is 'normal and inevitable' in the course of life with HIV; therefore starting to take it should not be perceived in terms of 'failure vs. success'. This criticism reflects a division between people who 'still can do perfectly well without drugs' and those who 'have had to start' ART, which has the potential for creating a relabelling effect, reinforcing an idealised HIV-positive identity as 'successful' and 'self-sufficient' in terms of health management.

4. The need for information and managing uncertainties

Uncertainties about available scientific knowledge about the disease, the expertise of medical professionals, the effects of treatment and the prognosis of the illness are often regarded as challenges in the self-management process. The feeling of uncertainty creates hopelessness about the success of the treatment, constraining incorporation of the illness into the self. It also increases lay ambivalence about the value of biomedical science. At the same time, uncertainty can create motivation to actively seek additional information about the disease (Miller, 1989; Alonzo & Raynolds, 1995; Brashers et al., 1999; Trainor & Ezer, 2000; Gabe et al., 2006; Baumgartner & David, 2009).

Participants expressed their need for information on several issues including the prognosis of the disease, when to start treatment, when and from whom they acquired HIV and how long they were going to live. Although there was no doubt about the usefulness of ART in principle, they also wondered if particular pills would work for them and about their side effects. Below I explain the need and the search for information about these issues and discuss the role of framing institutions as sources of information.

In the narratives, the felt need to 'know about it', to have a sense of certainty was reflected in initial reactions to being diagnosed with HIV. A participant said that 'the

first thing every person with HIV does is to get a pen and paper and start calculating' based on CD4 counts and information received from the doctor, trying to find the date and incident when they might have contracted HIV. This can be seen as important in terms of calculating how long they have been actually living with HIV so they can judge how long they are going to live. It is also important in terms of finding out how and from whom they contracted HIV, thus giving meaning to the 'reason' for being HIV-positive. The need for information here can be interpreted as seeking control. For instance, they might want to plan their future or inform former partners based on the information they have. The concept of 'control' should not be understood only in terms of actual behaviour. In Lewis's terms (1987, cited in Volker & Wu, 2011, p.1619), 'existential control', 'the attribution of meaning and purpose to an event' is also a need in chronic illness self-management. As one respondent said, 'Even if you're going to die, you want to know [the prognosis of the disease]. If I'm going to die, I want to die at least knowing about it'. In other words there is a need for information, even if the person can do nothing to change the course of events.

Although most of the participants' narratives demonstrated their belief that they were going to live a long and healthy life, due to the feeling of uncertainty, they still needed 'evidence'. Seeing healthy PLHIV who had been diagnosed many years ago often provided such evidence. For example, Melek, who had seen only one or two other people living with HIV, asked me about an HIV-positive NGO worker who had visited her in hospital. When I told her that he did not work there any more, she repeatedly asked: 'Please tell me the truth, has he died?' Another example was mentioned by a healthcare provider who worked on an HIV/AIDS hotline.⁶² A regular caller called only to ask if Magic Johnson was still alive. Information that PLHIV can live long and healthy lives was constantly being double-checked and confirmed in this way.

Information from doctors was not sufficient in terms of managing the uncertainties of the treatment and prognosis of the illness, especially among respondents diagnosed more than five years ago. They explained: 'Let alone psychological support [which is now relatively more accessible for PLHIV], we couldn't even get

⁶² Personal communication, 2008. The mentioned hotline was no longer active at the time of the research.

answers to our questions from doctors' about the treatment, how to store and take the pills and possible drug interactions. According to them, IDSs have become more knowledgeable about the issue in recent years, and PLHIV pressure has been a factor in this.

"The MOH training was very effective on the improvement of infection doctors. But perhaps more importantly, they had patients, to whom they were writing prescriptions. But in the course of the establishment of NGOs, they got together with these patients as human beings. That was maybe one of the biggest effects of the NGO. Before that, no one who has HIV showed up on World AIDS Days, stood up and declared what problems PLHIV were having." (PLHIV 24)

PLHIV also obtained information about the functionality of ART and the expertise of doctors from other PLHIV and the media. Information that is contradictory or disagrees with a person's own experience may result in mistrust of medical knowledge and practice. For example, a participant had struggled for a long time to change his drug regimen, said:

"... I read [from newspapers and internet] that they merged all pills into one tablet, but I take (...) 8 or 10 pills a day (...) it is nothing but a torture. (...) For 4 years [when I was on a different regimen which was offered to me previously] I wasn't right in the head (...) I was very angry and stressed [because of the side effects]. I used to take out my anger on my family. If there is such kind of a side effect they [doctors] need to solve this, right? I mean, if I were a doctor I would give my patient the best pill, without thinking about this or that American or Turkish company's profit." (Şahin, 55, male)

This person believed that instead of prescribing new medicines that are easier for PLHIV to use, doctors prefer to prescribe medicines produced by the pharmaceutical companies with which they have a financial agreement, turning a blind eye to the 'torture' that PLHIV experience. As seen in this example, in the absence of trust in doctors and the health system in general some participants linked the side effects of ART to the 'incapability' or even 'bad intention' of doctors. Side effects were not seen as the normal or potential effects of taking pills but as avoidable with correct regimens. The effect of this distrust in medical providers on PLHIV's concerns about receiving appropriate treatment is also demonstrated by Beer et al. (2012), whose research found that some PLHIV believed that healthcare providers 'do not know the true effects of HIV medications' and expressed their doubts about whether medication would cause more harm than good. According to Beer et al. (ibid, p.5), 'part of the suspicion about the ill effects of HIV medications

concerned beliefs that providers prescribe medications that are experimental and that a person who accepts medications is accepting being treated as a “guinea pig”.

In the narratives about the above ways in which PLHIV give meaning to the illness, its treatment, side effects and available information on all of these, the importance of framing institutions is prominent. As Watkins-Hayes et al. (2012) suggest, especially when the illness is highly stigmatised and management resources are very limited, institutions and agents other than medical providers are important resources for people in terms of integrating the illness into their identities and everyday lives. ‘Framing institutions generate language, adaptive skills, and practical knowledge that shape how individuals interpret a new life condition and whether they ultimately see it as a platform for growth’ (Watkins-Hayes et al., 2012, p.2030).

The significant commonalities, in terms of reframing HIV and ART, among people who received early and regular support from a PLHIV -NGO or a peer counsellor suggest that such framing agents are important in formulating prognostic knowledge, interpreting the meaning of treatment and evaluating the trustworthiness of medical knowledge and practice. They offer a conceptual framework and resources within which HIV can be reconstructed in a destigmatised way. Framing institutions not only effect the perception of illness but also offer ‘explicit and implicit directives’ (Watkins-Hayes et al., 2012) for managing health and social behaviour, as I discuss below.

5. Adherence to treatment and self-care

In the narratives, the word ‘treatment’ meant taking pills and having regular tests and check-ups, generally once every three months. Other health-related behaviour such as a good diet, exercise and safe sex were not mentioned as part of the treatment, but under the umbrella of ‘taking care of oneself’.⁶³ None of the

⁶³ This indicates that doctors do not emphasise these behaviours as a fundamental part of HIV treatment. Doctors who participated in this research as KIs explained that they do not approach their patients only from a biomedical perspective but that their recommendations cover a broad range of areas including the social and psychological aspects of living with HIV. However, as mentioned earlier, the doctors participating in this research do not represent all the infection specialists that PLHIV see.

participants reported trying alternative treatments, which is not surprising considering the general ‘tendency towards conventional medicine’ rather than ‘holistic complementary and alternative medicine’ in the country (Erci, 2007, p.766). However, a couple of participants were using immune boosters and some of the doctors who were interviewed as KIs mentioned that they had patients who opted for alternative treatment.⁶⁴

Most of the participants who were on ART stated that they ‘complied’ with the treatment. Some described themselves as ‘responsible patients’; for example, Zafer explained that he ‘tried to do everything that medical science asked of him’. Another participant said that his compliance with the treatment was based on his religious views.

“I believe it is a sin not to get treatment. It is a sin to use the body that was given to you by Allah like that. This is the body that I will revive after-death. This is my belief. You are going to return the body that was given by Allah.” (Objektif, 31, male)

Only one respondent admitted not taking her pills regularly. She not only skipped pills but also neglected her regular tests and check-ups. Her non-adherence was not based on poor knowledge or distrust in medicines or the medical profession, and her narrative did not reflect a negative framing. Her loneliness, low psychological mood and exhaustion from the bureaucracy of the health system were the reasons she gave for not keeping up with her treatment. There were also some gender-related constraints to her self-care. She was responsible for the housework and childcare in the large household of her parents-in-law. She also had difficulties living in a town where it is regarded as unacceptable for a woman to go out alone, even to attend hospital, .

Managing the side effects of drugs is an important aspect of adherence to treatment. Almost everybody on ART reported suffering from side effects, mostly early in their treatment. While most stated that the side effects faded or disappeared over time, some said that they had ways of managing them such as finding a better time to swallow the pills and/or more appropriate food to eat with them. The PLHIV’s narratives revealed that management of the side effects was

⁶⁴ Such as Armenicum, a drug developed in Armenia.

not fully covered by doctors, and PLHIV got information from others. Doctors' reluctance to discuss the side effects thoroughly was generally seen by the respondents as 'indifference' or inadequate medical knowledge. But it could also reflect doctors' concerns that discussing the possible side effects would worry their patients. Key informants and peer counsellors stated that when PLHIV hear about some of the side effects they can 'start waiting for them to appear', as also exemplified in some of the narratives.

Decisions about taking pills and opposition to the treatment regimen are demonstrated in some research as meaningful behaviour guided by rationales and principles that are important to the individual and are thus a way of asserting agency and control in their own life (Telford et al., 2006; Stevens & Hildebrandt, 2009). From an agency-oriented self-management approach, seeking additional information and identifying one's own responses to illness instead of strictly following health professionals' orders are important tasks (Koch et al., 2004). However, a patient's assertion of agency and control can challenge collaborative relationships with doctors, which are also seen as essential to self-management (Swendeman et al., 2009). Observational data and interviews with doctors showed that introducing information obtained from other sources and offering different ideas about treatment were not always welcomed favourably by doctors. As some of the key informants also argued, apart from the doctors' motive of maintaining power, the strong respect for them that is culturally common in Turkey makes it difficult for patients to be involved in treatment decisions.

The narratives of participants reflected this respect for doctors, which diminished, as mentioned in the previous chapter, when their trust was damaged and/or patients were subjected to stigmatisation from doctors. However, because of the perceived hierarchy between doctors and patients, some PLHIV could not easily bring their opinions or new information to their attention. A similar situation is documented by Chiu (2011, p.1658) in Taiwan, where cancer patients were hesitant to ask doctors for information because 'the doctor-patient relationship is traditionally doctor-dominated'.

The quote below shows how respect for the medical profession not only makes people hesitate to be involved in treatment decisions but can also become a reason

to oppose lay expertise. Şahin, who had serious doubts about his doctor's competence because of the side effects of the recommended treatment regimen, was also sceptical about and angry at expert patients:

"I'm telling you, when I first came here [NGO], I was looking at people talking, people acting like .. like they knew all the answers, like smarty pants. (...) .. I heard people talking like 'what's your level of this, what's your level of that? [referring to CD4 counts, viral loads etc.]?' and they were talking all about it! I get angry [with my self], I'm saying I'm not going to come here any more! (...) they're coming here and they're talking all at once, 'how is your HIV? how is your C4? (sic)', they're acting like doctors, they're saying 'change my drug'. What kind of speaking is that! (...) I'm still coming here, I hear them talking, they interrupt doctors speaking.." (Şahin, 55, male)

As Watkins-Hayes et al. (2012, p.2030) state, 'framing agents' interventions can coincide or conflict with those of the broader framing institution, adding further complexity to individuals' coping trajectories'. PLHIV who were getting advice from a support centre or other PLHIV were struggling to follow two contradictory recommendations at the same time, trying to be as knowledgeable about the disease as their doctors and to comply with the treatment. As a key informant put it, the principle is that 'you should be your own doctor but you shouldn't tell this to your doctor'. This indicates that a form of 'expert patient' is being developed, paying attention to not harming the doctor-patient relationship in a way that could hamper ongoing treatment.

6. 'The system' as a barrier to adherence and self-care

Participants' narratives pointed out the importance of 'health system-level factors' affecting adherence (Musheke et al., 2012). For the majority of participants, including those not on ART, treatment meant more than just taking pills; it also meant spending a considerable amount of time, money and effort on monitoring their health status. Although ART is provided free of charge and access to treatment is high in Turkey, there are problems related to the healthcare system such as the absence of some HIV-related testing facilities in hospitals, very long waiting periods for test results, the unavailability of some drugs in the country and problems caused by interruptions to access to the social security system. All of these problems create obstacles to successful treatment such as delays in starting treatment, the development of resistance to certain drugs and negative effects on

the person's emotional wellbeing. Consequently the procedures that PLHIV need to follow to renew their health insurance, reach a doctor, have a test done, collect the test results were important challenges and sometimes the main burden of living with HIV.

[I have] "nothing to say in particular [to describe my experiences in hospitals], but.. it's really rubbish. I mean, how much more difficult can this thing get? How much more ridiculous can it get? Imagine a place where the janitors, doctors, pharmacists, others, everybody is totally unaware of each other and you run around in a mad rush, you search for contracted pharmacies, pharmacists send you back to the hospital 4 times, 5 times, the use-by-dates are expiring and you can't find the doctor or you find them but they don't understand [the situation], you can't make the doctor and the pharmacists talk to each other, because I mean, of course not! ooh that's a luxury! Or you go to the pharmacist, they don't know [what to do], or you go to the head of hospital and they don't know, the doctor is unaware, I mean as I said, there's no need for all of that, I mean there is a ridiculous bureaucracy, I mean bureaucracy is not even the right name for it, this is disorder." (Zeynep, female)

These system-related problems were mentioned in nearly all of the participants' narratives. Dealing with this lack of order did not deter everybody, especially those with the financial resources to have tests in private clinics, the education necessary for effective communication or enough time or psychological strength to deal with the challenges. However, for some, the main challenge of living with HIV was 'going to the hospital'. For example, a woman who was infected by her late husband said:

"I'm still angry with him [late husband] because he makes me come all the way from there to here. (15 hours bus trip every three months, without money for accommodation)" (Melek)

This participant reported that her husband had cheated on her with a sex worker. She had suffered from AIDS and had 'returned from her deathbed'. When her husband died she was left with children and shame and with 'nothing', financially. It is a strong narrative point that despite all these burdens she expressed her anger in relation to the difficulty of commuting for treatment.

For another woman who did not take her medicines regularly, the exhausting process was a key factor in her giving up treatment.

"One day, a coincidence, I went to [a state hospital]. The lady doctor in the infections [department] said 'there is a mother just like you. She gave birth to two children' (...) 'the drugs are not working for her now ... she is waiting for

death. She shut herself up in home and she is waiting for death.' she said. .. [another doctor also said] 'yes (...) she gave up treatment because she was so exhausted I guess'. I am exhausted too. I am also a mother. I understand her very well. Because you deal with the tests and this and that and with the kids (...) and their sicknesses and your treatment, it's difficult. .. I mean the treatment of this illness is very difficult. Especially in Istanbul.. running between hospitals, striving with hospitals, striving with doctors and their assistants (...) chasing doctors in hospitals.." (Pelin)

The management of HIV involves a 'struggle against the system' which necessitates the exertion of a great amount of effort and energy. More than half of the participants' narratives included explanations about how they tried to go to hospital less frequently, have tests done faster, find blood from other sources when necessary and order unavailable drugs from other countries, and how they sought help from NGOs to overcome bureaucratic problems. Strategies that 'relied principally on developing skills to navigate the bureaucratic practices of the treatment system' are referred to as 'bureaucratic technologies' in Bernays et al.'s (2010, p.17) research on treatment experiences of PLHIV in Serbia who found that the anticipated restorative effect of ART was disrupted by 'the need to invest time in 'chasing treatment'', and the need to develop strategies to 'avoid getting lost' (Bernays et al., 2010, p.17) in the disorder.

7. Conclusion

This chapter has looked at the components of the management of physical health, pointing out the main challenges in fulfilling the tasks involved and the ways in which PLHIV assert agency in overcoming those challenges. It is seen that there are three most important challenges in management of physical health when living with HIV.

The first is the discrepancy between the 'normalised' perception of HIV constructed by PLHIV and the opposite perception in the general healthcare institution. A positive and optimistic perception of HIV was expressed in a narrative framework of comparisons between HIV and other illnesses in a way that suggested that HIV is like any other disease, equally 'normal' or even 'less serious'. The language and advice provided by support networks contributes to this reconstruction of illness detached from fear and self-blame. This perception of HIV can prevent the further internalisation of stigma and facilitate acceptance for PLHIV. It can also be

regarded as asserting agency through resisting stigma by constructing destigmatising discourse in personal narratives.

However, the potential empowering effect of this perception of illness is hindered by the stigma. When PLHIV's 'normalised' perception of HIV does not match general perceptions about healthcare settings there is a dilemma of defending normalisation and exceptionalism (Seeley et al., 2011, p.2) at the same time. On one hand there is a desire to be open about ones HIV status, since it is just like any other disease, while on the other, concealment of identity and confidentiality of medical records are regarded as the most important rights. This situation represents one of the main ways in which the stigma challenges chronic illness self-management.

The second major challenge in the management of physical health is to find a balance between compliance with medical advice and being a lay expert. Knowing and understanding the disease and its treatment, searching for information, active involvement in the treatment process and maintaining collaborative relationships with healthcare providers are all regarded as requirements for the successful management of health. However, fulfilling all of these requirements is not easy, especially where there is distrust of the medical profession, conflicting information from different sources and a culture of doctor-patient relationships that is doctor-dominated.

This chapter has shown that distrust of the medical profession, which is partly a result of stigmatisation by healthcare providers, adds to uncertainties about treatment and the need for new information. However, as Chiu (2011) states, while gathering new information from different sources empowers the patients it can have a limited effect on improving their involvement in treatment decisions when the doctor dominates their relationship. The patient's 'weakness' in this relationship is not only due to this culture of doctor dominance but also to the stigmatised identity of the patient. In this case, 'probing, impelling, but not offending doctors' (Chiu, 2011) appears to be the key to asserting agency in treatment.

Finally, this chapter has demonstrated the importance of health-system-level constraints. Successful health management requires the development of resilience to system-related problems and the acquirement of competency to overcome

barriers to continue the 'struggle'. As the narratives suggest, this struggle can be overwhelmingly exhausting and result in non-adherence to treatment. Becoming a resilient and competent PLHIV necessitates developing not only sufficient skills and knowledge but also emotional strength.

Chapter Eight

Managing social life and the shift in identity

1. Introduction

This chapter looks at the strategies that PLHIV constructed to manage their social relations and social identity. The main questions to be answered are 'What are the strategies developed by PLHIV to manage social relationships and social identity?' 'How do they assert agency in managing HIV in these domains' and 'What are the multiple social locations of individuals that allow or restrict the development of those strategies?'

I analysed the data gathered from the PLHIV by focusing on their narratives about change in their lives, attitudes and emotions, and the meanings attributed to those changes. I used concepts from the social-psychology literature on health-management and stigma-management to interpret the data. I have not employed the dichotomised models of 'successful vs. unsuccessful psychosocial adaptation' (Livneh & Martz 2007, p.16) discussed in Chapter 2.

The data suggested categorisation of the management strategies according to their contexts and functions. As recent approaches to the management of chronic illness and stigma defend, strategies which are conventionally considered to be maladaptive could in fact be adaptive in some circumstances (Anderson et al., 2009, p.1062) and thus should be understood as situation-specific (Livneh & Martz, 2007, p.16.). Also, the data did not allow for a 'static categorisation of individuals' (Goudge et al., 2009, p.100). As Paterson (2001, p.21) suggests, 'living with chronic illness was an ongoing and continually shifting process in which an illness-in-the foreground or wellness-in-the foreground perspective has specific functions in the person's world'. It was seen that individuals can switch between different strategies based on their needs at the time and can adopt an active or successful management strategy to resist stigma and at the same time not succeed in dealing with their negative emotions. Accordingly, I have presented categories of experience in the participants' incorporation of HIV into their social lives and identities. I explain the commonalities and differences among the participants to

show the factors affecting the construction and perceived meanings of a particular strategy.

In the first subsection I look at motives and strategies for concealing and disclosing HIV status. Secondly I discuss how the changes in social relationships are managed. The chapter then focuses on the cognitive and emotional aspects of integrating HIV into the social identity; but before that I first discuss the extent and the ways in which HIV is perceived as causing a shift in self-concept. In the last two subsections I look at the strategies for reducing negative emotions and constructing a valued identity, respectively.

2. Motives and strategies for concealment and disclosure

While most participants disclosed their status in health institutions, as mentioned in the previous chapter, they concealed it from family and friends and in the workplace for different reasons.⁶⁵ Of those who were married or in a relationship, only one person was not open to his partner. Only one participant had disclosed his status to co-workers.

There was no significant difference between women and men in terms of the people to whom participants disclosed their HIV status and their levels of disclosure. However, some differences between heterosexual and homosexual male participants were found. Homosexual participants were more open in general, particularly to their parents, about their HIV status. This is partly due to the fact that the married heterosexual men were in relatively less contact with their parents since they had formed their own families. It should be noted that disclosing HIV status to parents does not mean that these homosexual men disclosed their sexual identities as well. Four were open, four totally closed and one selectively disclosed his sexual identity in certain environments. Relatively limited disclosure by heterosexual men was also seen in their relationships with friends and other people outside their families. Half of the heterosexual men stated that 'no one' knew their HIV status apart from close family members and a couple of other people living with HIV.

⁶⁵ Disclosure to family members has been discussed in Chapter 6.

Another salient difference among the participants in terms of the importance of concealment was location. My observations, key informants' opinions and the narratives of PLHIV indicated that Ankara is seen as a city of civil servants in which people would hide themselves more than they would in Istanbul. Finally, a notable difference among the participants in terms of disclosure was that all of the participants who described themselves as religious (seven people) were concealing their HIV-positive identities from everybody except a couple of very close people.⁶⁶

Motives for disclosure

Three themes in the motives for disclosing HIV status to others emerged from the narratives. The first is the psychological need to share experiences and emotions with others. It was difficult for some people to repress their feelings and endure in silence: Pelin felt 'like I'm going to explode if I don't tell'.

As Turkey's PLHIV Stigma Index survey (SIT, 2010) shows, 78% of participants felt that disclosing their HIV status to others made them 'feel more empowered'. An explanation for the need for disclosure, expressed by one of the participants, was the value given to intimacy in interpersonal relationships in the communitarian culture of Turkey, which makes it more difficult to endure in silence:

"When you can not tell anything to anybody, it makes you feel much more uncomfortable, because you know.. maybe as a society, we are so used to share everything with some other people, perhaps we are so used to open up everything to everybody without reservation, I guess we have been brought up that way. Because of that, I mean, to remain quiet, to live this thing on our own, was a bit hard for me honestly." (Fidan, 27, female)

Research in different settings has demonstrated that patterns of concealment and disclosure can be 'rooted in cultural values' (Bond, 2010; Yoshioka & Schustack, 2001, p.70). For example, the common cultural reluctance to share personal information was found to be an 'additional self-imposed barrier to disclosure' for Asian PLHIV (Yoshioka & Schustack, 2011). The above quote suggests that in

⁶⁶ Seven participants defined themselves as 'religious' and six as 'believers'. While believers' narratives did not show significant commonalities, 'religious' people had similar representations of HIV, which will be mentioned again in this chapter.

contrast, the cultural need to share can be an additional motive for disclosure in Turkey.

This motive for disclosure was mostly expressed by participants with access to peer-support networks. Most of the participants who avoided talking about such issues were not in close contact with an NGO or other PLHIV.

The second main motive for disclosure was a feeling of moral responsibility. For example, disclosure of HIV status to a healthcare professional (a nurse when giving blood, a dentist) was explained in terms of responsibility. In spite of the negative results of disclosure such as mistreatment or the denial of healthcare, most participants preferred to be honest about their HIV status to protect medical staff.

"Well, of course, you feel exhausted but you don't give up the struggle. I felt very exhausted I said enough is enough, I mean, this is it, I won't tell anyone anymore. But this time I feel very disturbed, conscientiously. If a person is going to do something on my body and if this person is going to be infected with something, with my disease as the result of this job, this disturbs my conscience a lot." (Adnan, 43, male)

The 'responsibility to disclose' was not only related to the felt requirement of protecting the other person where there is a risk of HIV transmission; in more general terms, participants stated that hiding something is 'not morally right', is 'as bad as lying' and 'against honesty'. The discrepancy between concealment and morality was expressed not only by people who thought that one should be open but also by those who were determined to conceal their HIV-positive identity. The discomfort of behaving unethically, especially for the participants who described themselves as very religious and/or highly regarded in their community, is exemplified in Ahmet's and Fidan's accounts:

"There's only one thing.. some of my friends [who don't know my HIV status], say 'X (a respectful salutation) you are alone; don't go to the hospital by yourself, let one of us come with you'. When they say that, I couldn't figure out yet how to get away from this. But I've been thinking of a formula to solve this as well. And at this point of my life, I mean from now on, unfortunately my life will continue dissemblingly. I mean I will be pretending. I will have to pretend, from now on, I will lie, and I don't like to lie, I'm bad at lying, but I have to manage it somehow. This might be tough for me." (Ahmet, 40, male)

"Once, we [me and my husband] went there [parents-in-law's house in a village] in Ramadan (Islamic month of fasting) and we didn't fast. But we

woke up every night with them (for the meal consumed early in the morning) so that they won't know. (...) In the kitchen they [women] were preparing food for the evening meal and I was stealing some food every now and then, saying to my husband 'wait for me at the gardens' and I made him eat secretly. Because he needed to use his medicines. We woke up in the morning, he needed to have breakfast, to use his medicine. I took some food in secret and I said 'oh my God please forgive us, but I had to do this. I am not stealing. This is not stealing'." (Fidan, 27, female)

Concealment of HIV-positive identity was perceived to be against moral and/or religious beliefs. Phrases such as 'I have never lied in my life' and 'I am what I am' were recurrent in the narratives of the participants who expressed this opinion. The proverb *Allah'ın bildiğini kıldan esirgemek* (you shall not hide something that is known to God)⁶⁷ was used to explain why they did not want to hide their HIV status. However, it is important to note that the majority of the participants who expressed these reasons for disclosure had some people in their lives, mostly some family members, from whom they hid their HIV status.

Another motive for disclosure which is a type of selective disclosure was expressed in relation to the management of physical health. According to the view exemplified below, disclosure is needed to facilitate adherence to treatment and self-care:

"First of all, I don't anyway lie to my family, to my mother and father anyway. Apart from that, I don't think I should tell everybody. And there is no need for that. Apart from them [my family], I have a couple of close friends [whom I have told]. I don't think that I would tell others. I mean, when you tell [everybody] you can get everything into a mess. You would tell your family because you use pills. You should share [this information] with them, you should do this for yourself. Because you have to stay away from infections, you have to have a good diet. But apart from that, I don't have to tell everybody." (Zafer, 40, male)

Motives and strategies for concealment

As explained in the previous chapter, the concealment of HIV status from parents was mostly explained in terms of a motive for avoiding upsetting them or for protecting them from potential stigmatisation, whereas concealment from friends

⁶⁷ According to the Turkish Language Institute, this proverb means 'A person is responsible to God for the crime that s/he commits. The crime is known by God, therefore there is no need to hide it from other people'.

and co-workers was based on the fear of losing friends or losing the job. However, a broader feeling of insecurity accompanied the fears expressed in the narratives; almost all of the participants expressed awareness that their privacy and their right to work and to be protected from discrimination were not protected. This is one of the reasons why PLHIV, even those involved in activism and advocacy, were not open outside the boundaries of their closer environments.⁶⁸

The feeling of insecurity about rights behind this concealment was also explained with reference to the increasingly conservative political climate in the country.

"You'll see, they [the ruling party] will go to a witch-hunt and burn all of us. I believe that. And what I believe always happens. They, if they are selected again in this forthcoming elections (in which they've been selected again), I believe, they will cleanse us in the next 5 years. ... and you (me and people working at the NGO) will say 'ohh but the women and men in the Parliament were very nice to us', you will just stand in wonder." (Tutku, 55, female)

A participant repeatedly warned me that I should be careful to secure the respondents' anonymity and expressed his feeling of insecurity at the end of the interview:

"One never knows what this government would do. Look I'm telling you, they will start castrating people now. (referring to a proposed law about the punishment of rapists)" (Adem, 60s, male)

I was also explicitly warned by a respondent not to link the fear of stigma with conservative people's attitudes towards PLHIV. He added:

"I've always received support from conservative people, from ladies in *tesettür* (headscarf and light cover-all topcoat). (...) In society, there is this perception that conservatives necessarily approach you [HIV-positive people] negatively but that's not the case. Covered people (women wearing headscarf or *tesettür*) don't take money from me at the pharmacy. That friend of mine, working in *Diyanet* (Presidency of Religious Affairs in Turkey) is good to me. (...) There are good things going on in the state. No need to slander [damage the reputation of Turkey through false statements about the negative attitudes of conservatives towards PLHIV]." (Objektif, 31, male)

⁶⁸ Activism without disclosure and its possible reasons are one of the main themes discussed in the next chapter.

The possibility of increased visibility of PLHIV in the current political environment was a recurrent theme in the interviews with KIs involved in activism and advocacy, as I discuss in the next chapter.

Most of the PLHIV's strategies for concealment were expressed in the context of managing their health, since adherence and self-care require some behaviour such as attending hospitals frequently, taking medicine in public and asking permission for leave from the workplace which can arouse curiosity in others. For some participants who had other health problems through which their HIV status had been diagnosed, this other illness functioned as a pretext for their HIV-related health condition and health-related behaviour. In those cases, previous or ongoing real health problems were used as a cover. When a person did not have another health problem, they fabricated one as a pretext. For example, one of the participants explained that he had had to announce to his distant relatives and others that he had cancer, although his closer family knew the truth. He then had to cope with the sadness and concern of those who thought he had cancer. He actually felt very well and had no health problems at all, but was surrounded by people crying and pitying him.

Participants also stated that they developed behaviours for hiding the pills or prescriptions from others. Also, because of problems in the social security system, some of the participants, with financial resources, chose to pay for their tests and pills 'from their pockets', staying outside of the health insurance system. A participant explained that because he feared for his job he had his HIV-related tests carried out in a friend's name.

Another way of concealment was the use of different names and different means of communication with people who did and did not know their HIV status. Some people I met or interviewed were using nicknames in their relationships with other PLHIV. Even after their real names became known to the others as trust built over time, they still called each other by their nicknames. This is a habit that is acquired in due course with the aim of preventing unintentional disclosure of others' HIV status. Both the interviews and the observations found that protecting the privacy of others was considered as important as protecting one's own. I personally hesitated to approach people whom I knew when I saw them outside a PLHIV group with

other people around them. I was not sure whether or not I knew them by their real names; I did not want to cause inquiries and felt that my presence was a threat to their concealment. A participant who shared the same concerns about confidentiality said: ‘..in due course I gained this habit of calling people without using any names and having trivial chats’.

Concealment was not always perceived as a solution to avoiding stigma, since felt stigma itself can create major psychological problems. As Ahmet explained, concealment was accompanied by a constant fear and a need to check up:

“Sometimes, when I go to the (workplace removed), when I catch eyes with the director, I.. I pay a lot of attention ... [to see if] s/he is going to say something. Has s/he learned something? I shoot a glance to all of the administrative staff. I wait [to see] something [a sign] from them. [I wonder] if they have heard. I'm looking for a light. Not actually a light, a signal. Something like a signal. And when I don't see something like that, I say 'whew' (sigh of relief), I can be relaxed for today. They haven't heard anything today. Today is going to be a good day. But the next day.. is the same. When I go there the next day [I think] now, they must have heard it from somewhere, now, some information must have spread. For example, from the hospital where I go, the hospital where I have my tests done. For sure there must.. there might be someone who knows me and gets in touch with my workplace and so forth. Actually I know this is nonsense, maybe this is a very unnecessary paranoia but uhm, I have these kinds of psychological problems.” (Ahmet, 40, male)

Considering that violations of PLHIV’s rights in the workplace and health institutions are the problems most frequently reported in Turkey and that these violations are not being penalised, the insecurity and related fears of PLHIV cannot be seen as simply ‘unnecessary paranoia’.

Overall, the narratives about concealment and disclosure suggest that fears about the obstruction of healthcare, the loss of work and the exposure of family and friends to the HIV stigma are behind the concealment of HIV status despite strong motivation for disclosure. This discrepancy between the felt moral problem of concealment on one hand and the requirement for concealment on the other is an important source of discomfort for PLHIV. The framing institutions again play a role here. The non-stigmatising framing of illness and the need to raise awareness among the general public contribute to the felt need for disclosure. On the other hand, the rights discourse provides a source for defending the right to concealment. As mentioned earlier, the right to conceal one’s HIV status was the right most

referred to in the participants' narratives. Perceiving concealment as a right might be seen as a way of dealing with the moral problem in concealment.

3. Management of changes in social relationships

A frequently mentioned experience of the new life after HIV was loneliness and isolation. Especially in the first couple of months after diagnosis, ceasing any social contact and staying at home was a common experience. Some stated that they isolated themselves from their friends, family members or wider society. Distancing themselves from children for fear of passing on the disease or harming them psychologically caused major distress.

"Now, this doesn't have a treatment. I mean there is a treatment but not a complete treatment (meaning a cure). This will be with us for a lifetime. I feel the need to watch over myself at all times. I cannot even embrace my grandchild. I try to love them deep inside, in my mind. Wouldn't you be depressed if you were in my place?" (Adem, 60s, male)

"My mother, me and [my child] were living together, my mother is old, she's got hypertension, she's a person who takes medicines all the time. er and er because I didn't know [when diagnosed with HIV] what to expect er because in the end, it's an illness, it requires taking medicines. Thinking that it might affect the order of my life and that two people at home who deal with illnesses might negatively effect a growing child, her/his education, I sent [my child] to her/his mother's, on the very same day [I learned my HIV status]. Now I look back and think that I made a very wrong decision." (male, divorced, homosexual participant)

Both of the above cases reveal how the meanings of illness are reconstructed over time. The first quote, from Adem, shows that even if his doctor explained the means of transmission, a positive reframing of the illness and self-care behaviours had not occurred, probably because of the lack of regular counselling and of contact with other PLHIV. The other participant on the other hand, realised that giving his child away was a wrong decision after learning that living with HIV was not as difficult and harmful for people around him as he had believed.

The feelings of loneliness and self-isolation were explained in different ways. For example, *Objektif* compared his feeling of isolation to the experience of compulsory military duty, while *Tutku* described her situation as like being dead, stating that compared to this, death was nothing to be afraid of.

"I compulsorily isolated myself from the society. It's like military. It's like.. It's not like I'm in a prison but I can not act freely either." (Objektif, 31, male)

"The bad thing er the bad thing is not death, it's not the fear of death. I don't believe that any of the patients have that fear. Because for the last 10 years [after being diagnosed] many friends of mine have died, many people I knew died. Death .. is something totally different. You can die only once and I did die [the moment I learned my HIV status]. .. I know what death is like. I know it very well." (Tutku, 55, female)

Most of the participants stated that they started 'looking at life from a different perspective' after being diagnosed with HIV. Whether or not they had come close to dying did not appear to be a significant factor in this change, since most had experienced fear of death. They said that they now acknowledged the value of life and cherished it more than they had before. Spangers and Schwartz (1999) define such changes in individuals' internal standards, values and conceptualisations, which occur in the face of life-threatening or chronic diseases, as 'response shift'. According to them, response shift is an important mediator of the adaptation process to living with the illness.

The response shift affects social relationships.⁶⁹ Many participants stated that they had reconsidered their friendships. With a view to protecting their psychological wellbeing, some disengaged with existing friends who affected them negatively or amended the nature or frequency of the friendship. This kind of amendment of relationships with friends was sometimes referred to as 'becoming more selfish'.

For people who received unconditional support from their friends, partners or families, HIV was expressed as something that improved their relationships. 'To look on the bright side', they said, they got closer and based their relationships more on trust:

"One day, I was sitting alone in my room, locked myself in my room when my father called me, he said 'come down here let's eat some fruits and have some chat'. As soon as I went [to the living room] I threw myself into his arms and for the first time [after being diagnosed] I cried sobbing, for hours. (...) My father cried too. My mother started to cry too. Three of us cried. That day, what my father said was so nice. Uhm, 'I am X years old but I'm very

⁶⁹ Response shift also relates to how HIV is integrated into the identity, as I explain later in this chapter.

sound and very healthy and I'm still working and we have money. I will send you anywhere you want and I will absolutely get this thing treated. Nothing will happen to you', he said and hugged me. That was one of the most beautiful memories of my life." (Mehmet, 21, male)

Since most of the participants were recruited through a PLHIV-NGO, most of them explained that other PLHIV became their new friends. More than just a peer-support group, they considered them their new family or community. Zeki explained how he had felt when he first joined a PLHIV e-mail group:

"There were similar people, similar to me, people who feel the same way, although we weren't going through the same problems. You feel other people's problems, you think about those, you ponder upon those problems, you think about what can be done, what should be done, you know what I mean, as a matter of fact, it becomes a community. People living with HIV become a community. That's [what I think]. Today, in the world, there is such a subculture, you know what I mean, there is such a group. You know, people who go through the same things. Because, you have same experiences and then you become a distinctive culture, a distinctive group of people. This is how I feel. I mean, you don't know that before, you only realise when you penetrate into it. There is a distinctive community. There are blacks in the world, there are whites and yellows; and there are people living with HIV. There isn't such a group of people living with diabetes for instance, you know what I mean. But, here [in terms of HIV], there is one. Because [HIV] is a social phenomenon. There are prejudices, then there is discrimination and so forth, there is pressure. It's beyond an illness, this is something very different." (Zeki, 47, male)

Zeki considered PLHIV as a 'group' or a 'community' mainly because of the shared experiences of being subjected to prejudices and discrimination. In his account, we can see a reciprocal relationship between prejudice and perceived group membership. Prejudices against individuals, here, the negative evaluations of individuals living with HIV, are significantly based on the perceived association of these persons with an out-group (Crisp & Turner, 2010; Schaller & Neuberg, 2012). In turn, the experience of being subjected to prejudices cause individuals living with HIV to identify themselves with this group. As explained in the above quote, this can contribute to the formation of a social identity, 'which derives from his knowledge of his membership in a social group together with the value and emotional significance attached to that membership' (Tajfel, 1981 cited in de Fina et al., 2006, p.355).

The first contact with another person living with HIV face-to-face or by phone or e-mail was considered an important turning point in life by the majority of the participants.

“(...) I felt that I wasn't alone, I wasn't alone. That day, I told her [the first HIV-positive woman she ever met], I said 'it's like something, something like a drug is being injected into my brain'. Oh I said, you too [are HIV positive]? When I saw her I went like.. I mean it felt good.” (Tutku, 55, female)

One of the participants explained that the relationship between an HIV-positive person and the first other person living with HIV that gives her/him peer-support lasts forever and becomes 'like a relationship between master and apprentice. Or like a teacher and student' (KI15). On the other hand, three participants who were not recruited via an NGO stated that they did not want to see anybody else living with HIV as they 'did not need another reminder of HIV'. Despite this, two also said that talking with the one or two HIV-positive people they had met made them feel good.

Some participants were advised by their doctors not to contact other PLHIV.

[My doctor] “said 'you are a conscious, responsible patient. You are the one who responds best to the treatment. Don't go to support group meetings or your psychological state would get bad.” (Objektif, 31, male)

The recommendation that the patient should not get in touch with other PLHIV might be related to the doctor's desire to protect the patient's psychological wellbeing against the possible effects of seeing people who are very ill or suffering from side effects. It may also be related to the doctor's inclination to protect the patient from lay experts' knowledge, which might contradict the doctor's recommendations. A couple of the doctors who participated in this research mentioned that they were concerned about their patients receiving wrong or confusing information from PLHIV-NGOs. Although none mentioned recommending patients to stay away from peer-support groups, some of the civil society KIs explained that they had observed doctors who deliberately did not give their patients information about PLHIV networks because of the perceived threat to their power. My observations also found that not all doctors who gave HIV treatment were aware of such networks or of the content of the peer-support given in those networks.

Resuming sex life

Resuming sexual activity is an important part of the return to a 'normal' life for PLHIV who had an active sex life before being diagnosed with HIV (Seeley et al., 2009; Wamoyi et al., 2011). Since my interviews did not contain specific questions about their sex life, information about changes in sexual desires and practices could not be gathered from all participants. However, some explained that early after being diagnosed with HIV their desire for sex diminished due to the association between sexual activity and HIV, fear of harming their sexual partners and fear of re-infection or super-infection.

For PLHIV with an active sex life, regular condom use seemed to be an important component of their adjustment to their new lives. As mentioned in Chapter 4, condom use is not common in the country for several reasons. Reflecting this general lack of knowledge and practice of safe sex, most heterosexual men and women stated that before being diagnosed with HIV they 'did not have awareness about protection' or did not protect themselves 'enough'. They gained more information and become more conscious of safe sex after attending information meetings for PLHIV. Some stated that this lack of attention to safe sex was not only due to lack of education. For example, a young gay man explained that in the homosexual community, 'despite the fact that they're always being taught about condom use and are frequently given free condoms through projects, there is no safe sex in practice at all'. According to him, they start practicing safe sex only when they become infected or personally affected by HIV.

Meanings attributed to condom use reflected the meanings attributed to HIV and felt responsibility. For example, a young heterosexual man expressed two opposite views about condom use: one reflecting a quest to reduce felt guilt and responsibility and the other 'normalising' condom use. He explained his belief that no one really uses condoms: 'This thing [getting infected with HIV] happens to one person in a hundred'; this time it was he who was unlucky. He later stated that actually using a condom is very common. His idea that no one among the general public uses condoms might have reduced his feeling of guilt and responsibility for not previously using condoms himself. Everybody was equally negligent about this issue and he was just the unlucky one. On the other hand, when referring to his

current need to use condoms he expressed his belief that everybody uses condoms for different reasons, which might be seen as a way of normalising condom use.

“(...) people who don't want to have a baby protect themselves everyday. People who don't use or who don't want to use medicines (contraceptive pills) protect themselves everyday. Just like that, I'm going to be protecting myself everyday. (...) .. I will protect my self, I will take precautions, as do negatives (HIV-negative people). (...) And I have to. Let's suppose that we are doing this [using condom] not because of HIV but because we don't want children. This is how I look at it. This is how I can explain it [to my future wife]. All in all, everybody protects themselves.” (Tahir, 22, male)

The participants who mentioned the use of condoms emphasised that the function of a condom is not only to protect others but also to protect themselves from new infections (re-infection with HIV and other STDs). No one expressed a constant fear of passing the virus to their sexual partners when practicing safe sex. However, they mentioned that their partners were regularly tested for HIV.

Effecting change: influencing others stealthily

Some of the participants explained that they aimed to influence the people in their close social environments by giving them correct information about HIV/AIDS and trying to break their prejudices towards PLHIV and MARP. The most frequently mentioned way of influencing others' opinions was interrupting conversations among family and friends about a topic relevant to HIV/AIDS without making their HIV status explicit. For example, when the family or neighbours are watching television together and commenting on a news item about HIV/AIDS, the person living with HIV contributes to the conversation by correcting the information given or the language used in the news; such as 'Yes, but I heard that [PLHIV] don't look like that, they don't die that easily anymore – there is a treatment now'. When prejudices are expressed in a conversation, such as a statement that people with HIV/AIDS deserve to be ill because of their immoral behaviour, one way of breaking the prejudices was to state: 'But I've heard that there are other ways of transmission; what about innocent housewives and babies?'

Trying to influence the people around them was not limited to giving information on HIV/AIDS; it also involved commenting on people who are considered MARP. Similar to the situations described above, some participants mentioned how they

got involved in conversations when their friends, colleagues or family members were talking about homosexuality or transsexuality in a degrading way.

Participants who tried to influence the people around them were careful not to go too far, to avoid arousing curiosity about how or why they have such information or opinions. They tried not to attract suspicion about their own health or sexual identity. They generally said that they had read or heard the information somewhere and did not mention that they knew somebody who has HIV. If they thought HIV or sexuality-related issues would be difficult for the people in question to tolerate, they chose to talk about the right to health or the wrongness of discriminating against different people in general. One of the participants, a high school teacher, explained:

“You need to look at humans, as isolated from any kind of labels. (...) This is what I try to teach the children. But, I wish I felt so powerful that I could say HIV-positive or AIDS or.. (...) I wish I could say these. (...) I can't use [the power of my profession] efficiently, not yet. It's because of my own fears. (...) I mean, first of all I should be personally ready for that.”

One of the respondents who was actively working in peer-support and advocacy described a strategy she used when talking to people around her about equal treatment of PLHIV and people of different sexual orientation. She mentioned how the language she used when talking to relatives or neighbours was different from the language used in the civil society environment:

“When I explain the rights [of PLHIV or women's rights or LGBT rights], they give me bewildered looks. And then I realised that I speak another language. [I said to my self:] Go back. Think how you didn't know and didn't understand [these issues] before, try to look from that side. And .. when I tried to explain by looking from that side, I was understood much more easily. I mean, we are in a group in which everything is normal, everybody knows about rights and stuff but .. the society outside, is not like that at all. (...) I was also at that side once. Because I was also very rigidly conventional (...) you know how society teaches us those patriarchal things, I took them as rules and I was living with them, as if I was having faith in them (in religious terms). Even by then, I didn't judge different people, but I was finding them kind of strange. [I was thinking] like, why do they live like that? I mean, I didn't understand. So, [when trying to communicate with people] those thoughts of mine come to my mind. How would someone who doesn't know about rights look at a particular issue? I try to put myself into their shoes. So, it's empathy. I mean how would I react, what would I feel if I were in their shoes? This way of thinking is very facilitating for me [facilitating communication].”

The explanation about the language used by a particular group (a civil society network) indicates the formation of a sub-culture in which the rights and diversity of different groups of people are acknowledged.

4. Perception of the 'shift' in identity

Before discussing what kind of changes HIV causes in the self-concept and how PLHIV manage such changes it is important to ask whether HIV is perceived as a life changing experience by PLHIV. This is because the integration of HIV into the self-concept or the need to redefine the self is related not only to the actual changes in an individual's physical and social life but also, and perhaps more importantly, to the perceived importance and meanings of those changes. Although the participants' narratives were loaded with cases of negative change, not all of them talked about HIV as something that completely changed their life; and some, despite all their negative experiences, stated that 'at the end of the day, HIV changed my life for the better'. Therefore it is important to look not only at the changes that HIV created in their health and social life but also at the extent to which these experiences were perceived as important, positive or negative.

In this subsection I first look at the narratives of the participants to see the extent and the ways in which being diagnosed with HIV was represented as life changing. Rather than the actual changes, I focus on the perception and narrative representation of the changes. Secondly, I bring forward a point of discussion emerged in several participants' narratives: motivation for 'normality' versus consideration of one's HIV status as an important component to define social identity.

Perception of HIV as a turning point

Participants' life stories were analysed to see whether they separated them into two distinct parts, before and after HIV. Recurrent expressions in which HIV was mentioned as a beginning or an end of a life experience were identified. In addition, I identified the major losses and gains in participants' lives, explained in the narratives in relation to HIV. The number of participants who self-expressed HIV as a turning point is shown in the table below.

Table 10: HIV as a self-expressed turning point

HIV as a self-expressed turning point		
Yes	a positive turning point	7
	a negative turning point	5
	Yes, but not for better or worse	2
No	Explicit statement that 'nothing has changed'	5
	Not mentioned as a turning point	9
Total		28

Half of the participants self-expressed HIV as a turning point in their lives and of these, half stated that being diagnosed with HIV was a positive turning point, and as would be expected, most of their narratives were marked with what they have gained since their diagnosis. The positive changes included starting to know the value of their own life, starting to look at the brighter side at life, becoming stronger and more independent, becoming closer to God⁷⁰ and feeling reborn (when experiencing better health after AIDS-related illness). I discuss these in detail in the following subsections. Only one woman described HIV as a positive turning point in her life and only two women mentioned more gains than losses from HIV in their narratives.

However, when I looked at the narratives of the 13 people who expressed major losses due to HIV, only two expressed HIV as a negative turning point. This might be due to their strategies for reducing negative emotions and maintaining a positive self-concept, as I discuss in following subsections. In total, five participants self-expressed HIV as a negative turning point. They said that the new life after HIV was marked by social and psychological constraints. They perceived HIV as a burden and a source of worry that they will have to carry for the rest of their new life. It is interesting that none of the heterosexual male participants did state that they considered HIV diagnosis as a negative turning point, although considering that the married men received moral support from their wives this is understandable. However, as explained earlier, the narratives of single

⁷⁰ Not in terms of increased spirituality but of increased religious practice. I discuss 'becoming closer to God' later in this chapter, under 'positive reappraisal'.

heterosexual men were mostly dominated by the theme of their ruined future because of the perceived inability to marry and establish their own families. Not being able to get married was expressed by them as the most important thing that they have lost because of HIV. In spite of this, they did not express a perception of HIV as a negative turning point.

Among the people who self-expressed HIV as a tuning point, two said that although their lives with and without HIV were different, neither was better or worse than the other; they were just 'different'.

Half of the participants' narratives did not contain any explicit mention of their HIV diagnosis as a turning point. Among these, five specifically stated that it had not changed anything, emphasising a sense of normality that I discuss below. The rest of the narratives did not include a clear indication of the importance of HIV in terms of a life-changing experience.⁷¹ However, a closer look at the life stories of these participants shows that most had important negative life experiences before HIV such as rape, attempted suicide, gender transition or dramatic family problems. This suggests that HIV may not be considered as important as these previous life-changing experiences.

As mentioned above, the categorisation shown in Table 10 presents the self-expressed perception of HIV as a turning point; in other words, the narrative representation of the importance of HIV. From the perspective of narrative analysis, the motive behind a certain type of representation is important, as ideas are constructed and communicated to an audience through narratives. For example, participants who did not represent any account on whether or not HIV was a turning point for them might have wanted to maintain an impression of normality in their lives, even if they did not explicitly mention it. On the other hand, the narratives of people who emphasised the positive outcomes of HIV can be seen as an indication of wishful thinking. Most of the participants explained that they found this research very important in terms of communicating correct information and messages about PLHIV to the general public and other PLHIV. In this sense, participants who

⁷¹ Some of these were respondents from whom a long or detailed narrative could not be obtained using the particular interview method used in this research. See Chapter 3 for an explanation of this limitation.

emphasised positive outcomes may have been motivated to communicate optimistic messages to other PLHIV.

Incorporating HIV into the identity: normality vs. master status

“Look, you see, we're not even talking about HIV now. (...) I mean it's all.. we [me and my wife] don't even think about the HIV illness, we're just taking our pills regularly. We're going to our routine check-ups. I mean that's all. ... Do you have any question?” (Civa, 32, male)

The above sentences were common during many of the interviews. The incorporation of the illness into one's life is seen as central for chronic illness self-management. However, in terms of 'successful' self-management it is difficult to agree on the extent to which the illness and its consequences should be part of one's identity. As mentioned at the beginning of this subsection, some participants stated that being HIV-positive did not mean anything in particular for them because they were living their 'normal' lives except for taking some pills and going for health checks. Swendeman et al. (2009, p.1327) consider that 'motivation for normalcy, rather than either concealing HIV or making it the centre of identity' is a route to successful identity development when living with HIV.

Nevertheless, other research shows that self-management of HIV 'can involve a significant change to values, identity and activities that can be described in stronger terms than a return to 'normal" (Russell & Seeley, 2010, p.6). As explained in the following sections, some of the participants' narratives depicted a process of 'transformation' (Kralik et al., 2004) in which individuals perceived their illness-related experiences as contributing to finding new meanings that improved their self-perception and social life. Some also found that HIV acted as a tool to help them understand other forms of social inequality (such as gender and poverty) and to find a reason to fight against them.

Participants who were actively involved in HIV-related support and advocacy expressed their opinions about the incorporation of HIV into the self. Two different perspectives emerged about the reasons and functionality of motivation for normality and the development of a new identity. On one hand, 'taking pills and resuming one's normal life' was defended as the best means of self-management:

"I didn't make this [HIV] into the subject of my life and it is still not my intention to do so. This is not a subject of my life, you know what I mean? For some people, it might be, but for me it isn't, okay? I mean, I am going to live with that, [I think about] how I can live a good life, how I can live healthy, how I can be happy. [HIV] is not a subject in my life. It is not a kind of aim. Or I don't carry the hope that a drug will be invented soon and I will be saved. I am going to live with that. (...) I mean, some people.. in the beginning I was like them too. Like, 'oh if I eat this, if I eat that, those will have such and such benefits' and so on.. (...) But after a while I stopped doing that. Because after a while this becomes a subject, an aim in your life. (...) I won't do that. Because I want to move on with my life, like nothing happened. I want to take my pills and resume [my life]." (Zeki, 47, male)

This example shows opposition to incorporating HIV into the self as a central component or a master identity. On the other hand, as stated in the quote below, normalisation, in the sense of taking pills and resuming life, can prevent PLHIV from actively fighting HIV. Ferit expressed his belief that, as the subjects of the problems they encounter, PLHIV must take responsibility and fight both for their own and other PLHIV's lives. He criticised others, saying:

"Let's not be like turtles, let's be like porcupines, let's prick! (...) First of all, you should be a bit of a fighter, a bit crazy and you should have an ideal. If you don't have an ideal, if you think like 'okay never mind I'll swallow one pill a day and continue my life, maintain my sex life, sustain my job', then it's normal that you don't fight at all." (Ferit)

A respondent who was involved in support and advocacy made the following comment about the need to see HIV status as a main determining component of the self-concept:

"[There are] people who are happy to be living with their problems. [I don't need to live with this.] I see a lot of people who try to create an identity through their, say, homosexuality, their Kurdishness or religious identity, their richness or poorness, I mean, through just one attribute. The whole society consists of these people. (...) but as a person who already built your own identity, if you don't need a secondary factor, you would not use this. [Having said that, when a person is subjected to discrimination in their workplace, in their family, in everywhere, due to their HIV status] then this person does not have a chance to acquire an identity independent of HIV. I mean some processes could lead you to this point. (...) They are obliged to acquire identities through HIV. This is where the main discrimination is." (Taylan, 29, male)

This participant considered people who take HIV as a master status as people with no other meaning in their lives to build their identities on. The object of criticism is not the individuals who emphasise HIV's role in their identity but the process of

discrimination that confines people to this identity. From this point of view, building a new meaningful identity through one's HIV status is far from an ideal form of self-management, but it is something that has to be done.

Below I look at the self-management strategies used at emotional and cognitive levels. The strategies I refer to are not particular to any one of the groups I described above.

5. Reduction of negative emotional states

The management of emotions does not necessarily require a change in self-concept. The suppression of negative emotions, maintaining hope, finding solace and seeking help from professionals are among the ways the participants tried to reduce their negative emotional states, regardless of whether they had changed or even questioned their self-perceptions.

Denial or suppression of negative emotions is commonly referred to in the literature as a 'non-adaptive' or 'maladaptive' defence mechanism aimed at avoiding negative feelings. The participants' narratives showed that suppressing their feelings from time to time and trying to focus on other things such as work was common. This was explained using expressions such as 'there's no point [or no benefit] in thinking about it all the time'. Therefore, suppression of emotions is generally represented in the narratives generally as a deliberate strategy for resisting sinking into a negative mood rather than as a passive, unconscious defence mechanism such as complete denial or self-restraint. Although this strategy does not seek to eliminate the problem, it can be beneficial in terms of 'maintaining emotional balance under conditions that are beyond personal control or that may be unchangeable' (Livneh & Martz, 2007, p.17).

However, more persistent and detrimental ways of suppression were also visible in the narratives of some participants. For instance, heavy alcohol consumption and/or nightlife were mentioned by two participants, who stated that they rejected to confront reality in this way, but only in the early periods after their diagnosis. The commonality of those two participants is that both lacked family support even before the diagnosis, mainly because of their sexual identity (homosexual and transgender). Both had had other traumatic experiences before HIV, as victims of

sexual violence and hate crimes. The sample bias should be mentioned here: it is probable that PLHIV who were still in a suppression or denial phase would not have volunteered to participate in this research.

Suppression of the emotions can also take the form of completely refusing to talk about the problem. Two participants who defined their psychological mood as overly negative particularly stated that they did not want to talk about HIV with a professional counsellor or anyone else.⁷² As expected, the reasons were closely related to stigma. Tutku had had negative experiences with her family, health professionals and other PLHIV to whom she had tried to talk. In addition, she did not want to trigger emotions that she was struggling to control with the help of anti-depressant pills. For Adem, the main reason for suppressing his emotions was internalised stigma. When I asked him whether he would consider getting help from someone, he responded:

“No I didn’t talk to anyone. What shall I talk about? To begin with, this is something that is transmitted by sex. This is not something to be proud of. What is there to talk about?” (Adem, 60s, male)

Undervaluation of a problem is also considered a maladaptive or passive way of coping with or suppressing negative emotions (Martz & Livneh, 2007). The use of light and humorous language to describe their problems was clear in the narratives of four participants. Laughingly saying ‘Yeah, talk to me [for your research]. I have everything: abuse, rape, addiction.. [in my life story]’ or, ‘If I don’t die [from not taking my medicines] my doctor will kill me’ are examples of the recurrent humour in those participants’ narratives. Using light or neutral words such as ‘incident’ to describe a traumatic experience was also salient in their ways of expression. Looking at the self-described emotional states of those participants and the action they took against stigmatisation, it is not possible to argue that this kind of language use indicates passive acceptance (i.e. avoidance to confront the particular situation or emotion) (Goudge et al., 2009) or is a sign of the mature or successful management of feelings (Livneh & Martz, 2007).

⁷² Although these two participants were determined not to talk to anyone about their feelings, they participated in this research and did talk about their feelings. I believe that their trust in and respect for the gatekeepers who introduced me and my research to them were influential in their participation in the research.

One way of dealing with negative feelings is to maintain hope for the future. As mentioned in the previous chapter, most of the narratives openly demonstrated feelings of hopelessness about the possibility of a stigma-free society or the protection of PLHIV's rights, at least in the near future. However, participants' narratives demonstrated hope for a long life of good quality. As I explained in the previous chapter, this optimistic perception of their physical health was partially maintained by PLHIV networks acting as framing agents.

Another object of hope was that a cure for HIV would be invented. Participants' interest in seeking information about new developments towards vaccination and cure represented this hope.⁷³ There was no clear expression of whether they believed that a cure will be invented and become accessible within their lifetime, but some said: 'What we need to do is to survive until the cure is found, *İnşallah*'⁷⁴ (with the will of Allah). Hope for a cure was more common in the narratives of participants diagnosed with HIV in the last few years and participating in NGO training. However, this theme was totally absent in some interviews. When I asked this as an additional question at the end of the interview, a participant who has been living with HIV for five years explained how his hope has diminished with time:

"There will be some progress [in the treatment or cure of HIV/AIDS] for sure, I mean, yes, progress does occur in life; but I don't know whether I will catch up with it because ... I have talked about these issues in the past with people. I told people, that a drug, a vaccine, something will be found, maybe tomorrow maybe sooner. But those people whom I talked to are in the grave now. I mean, this is also a fact of life, I mean dying is also a fact of life. It doesn't matter if it's 3 days earlier or 3 days later. What matters is to appreciate today." (Zeki, 47, male)

Giving up hope in this case does not indicate maladaptive coping, especially as this person also had an active role in treatment activism and NGO networking. Replacing optimism about the future with appreciation of today⁷⁵ may instead indicate confrontation and acceptance. As this participant explained, people can 'get used to living with the idea of death' without losing the joy of life and without

⁷³ A couple of participants, who did not have close contacts with NGOs, specifically asked me to let them know about new research.

⁷⁴ It should be noted here that *İnşallah* does not necessarily imply religious fatalism; it is also used in secular contexts when expressing one's wishes.

⁷⁵ Appreciation of today or, in other words, positive appraisal is also a strategy for managing the emotions. However, as I explain in the following subsection, it is not only about reducing negative emotions but also about gaining new, more valuable personality traits.

giving up their hopes and plans for the future. The positive acceptance of the reality of death was also visible in the narrative of the participant who criticised the exclusion of AIDS from HIV activists' discourse, as mentioned in Chapter 7. I also observed that death can suddenly come into a conversation as something normal or mundane. The existence of the idea of death at the back of the mind revealed itself in concerns and jokes about death expressed in unexpected situations:

"So, Pinar, how is your thesis writing going? I hope, and I want you to finish it before we die."

Nearly all the participants had received professional help with coping with negative emotional states from a psychologist or psychiatrist at least once. Those who were regularly in touch with PLHIV-NGOs found the free counselling service very beneficial. People who were diagnosed before this service became available and those who were not in regular contact with the NGOs, especially participants from Ankara, saw a psychiatrist at a general hospital, mostly following referral by their IDSs. Apart from one or two participants who reported that 'the [anti-depressant] pills worked well', none of the participants who had seen a psychiatrist at a general hospital was satisfied with the help they received. The complaints included stigmatisation and the psychiatrist's 'indifference' or 'low level of knowledge' about HIV and PLHIV.

A few of the participants revealed that they had had moments of feeling suicidal, but none stated that they actually attempted to end their life. However, during my fieldwork one participant repeatedly mentioned thoughts of suicide.

6. Maintaining or enhancing a positive self-concept

Positive self-concept is a power resource facilitating the management of chronic illness (Miller, 1989). Self-concept includes a person's perceptions about the physical self (body image), functional self (role performance), personal self (moral self, self-ideal and self-expectancy) and self-esteem (self-worth) (Miller, 1989, p.7).

Narratives indicated that the effect of HIV on the self-concept was related to the main personality traits perceived by PLHIV to have been at the core of their identity prior to HIV. For example, for a person who self-described as being in control of life, losing this sense of control was the most damaging effect. For a participant who

described her/himself as honest and trustworthy, the requirement to conceal her/his HIV status was the main reason for self-conflict. For a person who emphasised success and respectability in life, HIV raised questions about failure. The below quote from a participant who was diagnosed two months before the interview exemplifies how the perception of illness and emotional responses to the diagnosis initially create conflict in the self-concept:

“In our body, in our blood, there is something which is not supposed to be there and you can never interfere in it. This really is a situation that renders you helpless. You use pills, you get treatment, you start the treatment in some way, but at the end of the day you know that it [HIV] will stay there and you won’t be able to kick this out. To a degree, this helplessness bothered me a lot. Because I am a very neat person in every phase of my life. Everything is well ordered, neat. I like having that control over every area of my life. But this, this remained out of my control areas. This bothered me too much. Psychologically, I was so tense and when I first heard that, in the evening of the day I learned that I am positive ... I stepped out on the balcony, no one was at home. I came up to a situation like, thinking ‘shall I throw myself down from here?’ I am a very religious person. I mean my faith just.. like evaporated. I know that suicide is a major sin. I was brought up with this culture since my childhood. I was brought up knowing this. But at that very moment, that knowledge of mine just evaporated.” (Ahmet, 40, male)

Participants’ narratives demonstrated that HIV had created unwanted changes in their perception of their personality which obstructed incorporation of the consequences of the illness into their identity. Therefore they needed either to recreate or redefine the personality trait in question or replace it with another valuable personality trait. In this process, resistance thinking, looking on the bright side, positive reappraisal and helping others appeared to be important strategies that PLHIV developed.

Passive acceptance vs. resistance thinking

One of the main problems that create conflict in the self-concept is the perceived responsibility for and related guilt about getting HIV. Asking ‘What did I do wrong?’ and ‘Why did this happen to me?’ is a common first reaction to being diagnosed with HIV. This kind of self-questioning was not apparent in any of the narratives of the women who stated that they had contracted HIV from their husbands. However, both the heterosexual and the homosexual men referred to a time in their lives when they had asked themselves these questions.

Spiritual belief seemed to be an important resource for answering those questions. Seven participants (four heterosexual men, one homosexual man, one woman and one transsexual woman) defined themselves as 'religious' (*dindar*) and six (one woman, one transsexual woman and two heterosexual and two homosexual men) as 'believers' (*inançlı*).⁷⁶ The view of HIV-positive status as something given by God and as destined was clear in these participants' narratives. However, there were differences in their understandings of HIV as 'destined'.

'Religious' participants had a common belief in terms of describing HIV as a 'test', since it is believed in Islam that Allah 'tries the servants' with various sorts of problems. This belief might be playing a role in finding inner strength and resilience in the face of the problems experienced due to HIV. However, five of the 'religious' participants described their psychological state as 'bad'. Also, as an indication of passive acceptance, a couple of heterosexual male participants expressed their opinion that Allah had given them the disease as a punishment. One said that this is how 'men pay for their sins' (infidelity, promiscuity, desire for sex). Another participant, who defined himself as very religious, saw HIV as a punishment for something he had done wrong, not in terms of sexual behaviour but in the broader sense of doing something unethical or improper. The interesting point about seeing HIV as a punishment for wrongdoing is that it did not necessarily lead to passive acceptance. The belief that HIV is Allah's punishment did not prevent these participants from arguing against stigmatisation. This belief did not, in their perception, justify the social exclusion and violation of the human rights of PLHIV.

On the other hand, in the narratives of 'believers', the idea of HIV as destined took a different form. 'Allah gave this to me for a reason' contributed to the construction of a valued identity, since it was believed that the reason was not punishment but to make them change their lives for the better or to help other people living with HIV, as I discuss later.

According to Goudge et al. (2009), 'resistance thinking' is a management strategy that includes the development of resistance to the idea of fault or responsibility.

⁷⁶ Two other participants described their relationship with God as 'different' and the remaining fourteen did not specifically mention their spiritual beliefs. However, this should not mean that they were all secular. This topic did not come out during all of the interviews.

Two interesting themes related to resistance thinking emerged from the narratives. The first is resistance to the idea of responsibility in heterosexual men's narratives by means of emphasising the low level of awareness of HIV and safe sex practices in the country. As exemplified in Tahir's story in the subsection on resuming sex life, acquiring HIV through unprotected sex was not perceived as a personal fault in terms of 'irresponsible risk-taking'. While not expressed openly by the participants, this perception suggests the belief that the fault is not in the individual but the social system that hinders condom use and the general lack of information on sexual health.

A second form of resistance thinking was seen in the narratives of homosexual and transgendered participants, in about half of whose narratives the theme of not being guilty showed itself in the context of sexual orientation or sexual identity more than in the context of being HIV-positive. Some of these participants put forward detailed explanations and arguments about homosexuality not being wrong, immoral or an illness. The emphasis on homosexuality was so great in some of the narratives that the interview seemed to be an interview on homosexuality rather than HIV. The narratives of nearly all the homosexual and transgendered participants showed that they had gone through a difficult process of realising and accepting their sexual or gender identity. It is seen that the resistance thinking that they developed in this process was transferred almost automatically and identically into the process of accepting HIV status.

This brings forward an important discussion about intersectionality. Within the conceptualisation of 'layered stigma', it is argued, people who are already socially excluded have fewer resources to cope with the consequences of stigma (Campbell & Deacon, 2006; DFID, 2007). However, the above situation suggests that the stigma that sexual minorities experience can also equip them with resilience to further stigmatisation. It is documented that discourses on and strategies for the management of sexual identity can provide homosexual men with readily-available tools for managing HIV-related stigma (Silversides, 2003). However, the important point in the narratives of the above homosexual men is that they resisted the idea of 'fault' or 'guilt' but not of 'responsibility'. 'I have chosen my life, and I will bear the difficulties that come with it' exemplifies this. In this resistance thinking there is opposition to the perceived association of HIV with

'immoral behaviour'. However, a challenge to the association of HIV with homosexuality is missing in this type of resistance thinking. While all the participants stated that 'HIV is not a homosexual disease' at some point in their interview, the participants who constantly defended homosexuality as not immoral did not challenge the perceived link between it and HIV.

Positive reappraisal

Positive reappraisal, as a way of dealing with negative emotions, focusing on the positive things instead of the negatives, is found to be associated with positive outcomes in the self-management of HIV (Folkman & Moskowitz, 2000; Schwarzer & Knoll, 2003). This cognitive adaptation strategy is also referred to in the health psychology literature as 'benefit-finding' (Sharpe & Curran, 2006). Through this way of thinking, PLHIV not only reduced negative emotions but also found a personality trait, which they considered valuable. Nearly half of the participants stated that they tried to focus on the positive outcomes of living with HIV. The most frequently-mentioned way of doing this was 'embracing' life more than they had before. Enjoying 'today', acknowledging 'the value' of every new day and 'digesting' every good moment were some of the ways they expressed this. Sevgi, who had been in hospital for a long time with AIDS-related illnesses and could do nothing but watch the ships go by on the Bosphorus from the window, said:

"And now [since recovery], I always watch those ships and take a deep breath. Those ships always remind me of the breath I am able to take. They make me say 'thank God I'm so lucky'. (...) Always, converting things, negative things into good icons and to see the good things that I have got .. makes me feel good." (Sevgi, 36, female)

Acknowledging the value of life and living in the moment can change not only the way of looking at life but also the way of living, as in the example below:

"I was making myself miserable trying to make more money. I decided not to make myself miserable. I was working extraordinarily stressfully. I decided not to work so stressfully. Apart from that, you recognise [the value of] life more. Because, [before HIV] you live in a way that is as if you will never die, you know what I mean? You feel, you realise how valuable the <moment> is." (Zeki, 47, male)

Embracing and reminding oneself of the value of life was not exclusive to participants who had recovered from AIDS-related illnesses. People who had not

had any health problems also mentioned positive reappraisal. As one of the youngest participants, in his early 20s, explained: 'The first question in every person's mind upon diagnosis is: "When am I going to die?" Even if you know very well that you're not going to die and you'll live quite a long life', this first experience of the fear of dying makes a person 'comprehend the value of life much more'.

Looking at the bright side sometimes leads to the thought, 'I'm glad I got HIV', as in a couple of participants' narratives:

"At the moment I generally look at the bright side. I mean at some situations I can say it's just as well that I am HIV [positive]. Or I want to say that. [LL]" (Mehmet, 21, male)

Three reasons for being 'glad' to have HIV were mentioned. The first is a belief that it was a reason for taking better care of one's health:

"This is what I want to add .. (after the initial interview is finished) I think that perhaps, if you were diagnosed on time, if you did not lose time, if, in a sense it's also related to the success [of treatment], I think that perhaps this situation is a good fortune. Because if you have a heart disease, if you have a problem in your lungs, kidneys, spleen, or elsewhere, there is this chance that those [diseases] can be detected during all these tests and examinations (HIV-related regular tests and check-ups). Precautions, measures are taken against those. (...) I mean serious examinations are done beforehand and you now know that your vital organs are.. you make sure of that [that your organs are safe]. [You know that the organs] are healthy, there is no problem about those. The problem here is that I have to take good care of this, take good care of that, I have to take care of my diet, I have to do exercises. Your life could climb higher than a certain level of quality of life. Because you have to eat well and properly, just like every healthy person you too have to eat well. Just like every healthy person you too have to do exercises. Just like every healthy person you too have to have certain check-ups done regularly. But not every healthy person does that. Here, we, are going to do that regularly, at certain intervals. In a sense maybe this is a uhm, luck, for us. This is my point of view, I mean when you look from another angle, it might be thought that you are lucky." (Ahmet, 40, male)

A second reason for being 'glad' to have HIV, as put forward by two participants, was that they had 'become closer to Allah'. They participants stated that their religious belief was already very strong before HIV, but after the diagnosis they had started or increased their practice of the five pillars of Islam, which made them feel closer to God and thus spiritually stronger.

Another reason that participants were 'glad to have HIV' was the thought that being HIV-positive made them 'stronger'. The narratives of five participants were marked by their enhanced sense of control and empowerment. They said that before their HIV diagnosis they were 'already ambitious', struggling for independence from family or social norms in general, prioritising 'standing on one's own feet' or fighting with injustice. Their diagnosis acted as an opportunity to gain their freedom and equip themselves with tools to that would help them to gain power in aspects of life that were important to them.

For example, in the case of a divorced female participant with a child who was living with her parents, her family's strict restriction of her life, including even basic decisions about going food-shopping, ended after she was diagnosed with HIV, with an AIDS related near-death experience. In another case, a young homosexual man was diagnosed with HIV in his teenage years when he was already trying to gain independence from his family and their expectations, including marriage. As in the previous example, his parents started to accept his demands, mainly because they were afraid to lose their child. In the process of gaining control in their life and feeling empowered, the advice and the language of rights communicated by the PLHIV support network served as tools and resources for empowerment:

"In the past, I was thinking sometimes, always, as I said there were some minor conflicts in the family and I was standing my ground, I was straining every nerve [to obtain my freedom]. Actually I knew that those [things that I demanded] were my rights. Or [I knew] that I was thinking differently from the society. I was saying [to my self] like, 'there is something wrong with that. Those thoughts are not in accord with me'. I started to demand and obtain [my rights] by myself, without a conscious awareness. I [then] learnt that, as a matter of fact, those were the things that I was entitled to." (Sevgi, 36, female)

An interesting point that emerged from the positive reappraisal narratives was the emphasis on 'enjoying oneself' and the 'doubts' that accompanied it. We had just come out of a nightclub as a group of friends in the early hours after midnight when one of the participants said:

"So, you're going to write this too in your thesis, right? Like, [makes a hand gesture as if picturing a headline] 'And this is how they were having fun!"

The fact that 'HIV-positive people do have fun' as much as other people is one of the messages given in speeches by most of the NGO representatives, both to

positively affect their clients and to inform the general public about the possibility of PLHIV pursuing 'normal' lives. However, it is interesting to note that the narratives about having a pleasurable time, having fun, laughing, enjoying oneself, especially soon after being diagnosed, included an element of questioning. The PLHIV themselves or others around them who knew their HIV status were unsure if being happy is 'normal' in this situation. For example, Murat 'surprised' himself when he found he was having a good time:

"And you know what I did? [after stepping out from the NGO], for the first time I walked from (place name removed) to (another place at about one hour walking distance). I wanted to walk. (...) I was walking, sitting, thinking. And laughing. And then, I allowed myself a day off, I mean I rewarded myself, by myself. How? .. I did something different. (...) I had to go home but I didn't. I didn't and I walked. I went to this coffee place. I met my old friends, I had a lot of fun, which I thought I shouldn't have had. Because, come on! it's been only 15 days since you've been diagnosed. What on earth are you doing, right? [SL]" (Murat, 23, male)

Another 'positive and cheerful' participant explained other PLHIVs doubts:

"At first, they have found me very odd, like 'what is this joy, what is this happiness about?' (...) one year later, they, my friends, came to a decision that it's my nature. I mean, when they get to know me, they said okay [this person] is not pretending [to be happy]. [Before that,] they thought I was a bit crazy. They were waiting for a breakdown." (Sevgi, 36, female)

These examples show that while there is motivation for living as 'normally' as possible and holding on to life more tightly than before, the idea that being diagnosed with HIV is supposed to be the end of the world throws suspicion on the normality of enjoying oneself.

Helping others

"It makes me feel happy to see that those eyes full of fear turn into glowing eyes"

Ten PLHIV among the participants (four interviewed as KIs) were involved to varying degrees in PLHIV support and/or advocacy. Four worked as peer

counsellors or caregivers at the time of the interviews or earlier. Their accounts⁷⁷ suggest that helping other PLHIV is an important part of enhancing a positive self-concept. They felt satisfaction at the positive changes they brought about in others' lives. One participant thought that this might be the main purpose for which 'God gave this to me':

"And.. it's a very weird thought, I sometimes think like, God has chosen me specifically, I mean, you know we always make a connection about being HIV-positive, [I think like] God especially brought me to the final stage [of AIDS] and specifically made me suffer, so that I could help people who are diagnosed, that I could understand them better or that I could know what people who stay in hospital go through. Once I heard about someone who is in hospital, I used to go to hospital and hold their hands. [I used to say to them] 'I have also done this and that, I also went through this and that'. When I used to say 'this is how you are feeling, this is what you are thinking' they used to ask 'how do you know that?' [and I used to answer] 'because I also felt this. Be assured that this will pass, because treatments are very successful and you are safe [here] and the doctors are very good' and so forth. Later, the doctors told me that this caused a significant change; this had a very good effect [on their patients]."

Not only peer counselling and care but also being involved in minor work related to PLHIV support and advocacy from behind the scenes was a factor in feeling 'useful'.⁷⁸ Some of the participants who were not directly communicating with or helping PLHIV but were helping in civil society work with technical issues or awareness activities also expressed satisfaction at having this valuable role in life.

Apart from feeling satisfied or useful there is another important outcome of helping others, as seen in the accounts of people who were actively involved in peer counselling. Some of the narratives suggested that in the interaction between the counsellor and the counselee, counsellors also realised or dealt with their own issues. The quote below exemplifies this:

"I had difficulty once, when talking to a counselee. (...) [the counselee] articulated her/his feelings so well. The anger, the rage against (persons and situations removed) ... I was just listening [to the counselee's story which is almost identical with mine]. As s/he talked and cried, I got a lump in my

⁷⁷ Considering the very limited number of people involved in peer-support, care and counselling, no information (sex, age or even the previously used pseudonyms) is used in the quotes in this section in order to secure anonymity.

⁷⁸ Different forms and degrees of involvement in activism and advocacy are explained in the next chapter.

throat. And I realised, when s/he was telling me [her/his story], that a voice in me, a voice which was turned off, which has a taped mouth, which I deferred, saying 'let it slide', which I never let out, that voice started to talk. After that, I thought like, you know I have this thing about looking at the positive side, I said [to my self] at least I [now know that] there is such a voice in me, I listened to it only once, and now it's over. There is no need to keep it hot on the agenda, [listen to it] over and over again. Because this wouldn't bring me in anything."

Another aspect of being involved in peer-support, care and/or advocacy is that a person might divide her/his identity into two: a person living with HIV and a helper. This division is visible in cases where two or more different names, nicknames, e-mail addresses or social media accounts are used to separate and protect the two identities. The role of helper was described by a participant as both empowering and useful for dealing with negative experiences:

"One thing I was very surprised about myself is that, After I was discharged from the hospital, I went to visit my doctor at the hospital once, and I realised that I can't even look at the rooms, at the wards of the hospital, it made me feel very.. bad. And then when I used to hear about people, being at the final stage [of AIDS] staying at the hospital, I used to go visit them. No fear, no depressive feelings at all. [in one year] I visited 4-5 people in hospitals and within one week or two; I was hearing the news that they passed away, all of them. Normally, I was supposed to be very much upset and think like they have died so I'm going to die too. That's what could happen, so they say. (person removed) said 'How do you carry that load? This is very heavy load, psychologically.' I said 'I don't know how I carry that. But, it does not make me.. it does not affect me badly. At least, they passed away knowing that they could've survived⁷⁹.' And [this person] told me .. 'you could think of it like that .. not all doctors carry the same disease with their patients, or, not all lawyers go to jail with their clients. This is in fact something like that. I mean, everybody is going through their own processes.' I said 'yes, this is superb, this sentence is superb'. I don't know the reason. I mean I don't know how I can carry it really. But since then, I'm saying this to my self. This is something like lawyers not going to jail with their clients but defending all their rights."

Recognising other prejudices

A specific way of acquiring a valuable quality for positive self-perception was to recognise other forms of inequality and prejudice and to tackle them. This theme was only seen in the narratives of people who had been in frequent contact with

⁷⁹ This narrative point about the need to 'know about it even if you are dying' was explained in the previous chapter under 'managing uncertainties'.

PLHIV networks. The realisation and elimination of one's own prejudices can happen through two processes. Firstly, as I observed, the institutionalised PLHIV network communicated the idea that 'we are all different; all equal' to its clients. The message itself might not be enough, but interaction between clients can positively add to it. For instance, as the KI's observations support, a person from a conservative cultural background might have communicated with or even seen a transgendered individual for first time in her/his life in this environment to which they both came with the same purpose.

An interesting point in a woman's narrative is that tackling one's own prejudices can include an 'ethical approach' to heterosexual men, which can be difficult for women who have contracted HIV through their husbands. This participant explained what her thoughts were when she was talking to another HIV-positive woman:

"On one hand you feel like saying 'God damn these men, they cheat on us, women' but on the other hand, you should also need not to judge and uhm your husband has been diagnosed with HIV too, I mean he is also having this shock, this trauma. (...) If it was the woman who cheated on her husband, were we going to say 'God damn these women, they cheat on men'?"

Finding 'unity', 'solidarity' or a sense of 'sameness' in the common experience of being 'ill' and/or stigmatised can help people to realise, reconsider and overcome their own prejudices. However, a couple of the participants' narratives and my observations suggested that being a heterogeneous group does not necessarily bring about this positive outcome:

"Of course, people's ego's (conceit) are very strong [in this group], as in every social group. Not everybody is the same. In social groups, generally, people are so.. they resemble each other, they come from similar social structures, cultures, family structures, life styles etc. But here [among PLHIV], this is not the case. People are very different from each other. People from very different social groups are together. This is a group where there is a lot of fighting, where egos are very high. One of the things that hurts me the most is.. of course I have lost many people that I loved, but one of the things that hurts me the most was the quarrel between two friends (place removed). It was literally a quarrel. One of them insulted the other very much. And, the day after we heard that this friend of ours [who was insulted] got very sad and had (health problem removed). Two days later, s/he died. And what had caused this was a quarrel. You can't find anything like that anywhere else [in any other social group]." (Zeki, 47, male)

It is seen that, while the differences between PLHIV interacting in a network can lead to transformation in people as they recognise their own prejudices, they can also damage solidarity. The above quote implies that the lack of solidarity is literally a matter of life and death and suggests that PLHIV ‘should’ show solidarity to one another. I discuss how the heterogeneous character of the HIV ‘community’ can simultaneously facilitate and restrict solidarity in the next chapter when discussing activism.

7. Conclusion

Whether people perceived HIV as life-changing or not was mostly expressed in terms of their social and cognitive adjustments and the outcomes of being HIV-positive. In other words, the main reference point for evaluation of the importance of HIV was not related to their altered health. This is partly because of the sample bias: the sample included few people who had experienced HIV-related health problems that had affected their physical ability. This highlights the importance of identity and stigma in HIV self-management compared to other chronic illness self management.

The felt requirement for concealment due to the fear of stigma not only causes isolation and loneliness but also creates a ‘moral’ conflict within the self when concealment is perceived as morally wrong and disclosure is perceived as required for educating others. This discomforting moral conflict can be solved in two ways; by influencing others stealthily and by defending the ‘right to conceal’.

Along with the narratives about its negative social outcomes and the benefits of being HIV-positive, living with HIV was also represented as ‘just taking pills’ or with a focus on ‘the bright side’, reflecting a desire for ‘normality’ and a sense of empowerment respectively. In terms of incorporating HIV into the identity, the desire for normality and the development of a new valuable identity had different meanings. The former was criticised for leading to a passive PLHIV identity by participants who emphasised the need of visibility and the greater involvement of PLHIV. Development of a new identity through HIV-related experiences, on the other hand, was criticised as accepting HIV as a master status. This discussion points out that a particular form of incorporation of HIV into the identity is not a prerequisite for ‘successful’ self-management.

The experiences of PLHIV in their social relationships pointed out the importance of peer-support in a context where living with HIV has not become an individually managed, medicalised process and where support and counselling services for PLHIV are very limited. Connection with other PLHIV contributed to a 'sense of purpose arising from sharing the same situation with others' (Seeley et al., 2011, p.12). Joining a PLHIV group can be considered as a way of 'claiming a positive identity' and a way of 'confronting stigma' (Seeley et al., 2011, p.5).

I link the perception of HIV as a turning point, motivation for 'normality' and conflicting motivations about concealment and disclosure to resistance to stigma at the individual and the collective level in the next chapter through a discussion of their connections to the discursive structures behind HIV-related stigma.

Chapter Nine

Implications of discursive structures on agency: Illness identities and social activism

1. Introduction

This chapter investigates the implications of the discursive structure around HIV/AIDS in Turkey for PLHIV's agency at the subjective and collective levels. One of the main aims of this research is to reveal factors that constrain or enable PLHIV to resist or challenge the stigma attached to HIV/AIDS. In the last three chapters I have discussed various factors that positively and negatively affect PLHIV's experiences and management of stigma. This chapter focuses on the link between resistance to the HIV stigma at the personal and collective levels and the overarching discourses shaping HIV-related stigma. Looking at the ways in which broader power structures are reflected and negotiated in personal narratives and collective action, this chapter addresses the research question: 'What are the ways and forms of the construction of politicised illness identities and political activism' within the discursive structure described in the 5th Chapter?

With this aim, I focus on the narratives of participants who were involved in activism in varying forms and degrees and on those who represented a politicised illness identity. I compare participants' narratives in terms of the extent to which broader power relations were represented, and the forms in which they appeared. I also compare data from PLHIV interviews with data from KI interviews, looking at, for instance, whether ideas about possible stigma-reduction strategies mentioned by KIs correspond to stigma-management strategies used or advocated by PLHIV. The presentation of data in this chapter is slightly different than the previous chapters. I use quotes from the participants' narratives predominantly in the first subsection and not so much in the subsequent ones, since those subsections are mostly structured around the systematic comparisons among the participants.

The analysis is guided by the literature on illness narratives for the identification of narrative forms, and by an intersectional approach for the identification of power

structures that combine with HIV-stigma. From an intersectional perspective, I ask whether HIV acts as a ‘catalyser’ (Berger, 2004) for the construction of a politicised identity by making people more aware of their other oppressed identities. Based on the literature about HIV/AIDS activism, I investigate the extent to which political criticism is transformed into political activism.

First, I discuss the reconstruction of HIV through ‘narratives of injustice and neglect’. I link this narrative reconstruction with biological citizenship; since this concept ‘can open up spaces for the articulation of “politicized illness experiences”, focusing attention on the wider political-economic forces that structure health’ (Orsini, 2006, p.14). Secondly, I focus on the participants’ involvement in activism in varying degrees and forms to identify the effects of politicised illness identity and the intersection of their other social identities. I mention the reasons for PLHIV’s limited participation in civil action and activists’ reluctance of to disclose their HIV status publicly. Finally, I discuss the ‘conditions’ of normalisation and visibility to demonstrate how cultural immunity and rights-based discourses are negotiated by PLHIV at the individual and collective levels.

2. ‘Politicized illness experiences’ and ‘biological citizenship’

Participants’ accounts of their HIV-related experiences and other events in their lives referred to other social inequalities in the country.⁸⁰ It was notable that the majority mentioned current social/political issues to varying degrees without me asking any questions. ‘The general problems of the country’ were constantly present in the background of some of the participants’ narratives. In a few cases these broader problems were given as the reason they had become infected with HIV, for the increase in the number of HIV/AIDS cases in the country or for the problems they had experienced in treatment. However, most of these narratives linked broader problems with the individual experience of being stigmatised. Even where a causal relationship was not suggested by the participant, the narratives still include some accounts of political criticism in the form of background information to a life event. Below, I exemplify these accounts, explain what is meant by ‘other

⁸⁰ This was partially mentioned in the previous chapter, under ‘recognising other prejudices’, and was discussed in relation with maintaining a positive self concept. But here, it will be discussed from a different angle, in relation with ‘political reconstruction of illness’ and activism.

injustices' or 'other problems' of the country and link the 'reconstruction of illness as political criticism' with biological citizenship.

The idea of a 'damaged biology' of the person or the population, caused by the state, is the basis for citizenship claims, according to Petryna's (cited in Rose & Novas, 2003) original description of biological citizenship. This idea can be seen in the accounts of people who found the state responsible for the spread of HIV or even for their own HIV status. The quote below is from a woman who stated that she had acquired HIV from her late husband, who had sex with a foreign sex worker and later died of AIDS:

"The blame is on my husband <and> on the Minister of Health. They should not get people [foreign nationals] in [the country] without testing [for HIV], they should not give permission to people who are not clean. [I heard that there are countries that has this regulation] I said it's very good for them. This lady [the foreign sex worker from whom her husband was infected] must have passed [the virus] to thousands of people." (Melek)

This account directly reflects the discourse of cultural immunity, as it sees 'the foreign sex worker' as the 'source' of the participant's HIV status. Her criticism is of the state for not protecting its citizens from this foreign source of danger.

Another participant found the state responsible for the continuing transmission of HIV, but from a completely different point of view. He argued that the state constantly ignores the existence of PLHIV. In an exasperated manner, he explained that he never got any answers to his written demands and complaints from some state authorities. Slamming his fist on the table and the wall, he said:

"If you ('state authorities') don't do anything for people like us, you will be condoning me putting my blood in a syringe and infecting everybody I bump into; or becoming a transvestite and infecting thousands of people a year."

His demands included job security, easier access to the social security system, the reduction of stigmatisation of PLHIV and sexual minorities and the provision of psychological support for PLHIV.

Problems in treatment were also explained by a couple of participants in terms of the state's responsibilities. Taylan commented on the reasons for doctors' perceived lack of accurate and up-to-date knowledge of HIV treatment:

"If the doctor doesn't know what to do, I cannot let the initiative to the doctor. The doctor might be someone who doesn't like to read [treatment] guidelines. They have such a right, don't they? But, if you, as a state, develop a responsibility to educate a person as an infection doctor; and if you have a knowledge that 3 or 3 million of your citizens can be HIV positive, (...) if there is a higher, more general framework called citizenship, it is actually your [the state's] responsibility to oblige your doctor to be informed on this area [of expertise]. (...) If you leave the initiative to [the doctors], [they are] not obliged to read a 25-volume encyclopaedia. But, someone has to explain the requirements of undertaking a treatment to them. This is the Ministry of Health." (Taylan, 29, male)

The same person took the same stance on communication problems between doctors and patients:

"When I look from the doctor's perspective, I mean the man is right! I mean, when he has to explain the treatment or to administer treatment to an illiterate (none or less educated) patient, he gets angry with the patient because he remained illiterate; he gets angry with the state because it made that guy [the patient] remain illiterate; and he gets angry with himself because he is practising medicine for this state." (Taylan, 29, male)

Criticism of the doctor's discriminatory attitudes were also perceived and interpreted by a respondent within a framework of demanding public services as a citizen:

"'Look Ms. Doctor', I said, 'with all due respect, since I am covered for insurance (by social security system), and since I didn't come here for fun, I came here for [medical] examination, I came here with the opportunities that are given to me by the state, and you are working here on behalf of the state' (...) [she replied] 'you should have thought about this before you got this' [HIV]." (Tibethan, 31, male)

Problems in the general health system were also linked to 'corruption' in the system:

"You go through these [for having a minor operation at the hospital], while feeling how distorted, how corrupted the system is at the hospitals (...) I mean because I have a Green Card⁸¹, they wanted to put me under anaesthetics and go through a proper surgery procedure and go to

⁸¹ Social security for people on a low income

another department [at the hospital], since all of the doctors there will be given some commission (from the hospital's revenue for this surgery).⁸² The hospital will take some money from the state for this surgery. (İlker, 40, male)

A good service from and good communication with doctors were perceived in relation to the 'corrupted system' as well:

"But I want my doctor's name to appear [in your thesis]. Yes. His recent behaviour to me was so humane, I didn't expect [such a nice behaviour from a doctor] .. um because in the system in Turkey, if you want a good, a real doctor in terms of doctor-patient relationship you have to pay for it. If you don't have money, it's very difficult, you languish." (Tutku, 55, female)

As mentioned above, political criticism in the narratives was not only seen in accounts directly related to illness experiences but also covered broader issues. The senses of distrust and insecurity, which were recurrent themes in the narratives, as repeated in the previous chapters, are again most salient themes in the criticisms of the society the participants lived in. All the participants showed that they were aware of the lack of a system to protect them from discrimination, for instance if they are fired from their jobs or denied surgery on the basis of their HIV status. Findings presented in the previous chapters have explained how feelings of insecurity and distrust contribute to the fear of stigma and are a major obstacle to disclosure. These feelings are overtly expressed in the example below. However, this participant stated that not only PLHIV and sexual minorities but also other people, ordinary people who are exploited, oppressed, disadvantaged by the power inequalities in society, have a similar problem in terms of not being valued and respected as citizens. After a long pause, following 'We [homosexual men] are fed up with being second, third class citizens in Turkey's society', Murat continued:

"I feel sad. Really I mean I feel sad for the country. ... There are so many things that should not have happened. I don't believe in this country and I don't trust it. And I'm telling it frankly. Because, there is nothing done in this country for anybody, not only for us. I'm not telling this thinking about my self only, or about gays only. (...) People at the top always look after their own interests. They have always made people lose their health, their

⁸² Unnecessary screenings and medicines prescribed in hospitals to get extra money from the state, as a way of exploiting the social security system, is a widely known and discussed issue in the country.

privacy, their honour, their pride, just for the sake of keeping their own positions. (Here, he talks about the conflict between the state's armed forces and PKK, Kurdish guerrilla movement, and about thousands of young Turkish and Kurdish people who died) How can I trust in this country, this state, this nation? .. Let alone my own rights, I'm talking about the general public. I'm talking about people dying everyday." (Murat, 23, male)

This idea of 'ordinary people' also being exploited and neglected by people in power was explained by a respondent in terms of the state-citizen relationship. As is made clear in the quotation below, strong respect for the state in Turkey was seen as the key to understanding the state's neglect, oppression and discrimination of PLHIV, LGBT and all other 'ordinary' people who are 'others' in some ways:

"The idea that I want to bring in is that the state should be there to serve me; not me to serve the state. (...) But in our country, the structure that had occurred is [the opposite] (...) and this is not related to laicism, to democracy; they should have put the state in our service but they have put us in the service of the state. (...) The state is responsible for providing its citizens with all kinds of opportunities, including health services and the right to live. (...) The state is a state only if I exist. If I don't exist, there is no meaning of this state at all. (...) The state, in this country .. should not despise sex workers, should not despise Kurds, should be in the service of Alewi. (...) Let me close this topic with a nice quote from Kanuni (Sultan Suleiman, 'the Magnificent'⁸³), as we are a society that valorises the idea of the state that much. He said 'The people think of wealth and power as the greatest fate; but in this world a spell of health is the best state'⁸⁴. If I am not healthy, [it means that] this state hasn't been beneficial for me at all. [It] also [means that] I can't be of any use to the state. (...) [The quote above] expresses the importance given to health by one of the very important emperors of the Ottoman State, which we defend very much, which we are very proud of. (...) There would be no problem if I know that the state is there to serve me. There would be no problem if I know that the state is there to serve Kurds, Alewi, Sunni, women, the oppressed, the despised. This is how I think."

The idea expressed above is closely related to the discussion about rights discourses in Chapter 5. This is a criticism of the prioritisation of society over individual rights, or in other words, a criticism of the maxim: 'Let the man live so

⁸³ The tenth and longest-reigning emperor of the Ottoman Empire in the 16th Century.

⁸⁴ *Cihanda muteber bir nesne yoktur devlet gibi. Olmaya devlet cihanda bir nefes sihhat gibi* (note: the participant did not say the correct version).

that the state lives',⁸⁵ which is defended by the current government. While prioritisation of 'the state' over the individual was criticised in some narratives, as exemplified above, some of the respondents' accounts and my observations showed that this idea might be shared by some PLHIV. For example, the expensive treatment they were given was expressed by a couple of PLHIV as a 'burden on our state'.

To address the main research question it is important to understand the role of this political criticism in challenging stigma. Two important questions are useful to address important discussion points in this chapter, namely intersectionality and activism. Firstly, is the political criticism in the narratives a reflection of the already-politicised identities of the participants, or did their illness-related experience cause them to take a more politicised view of the world than they held before? This question is important in terms of understanding the extent to which HIV acts as a 'catalyser' (Berger, 2004) for the construction of a politicised identity by making people more aware of their other oppressed identities. From an intersectional perspective, it is important to ask how this process works for people from different backgrounds. Another important question about biological citizenship and the political criticism in the narratives is 'to what extent is this "political criticism" transformed into "political activism"?' I address these two questions below through a detailed investigation of and comparison between the narratives of the participants which did and did not represent political criticism and various forms of activism.

Reconstruction of HIV situated in the context of injustice and neglect

People's 'ability to problematise' their illness-related experiences depends on a number of factors, including their social status and means of infection (Orsini, 2006, p.2). In order to understand the factors that contributed to the reconstruction of illness as political criticism I have categorised the narratives in terms of the degree and form of political criticism they represented. When conceptualising illness narratives, Williams identifies narratives that carry a 'highly political image of the social world' in terms of locating both the illness itself and the professional

⁸⁵ Recep Tayyip Erdoan, the PM, in MOH 2010; Kapusuz 2011

response to it in a world of power inequalities. We can conceptualise a narrative as 'framed within a political criticism' when not only the narratives of illness but also accounts of other life events in the narratives draw upon images of an unjust society (Williams, 1984, p.185). I have categorised the narratives of PLHIV accordingly, identifying an 'injustice frame' in them (Orsini, 2006).

While most of the participants mentioned broader systems of injustice in the country to some degree, not all of their narratives were 'framed' within a broader political criticism. Eight participants' narratives were classified as 'framed within a political criticism'; six represented some degree of political criticism; and the other fourteen occasionally mentioned broader social inequalities. Below, I present some factors that were found to be related to the construction of narrative as political criticism: gender and sexual identity, other negative life experiences before HIV, perceived personal responsibility, spiritual beliefs, time since diagnosis and contact with an NGO acting as a framing agent.⁸⁶

Six of the eight people whose narratives represented political criticism as narrative were members of sexual minorities and included one transsexual woman. This means that more than half of the participants with sexual minority status located their illness within a broader criticism of the social world, while the majority of the other participants (Sample Group-B⁸⁷) did not develop such criticism. Another salient point is that in the Sample Group-B (14 participants), the people who mentioned broader social problems more than the others were mostly women, who talked about gender inequalities to some degree. Although none of the heterosexual women located HIV in a frame of injustice they criticised the world they lived in more than their male counterparts did. In other words, HIV-related experiences were perceived within the criticism of broader social inequalities, mostly by sexual minorities, then by heterosexual women, and then by heterosexual men.

⁸⁶ Other than those characteristics of the participants, no other significant factor was found in terms of affecting the construction of narratives in a political framework. For example, poverty, which might be thought as an important basis for an intersectional identity, did not show itself as a basis for political criticism. This might be due to the characteristics of the overall sample, as I did not have a chance to talk to more people from economically disadvantaged backgrounds.

⁸⁷ See the sample design in Chapter 3.

This is partly related to the participants' other traumatic life experiences before being diagnosed with HIV. While only two of the heterosexual men had experienced dramatic events that negatively affected their lives and psychological well-being, almost all the homosexual men had suffered from such events before their diagnosis, including being repeatedly raped in childhood, being bullied at school because of their sexual identity, a limited period of transgendered identity,⁸⁸ being forced to marry a woman and some other dramatic incidents unrelated to sexual identity, such as family problems. The majority of the people whose narratives included other traumatic life events before HIV represented a form of narrative of political criticism. Women's narratives also represented traumatic events related to gender; however, their life experiences were not represented within a frame of injustice as in the narratives of sexual minorities.

In his research on biological citizenship in the narratives of people with Hepatitis C, Orsini (2006) points to an important relationship between a person's perceived responsibility for their infection and the degree to which they situated their illness-related experiences in an 'injustice frame'. He found that people who acquired hepatitis through intravenous drug use and who perceived the infection as the 'price one paid for choosing a "dangerous" lifestyle' (Orsini, 2006, p.9) did not express their experiences in a politicised frame as others infected through tainted blood did. In this research, there was no particular group of participants who considered HIV the price of a 'dangerous lifestyle'. Homosexual and transsexual participants did not perceive HIV in this way, and thus did not find any obstacle to situating their experiences in a context of an injustice frame. On the contrary, their perceptions of being denied and/or unwanted citizens as LGBTs contributed to their criticism.

The group of participants who considered HIV a 'price to pay' were those who identified themselves as 'religious'. A closer look at the people whose narratives could be classified as political criticism shows that only one of them identified herself as a religious person. Religiosity might contribute to a sense of 'divine justice' rather than a sense of broader societal injustice.⁸⁹ The fact that the only

⁸⁸ One male homosexual participant defined himself as male-to-female transsexual for a short period of his life.

⁸⁹ It should be remembered, however, that even if those participants perceived HIV as a

religious person who presented a political criticism framework is transsexual again points out the importance of sexual identity-related problems in the perception of the social world as a place of injustice.

As mentioned in Chapter 7, reframing HIV showed differences between participants who were diagnosed with HIV more than five years ago and those diagnosed more recently. A comparison between these two groups in terms of the forms of their narratives revealed that they also differed; more than half of the people who were diagnosed five or more years ago mentioned broader social problems in relation to HIV more than other participants did. It is possible to state that such a link between a personal history of being HIV-positive and broader social/political problems is developed within time, through experience. However, it is also possible to argue that PLHIV faced much more severe problems and had less institutional or even personal support 5 years ago. This might have caused people who were diagnosed earlier to individually or collectively question the system and/or their individual history in connection with broader social and political issues.

Does this mean that PLHIV will be less politicised when institutional support, care and help are more easily available and treatment is more individualised? To answer this, we should look at the role of support groups as framing agents in the reconstruction of illness within a framework of political criticism. Illness narratives are influenced to a great extent by the framing agents, as mentioned in Chapters 7 and 8. This influence was seen in participants' perceptions of HIV as a disease. However, the same influence is not seen in terms of the reconstruction of the illness narrative as political criticism. Eight people whose narratives represented an injustice frame were heterogeneous in terms of their relationship with an NGO; and among eleven who were NGO clients, six did not develop such narratives.

To sum up, participants who suffered from their 'othered' identities prior to HIV, most of whom were members of sexual minorities, were more likely to reconstruct HIV within a framework of political criticism. Injustice and neglect on the part of the state and society were salient themes in their criticism. Contact with an NGO did

punishment from Allah, they were still making the point that they did not deserve discrimination or mistreatment from society. Therefore, while not locating their HIV-related experiences within a political framework, HIV-related discrimination was not seen as legitimate.

not play a role in the formation of the politicised illness narrative. In order to see whether the reconstruction of HIV in a political framework translates into activism, I take a closer look at the participants' involvement in various forms of activism to varying degrees in the following subsection.

3. Gender, illness perceptions and political activism

To understand the paths that led some people to activism, I compare the participants in terms of their involvement in activism. The forms and degree of their involvement in activism were categorised into six.⁹⁰ Among 28 participants living with HIV, including those who were interviewed as KIs, five worked for or with a PLHIV-NGO in activities that involved selective, limited disclosure of HIV-positive identity including providing peer counselling, visiting other PLHIV and their families, holding seminars with small groups and giving reportage to the media (with HIV-positive identity disclosed only to the reporter and real names and photographs are not used). Another group of five participants actively worked for or with this type of NGO and did not disclose their HIV status to strangers. Examples of the type of work they did are collecting signatures for a campaign, visiting government and health institutions or working in the background for the preparation of documents or World AIDS Day marches. Four other participants who were clients of a PLHIV-NGO were contributing to its activities with small voluntary jobs such as distributing condoms or brochures to friends and helping with logistics. Apart from these, one person was active on an online forum where PLHIV communicate with each other using nicknames and provide information about HIV/AIDS to people who have questions and concerns about HIV; one person worked actively in an LGBT-NGO and another had worked in both HIV/AIDS and LGBT organisations in the past, but neither was active in a PLHIV-NGO at the time of the interviews. The remaining eleven participants were not involved in any kind of activity related to HIV/AIDS help, support, awareness-raising or advocacy. Based on comparisons between those groups,⁹¹ below I discuss the effects of gender, politicised illness identity and perceptions of HIV as turning points on the participants' involvement in activism.

⁹⁰ I compared a) the first two 'more active' groups with each other; b) these two groups with the rest; and c) 11 people who were not involved in activism with the rest.

⁹¹ Some of those participants explained that they tried to have an influence their closer social environment, as explained in Chapter 8 under 'Influencing others by stealth'.

The role of gender in involvement in PLHIV groups and activism

The most significant difference between heterosexual men, women and participants with sexual minority status is that heterosexual men participated least in activism. The majority were not involved in any kind of HIV-related activity, while only three of those in the sexual minority category were *not* involved. The four women who were involved in activism to different degrees received strong support from their parents (divorced or widowed women) or partners (HIV-positive husband or HIV-negative partner). All four had a crucial role in uniting PLHIV under a group or organisation and all worked actively in peer-support, care or background duties. Of the three women not involved in activism, one was illiterate and poor and lived in a remote rural area; one had no support at all from her family and experienced deep psychological distress, and one had a supportive HIV-positive husband but had not disclosed her HIV status to her parents.

The literature on health-related social movements shows that women often appear to be the key actors in mobilising people around health issues (Williams et al., 1995, p.119). Women's greater participation in HIV-related activism is also demonstrated by Russell and Seeley (2010), who observe that women have 'greater purpose and confidence' in participating in public activities, raising awareness, improving access to health services and lobbying. According to Brown (1995, p.106), women's greater participation in health-related social movements (HSM) is partly due to the fact that they are seen as the 'chief health arrangers' for their families and partly because their childcare role makes them more concerned about these issues than men. However, this can be seen as a limited and gender-role-based explanation. To consider women's leadership roles in activism in relation to their empowerment process might offer better understanding. As Russell and Seeley (2010) state, participation in activism through HIV organisations can give women 'new opportunities to engage in civil society and the public sphere, opportunities that men had already had'. Thus engagement in activism as part of a transformation process can increase women's agency in their social life.

However, in Turkey there are major constraints to women's participation in activism. First of all, as KIs stated, it is difficult for NGOs to reach HIV-positive women and persuade them to come into an environment where they can simply talk to other

PLHIV. Let alone being involved in activism, women are reluctant to be involved in HIV-related training or in regular contact with other PLHIV. There are many other factors such as household and child care responsibilities that might be considered as a priority. Women may be caring for their ill husbands, since care-giving is considered their social, and in some settings religious, responsibility (Fathalla, 2008, Aga et al., 2009, p.38). Women may also have less financial resources than men. For example, three female and no male participants mentioned financial losses due to HIV; and the only two participants who defined themselves as poor were women.

More importantly in the context of Turkey, the confinement of women to the private sphere in the family, contributes to the invisibility of HIV-positive women. And in a context where it is difficult to communicate about sexual and reproductive health it is not surprising that women are reluctant to participate in training or other activities that involve information and open discussion of sex and even 'immoral' sexual behaviour.

Another important point that I observed is that women's involvement in civil society activities related to HIV/AIDS is affected by general perceptions of HIV-positive women and men in society. As female sex workers are seen as the 'source' of HIV even in official discourse, some women may not want to be identified with sex work or be in the same environment as an 'indecent' woman. An example of this was explained in a KI's narrative: an HIV-positive woman who had been visited in hospital by some members of civil society did not want to talk to or shake hands with the visitors, implicitly stating 'I am not like you'. Also, and perhaps more importantly, if a woman is infected by her husband and is angry not only with him but with all men living with HIV, as Melek was, she may not want to talk to men living with HIV. Furthermore, it would be very difficult to internalise the principles of a rights-based NGO in terms of being considered equal to those men or non-judgemental of them. As a 'victim', she would not want to defend the rights of her 'perpetrator'.

The data of this study do not allow understanding the experiences of women living isolated lives. The difficulty for both a researcher and NGOs in reaching these women, as also foreign women and sex workers, is an indication that most women

live more isolated lives than HIV-positive men. Among the women whom I interviewed, only two had ever spoken to other PLHIV. The only two people who refused an interview with me were women.⁹²

With regard to other MARP that seem to be important actors in AIDS activism in the literature, the involvement of sex workers, IDUs and LGBT organisations in Turkey is limited. According to a recent report (IKGV, 2011), sex workers cannot prioritise their own or public health due to other concerns such as police violence and poor living and working conditions, and there are legal and social obstacles to sex workers' uniting and working with civil society organisations.

The limited participation of the LGBT community in AIDS activism has been mentioned in Chapters 4 and 5. The reasons can be summarised as follows: the homosexual community perceives HIV/AIDS as a heterosexual disease in Turkey, does not want to reproduce the association of HIV/AIDS with homosexuality and has not experienced an AIDS crisis in the community. Another very important reason is that, as a KI from an LGBT organisation stated, it might be easier and more acceptable for an HIV-positive person to claim their rights through the right to health, since LGBT's rights are constantly denied. In this sense, mobilisation of the already-available resources of an already-stigmatised community cannot contribute to AIDS activism as in the US; on the contrary, it could impede its process. This is a possible reason behind suggestions to use 'good examples' as the face of PLHIV in Turkey. As explained in the Chapter 5, this was defended by some KIs in civil society and the medical profession who call for the normalisation of HIV/AIDS. Although the LGBT community is not a leading actor, its involvement in activism and advocacy cannot be overlooked. Below, I describe the involvement of individual homosexual men in PLHIV peer groups and activism.

According to my observations, homosexual men's involvement in PLHIV groups and activities was greater than that of heterosexual men. The narratives of some of the KIs in civil society and a few heterosexual participants suggested that the higher visibility of homosexual men might be a reason for women and heterosexual

⁹² I personally talked to them and gave them informed consent forms. There must have been other people who refused to talk to me after the gatekeeper explained and gave out the consent form; but I was not made aware of those cases.

men to be less involved in PLHIV groups and activities. This contributes to a picture of a male-dominated social environment which women are reluctant to enter. Heterosexual men, on the other hand, can find the presence of gay men repulsive due to negative attitudes towards them in society.

According to some KIs in civil society, the higher visibility of homosexual HIV-positive men is because they receive more support from friends because they have a 'community', they accept their HIV status more easily and are generally more open about their status. Comparisons between homosexual and heterosexual participants offer insights about those arguments. All of the participants with sexual minority status were recruited through a PLHIV-NGO. Only one homosexual man had been active in an LGBT-NGO in the past: all the others explicitly stated that they did not have and would not consider having contacts with an NGO on the basis of their sexual identity. In other words, they did consider themselves as belonging to the PLHIV community more than to a homosexual community.

In contrast, heterosexual men appeared to be less in contact with other PLHIV. Homosexual participants were more open in general, to parents and friends; but not all disclosed their sexual identity. Limited disclosure by heterosexual men was seen in their contacts with friends. No one apart from close family members and a couple of other PLHIV knew the HIV status of half of the heterosexual men. However, those results are partially related to the sample bias; most of the heterosexual men I interviewed were living in Ankara and were not in close contact with a PLHIV-NGO. With regard to their acceptance of HIV, as mentioned in the previous chapter the cognitive process of 'resistance thinking' (Goudge et al., 2009) that homosexual men develop in the process of accepting their sexual identity is transferred to the process of their acceptance of HIV status. As it is seen in the previous subsection, male homosexual participants were more likely to construct illness narratives in a political criticism framework.

Reconstructions of illness and political activism

Considering the different explanations in the literature about AIDS activism, it is important to ask whether political criticism or more subjective perceptions of the personal journey with HIV are more important in terms of people's involvement in activism. For instance, Robins (2005) explains the importance of quasi-religious

perceptions of HIV-related experiences in commitment to activism, while Brown (2004) states that health-related activism is based on politicised illness identities.

Not all of those in the first two more politically active groups (working with selective disclosure and actively working without disclosure) represented a narrative in the form of political criticism. Of the ten people in this group, the narratives of three could be classified in political criticism, and three did not include political criticism. The remaining four included some criticism of other social problems, but these were not dominant or did not provide a background for the narrative. Two women referred to being female when telling their stories but did not locate their stories within a broader gender frame. The other two men occasionally mentioned Turkey's general problems in terms of social, economic and cultural differences and moral values.

Looking from the other side, i.e. looking at the level of activism, the eight people who generated narratives in the form of political criticism were not necessarily involved in HIV activism. Three worked with or in a PLHIV-NGO with or without disclosing their HIV status to others; two worked in other NGOs but were not currently involved in HIV/AIDS, and two were helping with condom distribution or some logistics every now and then; one was not involved in activities of this kind.

Politicised illness identity does not necessarily lead to commitment to activism for several reasons. For example, in the context of high stigmatisation and poor psychological support and counselling, a weak emotional state could be an obstacle to involvement in activism regardless of a strongly politicised illness identity. All of the participants in the more active groups described their emotional or psychological moods as 'good' or 'very good'. Considering the peer counsellors' narratives about how helpful peer counselling is for building a valued self-perception, it is possible to say that involvement in any kind of HIV-related work contributes to a feeling of being useful and hence a good psychological state. It is also possible to say that in order to be involved in such work people need to find their own psychological stability and strength. Looking closely at the narratives that include political criticism, some of these participants defined their psychological moods as 'very bad', while some were feeling 'very good'. As involvement in HIV-related work requires a certain level of psychological wellbeing, it is understandable

that not all people who have a political frame of illness were involved in activism. In addition, feeling good or very good might also be related to socio-economic status as people in this specific activist group described themselves as coming from relatively high educational and economic backgrounds.

Robins (2005, p.11) states that conventional social movement theories that 'focus on rational and instrumental behaviour and political process of mobilization' offer a limited perspective for the understanding of engagement in HIV/AIDS activism. According to him, commitment to a 'new life' and activism can be perceived by PLHIV as a 'quasi-religious' experience (Robins 2005, p.1). Among the participants who worked as peer counsellors, one thought that the reason 'God gave this to me' is to make them help other people. Apart from this, the perception of activism or of being diagnosed with HIV in spiritual terms was not salient in any of the participants in the activist groups. Still, more than half of the participants defined themselves as believers. The difference between defining oneself as a 'believer' and as 'religious' is important here. None of the activists defined themselves as religious. As mentioned earlier, religiosity was seen as contributing to different forms of narratives that are far from political criticism, except from a transgendered participant.

Robin's (2005) study also shows that recovery from AIDS, when perceived as starting a new life, contributes to commitment to AIDS activism. In this research, perception of life with HIV as a new life was not necessarily expressed in terms of recovering health,⁹³ yet in terms of perceptions of being diagnosed with HIV as a turning point, there is a difference between the active and non-active groups. The majority of participants in the more active group considered being diagnosed with HIV a turning point, most in the positive sense but some in a negative or more neutral sense, while more than half of the participants who were not involved in any kind of activism did not perceive HIV as a turning point in their lives. Also, the majority of these participants had not experienced life-threatening HIV-related illness. It is also notable that none of the heterosexual male participants mentioned such an experience. As mentioned earlier, of the six participants who reported that they had come close to death, four were woman. Few people in the active groups

⁹³ See Chapter 8.

experienced an HIV-related near-death condition, and those who did included two women.

To summarise, the activist participants were not a homogeneous group in terms of narrative reconstruction as political criticism or the ways of enhancing a valuable identity discussed in the previous chapter. The main commonality among them was that they perceived HIV as a turning-point. Neither politicised illness identity nor contact with PLHIV is necessarily related to activism. However, the non-active participants were mostly people who did not see HIV as a turning-point and had not experienced serious ill-health due to HIV. This point brings us to discussion of whether the motivation behind activism has diminished with the availability of ART due to the individualisation and medicalisation of life with HIV. Below, I discuss whether this is the case in Turkey, obstacles to involvement in activism and the forms of activism that the dominant discursive structure around HIV/AIDS creates or allows.

4. ART, normalisation and activism

The forms and intensity of AIDS activism in certain settings have been related to the availability and experience of ART. As Robins (2004) demonstrates, experiences of ART have implications not only for the construction of HIV-positive identities at a subjective level but also for the form of social movements around HIV/AIDS. For instance, activists in the US aimed to influence the production of scientific knowledge by focusing on research funding and protocols for trials, while the focus in South Africa was on the struggle to access ART medicines (Robins, 2004, p.651). It is argued that in the UK the availability of ART has contributed to the ‘individualising and normalising processes of “medicalisation” which have became ‘obstacles to collectivist forms of mobilisation’ or have even ‘killed activism’ (Robins, 2004, p.iii).

In Turkey, where ‘ART has been made available from the beginning’, where the medical profession could not be effectively involved in the production of scientific knowledge about HIV/AIDS and where there has been no ‘AIDS shock’ with large numbers of people dying every day, the ‘cultures of activism’ (Robins, 2004) is expected to be different. It is not possible to say that in Turkey, access to treatment

has not contributed to the individualisation, medicalisation and normalisation of HIV and its treatment.

When discussing the ‘normalisation’ of HIV in Turkey, I distinguish between three different meanings this terms refers to. First is the perception of HIV as a ‘normal’ chronic illness ‘that could be treated much like diabetes’ (Robins, 2004), by the public, but most importantly by healthcare providers. This is the opposite of ‘HIV exceptionalism’ (de Cock & Johnson, 1998), the treatment of HIV differently from other infectious and chronic diseases, and is advocated as an important stigma-reduction strategy that was suggested by the KIs participated in this research, as I explained in Chapter 5. As demonstrated in Chapter 6 and 7, HIV is not perceived in Turkey as ‘like any other’ infectious or chronic diseases, with the exception of doctors specialising in HIV/AIDS.

The second meaning of ‘normalisation of HIV’ is the perception of HIV as a ‘normal’ disease, as detached from the idea of death and from its moral connotations, in the minds of PLHIV. I explained in the previous chapters that especially recently-diagnosed participants were more likely to perceive their condition in a ‘normalisation’ framework, seeing it as a ‘manageable chronic disease like diabetes’. However, this is not sufficient to claim that HIV has been ‘normalised’ when the general public perception remains unchanged and the management of health for PLHIV remains problematic.

A third aspect of ‘normalisation’ of HIV is the motivation for or the perceived state of a life which is ‘normal’, just like it was before being diagnosed with HIV. As mentioned previously, this motivation (or perception) is discussed in the literature as a component of cognitive adjustment. Going back to the ‘normal’ life has been discussed in the literature within the context of work and productivity. It has been argued that restarting work after recovery from illness can help PLHIV to regain their economic power and social roles. ART’s ‘capacity to restore health and productivity has generated significant hope that universal access to HIV treatment will assist social integration and consequently have a positive influence in reducing stigma’ (WHO, 2005, cited in Bernays et al., 2010, p.14). However, this relationship between access to ART, economic productivity and the normalisation of HIV should be context-specific. For example, as Bernays et al. (2010, p.18) state, ‘the

obstacles to gaining social credibility by being involved in subsistence agriculture are vastly different to the obstacles to gaining entry into a more formal employment economy.' In Turkey, HIV status is used as an excuse for dismissal from work, and PLHIV's right to work is not secured by law. In this context, being able to work because one is in good health due to ART does not contribute to normalisation, nor does it reduce the stigma.

PLHIV's 'capacities to benefit from the anticipated restorative effects of universal HIV treatment access are constrained by an intersection of powerful sociocultural dynamics' (Bernays et al., 2010, p.18). Problems not only of job security but also with managing their health⁹⁴ and the general context of insecurity are obstacles to PLHIV's feeling of 'normality'. Consequently, even if they perceive HIV as a 'normal', manageable condition and are motivated to resume their lives as if nothing has changed, external conditions do not allow them to do so. It is not possible to claim that the participants who did not present a politicised illness narrative, participated in activism or perceived HIV as a turning-point were not people who have normalised living with HIV. Their narratives represented a motivation for normality; but also, a motivation to do something to achieve that normalisation.

Bernays et al. (2010) explain that in Serbia, where ART is fully funded by the state and HIV is considered a threat to the national fabric as in Turkey, this situation creates 'a cultural framework which encourages HIV positive patients to be both passive and grateful for what is available and cautions against expecting or asking for more'. In this context 'PLHIV's energies are orientated towards short-term, individualising strategies to mediate the harms of treatment insecurity and multi-factorial stigma' (Bernays et al., 2010, pp.17-18). The individual strategies used by the participants and described in the previous chapters, especially their struggles with the system and healthcare providers, are the most important forms of agency for PLHIV. As stated by Bernays et al. (2010, p.18), 'although not articulated as a process of empowerment, getting by with HIV without being identified as being HIV positive is still experienced as a form of agency by PLHIV in that it allows them to individually manage their life day to day.' If this is the main struggle at the individual

⁹⁴ See Chapter 7 for obstacles and management strategies in treatment and self-care.

level, then we must ask what the implications of this context are for forms of social activism and citizenship at the collective level.

Considering the dominant discursive framework around PLHIV it is not surprising that HIV/AIDS advocacy and activism take relatively 'hidden' forms. The actors are hidden, civil society demands are kept at the lowest level, PLHIV's problems are tried to be solved individually, without disclosing the person's identity, and the right to health is verbalised more than MARP's rights. The construction and negotiation of civil society discourses vis-à-vis the dominant discourse were explained in the Chapter 5. Below, I look at some of the obstacles to PLHIV's involvement in civil society and the reasons behind the reluctance of those who are actively working in civil society to publically disclose their HIV status.

First of all, people living with HIV constitute a very heterogeneous population. General perceptions about PLHIV as 'marginal' and 'immoral' can be held also by the PLHIV themselves. In this case, being in solidarity with all PLHIV regardless of their different backgrounds and embracing the idea that all PLHIV's rights should be equally defended may be difficult, as exemplified by a participant who stated that he would like to work for an NGO, but only under certain conditions:

"I don't want to meet up with [HIV-positive] prostitutes or people like that, people who think like 'my life was ruined and everybody else's life should be so'. I hear about [people like] that, they are on the wrong track (leading an 'immoral' life), they don't fear from violating *kul hakki* (rightful due)⁹⁵. I could meet up with [HIV-positive] drug addicts but I wouldn't meet up with a Russian woman or a person who thinks like 'let's throw caution to the wind' (keep practicing unprotected sex)." (Objektif, 31, male)

This kind of separation between themselves and other PLHIV was seen in a couple of participants' narratives.

Secondly, a much more frequently-mentioned theme about reluctance to participate in activism was a lack of hope about the ability to create change, based on society and the state's perceived resistance to listening and responding to rights claims. The quote below explains why a person with a highly-politicised identity was not

⁹⁵ Explained in Chapter 6.

involved in activism. The respondent talked about his previous experience of the foundation of an LGBT-NGO:

"At that time ... one of the newspapers headlines [about us] was '[They are] selling escargot in a Muslim neighbourhood' (to sell (here, to advocate) something that is not only unnecessary but also sinful). I liked that headline the most. [LL:] They're right! I mean, why on earth are you riding for a fall? I mean, just don't meddle! In this country, .. since problems are always treated as if they don't exist; if you do something [about a problem] the only consequence is that you make yourself visible as 'sharp' and they file you down. (...) Of course it is nice to have more rights, to demand more rights; but in this country, coal miners in *Zonguldak* (A Black Sea regional city that is remembered for its coal mines where many miners die] don't have rights either, or women, who are beaten by their husbands everyday, don't have any right what so ever. Let alone ours [:LL]."

Finally, fear and/or unwillingness of disclosing HIV status must be included in relation to involvement in activism. As mentioned earlier, participants who worked in civil society were selectively disclosing their status; and besides, disclosure was not promoted in PLHIV peer-groups. This does not mean that PLHIV were advised to conceal their status; peer counsellors and professionals did not want to influence their decisions. Yet as mentioned, the right to conceal one's identity was dominant in the narratives of participants who were clients of NGOs.

To date, only two people have publicly disclosed their HIV-positive identities to contribute to raising awareness and reducing stigma in Turkey.⁹⁶ They have appeared on television programmes, shared their stories and voiced their demands without concealing their faces, their full names or their affiliations. Their stories tell a lot about the 'conditions of visibility' for PLHIV in Turkey.⁹⁷ Both men have declared that they acquired HIV from unprotected sex with a foreign woman when working abroad, which 'confirms' the discourse that HIV is a 'foreign' disease. Commenting on Romania, where he worked, Selahattin explained that 'everything was different from Turkey, especially about sexuality; there was no prejudice'.

⁹⁶ It should be noted however that, Ekerbiçer's protest was a one-off action, which had a short-term appearance in the media. Selahattin on the other hand contributed to AIDS activism for 15 years.

⁹⁷ Neither could be interviewed for this research. Selahattin Demirer lost his life in April 2010. Halil Ekerbiçer went public after my fieldwork period. The Appendix 7 contains a summary of their stories based on the book by Selahattin and my personal communications with him, and on media news about both of them.

Both men were married (one acquired HIV when he was still single, but was diagnosed when he was married) who lived in small towns where they were the only HIV-positive person that people had ever seen. They did not live 'marginal' lives and 'looked like typical Turkish men'. When Selahattin appeared in front of the press, the reporter commented:

"He was much more healthy, dignified and conscious than we ever expected. He has spoken freely about what he experienced; he did not shy away. He did not have a marginal life. He is just an Anatolian person."

Selahattin explained that 'at first people [in my home town] did not want me near them. I thought, "It's better to die once than to die every day". So I explained my disease to everybody. I chatted with them. I convinced them'. Because both of them were 'typical Turkish men', they were able to go and sit in a coffee house in a small town and chat with other men there who could identify and empathise with them. They were good examples of how HIV can 'happen to anyone'.

Selahattin explained his motives for going public with his status:

'I declared that I was HIV positive [in 1995]. They say that I am the first person in Turkey who declared their name and disease like that. I did so because I didn't want anyone else to go through what I had to experience. Because I had nothing to lose. I had already lost my wife, my child⁹⁸ and my job'.

Ekerbiçer, too, lost his job and was abandoned by his wife. He was also about to lose his health due to problems with accessing treatment. He decided to take action because 'I didn't come into this world to be an audience; I came to be an actor.'

Their messages have commonalities. Apart from the aim of raising awareness about HIV/AIDS among the general public, they both challenged the stigma by emphasizing the right to be treated humanely. Selahattin repeated the phrase: 'We too are humans. Our only wish is that society treats us without prejudice'; Ekerbiçer stated: 'A person can be atheist, Muslim or AIDS, but is still a human being and has the right to live like a human being.'

⁹⁸ His wife died of AIDS because she abandoned her treatment. Their daughter died due to medical malpractice in an emergency, and not of AIDS, according to Selahattin.

There is a considerable difference between their messages, however. Ekerbiçer's protest strongly criticised the health system and the state. He has criticised the MOH for his problems in accessing treatment and finding a job, and for the lack of knowledge about HIV/AIDS:

"When I came here [from South Africa where he was diagnosed and treated], I became registered as 'the AIDS case in [where he lives]' in the statistics. But no one asks if this person is living? Can he get his drugs? Is he insured? Is he hungry? (...) I have to be under permanent control of health institutions. I cuddle my grandchildren. Who will be held responsible, if I pass them the disease? (...) [when I talk to the public I see that] no one told those citizens anything [about HIV/AIDS]. No one has heard of anything. Is it their fault that they have not heard? (...) If our disease is an obstacle [for finding a job], then the Ministry of Health should step in and say 'all right, those guys [PLHIV] are transmissible, so I will keep them in prison; or, no they are not transmissible, I will keep them in society'. I mean, they should say what is to be done."

Because Ekerbiçer had been formerly treated in South Africa he was overwhelmed by and could not deal with the system-related problems in his treatment in Turkey, which are explained in Chapter 7. The Positive Living Association directed him to an HIV/AIDS specialist and helped him to sort out his insurance problem. Ekerbiçer commented: 'What I don't understand is why the Ministry of Health can't do what an NGO can do. If an NGO can do these things, shut down the Ministry. If I hadn't found that NGO, I wouldn't be here talking to you.'

Selahattin, on the other hand, was 'lucky' that he was diagnosed and treated from the beginning at a hospital that is considered as one of the best for HIV/AIDS treatment. For a long time before there were any PLHIV-NGOs he collaborated with AIDS Savaşım Derneği, an organisation led by medical professionals. Although Selahattin mentioned problems related to mistreatment from health professionals, he emphasised that PLHIV should trust their doctors and their knowledge.

Other PLHIV's reluctance to disclose their status publicly for the cause of activism could have many reasons. Fear of stigma, including not only the fear of being abandoned or isolated but the denial of work, housing and healthcare and even fear of violence can be a reason. As mentioned earlier, some respondents explained that they concealed their status to protect not themselves, but their families.

For PLHIV who are not 'typical Turkish' men or women, for transsexuals, for sex workers, for homosexual men, there may be reasons other than the fear of stigma. It is possible that even though they do not hide their HIV status they fear that its public disclosure would do more harm than good to AIDS activism in Turkey at present because it would fuel prejudice, affirming the association of HIV/AIDS with unwanted social behaviours and populations. Even if this is not their personal view they may not be given the opportunity to speak out on behalf of PLHIV. As mentioned in Chapter 5 when discussing NGO discourses, 'good' or 'innocent' examples are sometimes deliberately chosen as the face of PLHIV.⁹⁹

Going back to the reasons behind activism without (or with limited) disclosure, the need for a wider identity (Bond, 2010) should also be discussed. Shih (2004, p.179) explains that stigmatised individuals can 'draw upon their alternate identities to protect themselves from stigma.' They can 'strategically emphasize identities that are valued and de-emphasize identities that are not in any given social context' (Shih, 2004, p.179). However, as Bond (2010) suggests, some activists' decision not to disclose their status in every context cannot be explained only in terms of protection from stigma. It can be 'partly an attempt at normalcy, a reflection of the inability to live continually in crisis mode'. Limited disclosure of HIV status is also about 'respect, privacy and a need for a wider identity' instead of an identity fixed as a PLHIV (Bond, 2010, p.11).

5. Conclusion

This chapter has looked at the implications of the overarching discourses around HIV/AIDS on the formation of individual agencies of PLHIV and on social activism.

Many participants in this research questioned or criticised the state for different reasons: for not protecting them from the disease, for not informing them and/or doctors adequately, for the corrupt and overly bureaucratised health system, for neglecting them as citizens, for not protecting them from discrimination and for directly discriminating against them. Keyder et al. (2007) argue that in Turkey,

⁹⁹ Because of the limited number of occasions and a very limited number of persons who have selectively disclosed their status in such occasions, details about this issue are not given with a view to protect confidentiality and anonymity.

hospitals are one of the most important institutions where people come face to face with the state and begin to assess their values as citizens.

In this context it is not surprising that PLHIV interpreted their illness-related experiences within a framework of political criticism. Although it cannot be generalised to all PLHIV, denial of ‘undesired’ populations and behaviours, the de-prioritisation of HIV and inaction on the part of the state, which are all components of the cultural immunity discourse, contribute to their perception of themselves as unwanted, undeserving citizens. I have argued that feelings of insecurity and distrust, which have been recurrent themes in the previous chapters, as outcomes of stigmatisation, contributed to this political criticism. However, this criticism is not easily transformed into action against stigma, as insecurity and distrust also created fear and became a constraining factor in challenging stigma at the level of action.

The role of NGOs as framing agents is seen in their clients’ narratives which construct HIV as a ‘normal, manageable chronic disease that can happen to anyone’, but does not contribute to the reconstruction of illness in a political criticism framework. Observational data confirm that locating HIV in a political criticism framework is not a priority on the NGOs’ agenda for two possible reasons. Firstly, considering the low level of knowledge about HIV among both the general public and newly-diagnosed PLHIV themselves, the normalisation of HIV may be considered a priority. Personal, mostly emotional, support is NGOs’ primary aim. In this sense, the reconstruction of HIV as normal and manageable might be considered more important in terms of helping and supporting PLHIV and their families than locating it within a broader political framework. Secondly, as mentioned in Chapter 5, defending PLHIV’s rights through a broader rights discourse is perceived as having the potential to cause more harm than benefit, where conducting NGO activities in the current relationship between the NGOs and the state institutions is concerned.

The ‘normalisation’ of HIV-positive identity, in the sense of presenting HIV as a disease of ‘ordinary people’, can itself be restigmatising because the ‘we are just like you’ discourse represents the HIV-positive identity as ‘ordinary’ and just like that of the stigmatising ‘normals’. In doing so, it ‘approves the normality of the

stigmatising audience' (Finn & Sarangi 2009, p.56). In other words, the emphasis on the idea that any 'normal' person can acquire HIV is not sufficient for challenging the moral discourses behind stigmatisation, when PLHIV who are not perceived as 'ordinary', such as IV drug users, sex workers, transsexuals or women with 'marginal' lifestyles continue to be invisible in AIDS activism. HIV-positive individual are represented as 'typical Turkish' men or women, with a view to challenge the association of HIV/AIDS with marginality and immorality. However it is possible that when PLHIV resist one form of discourse they might be caught up in another, both of which legitimise 'normality' of the stigmatising audience. To sum up, 'we are just like you' as a counter-argument to 'HIV is not our disease' could actually affirm the cultural immunity discourse, if 'we' does not include any of the populations that are denied in the first place.

Chapter Ten: Conclusion

1. Introduction

This chapter draws together the main arguments of the thesis, and highlights the main findings that contribute to further understandings of how HIV-related discourses are formed and how HIV as a chronic illness and the stigma attached to the disease are managed by PLHIV.

I will first discuss the findings presented in Chapter 5, revisiting the conceptual framework on the discursive formation of diseases. I will point out the ways in which the relationship between medical knowledge and social control as discussed in the literature takes a rather different form in the context of Turkey. Secondly, I will focus on the role of the institution of the family in Turkey both in terms of the support offered by family but also its role in contributing to internalised stigma, which was discussed in Chapter 6. These processes are interpreted by focusing on the role of patriarchal discourse in the specific context of Turkey. The key findings from Chapters 7, 8 and 9 are then examined to show their contribution to understandings of how PLHIV manage their physical health, social identity and stigma. Finally, I will put forward the perceptions of risk and responsibility that have emerged in this particular research context, along with some other contextual factors that could contribute to diminished stigma.

This chapter ends by highlighting areas for further research and the policy agendas which the thesis informs. Although this research was not policy-oriented, two areas of policy debate arising from the thesis are explored. This is a particularly timely contribution, considering the 'absence' of a comprehensive HIV/AIDS policy that was regarded as an important problem by the participants of this research, and considering the recent formation of a 'working group' on HIV/AIDS under the Ministry of Health.

2. Contributions to existing theories and understanding

The analysis presented in Chapter 5, on the construction of HIV-related discourses in Turkey, was informed by a theoretical lens that views diseases as discursive formations. One of the components of this conceptual framework was the Foucauldian analysis of power/knowledge unity (see Chapter 2, pp. 25-28) that sees medical knowledge as a means of social control and regulation. The relationship between power and knowledge is a two-way process. On one hand, the knowledge from scientific observations creates notions about what is normal and what is deviant, thus serves a basis for power of controlling populations. On the other hand, instruments of control serve to make the controlled people the object of scientific analysis. The data presented in Chapter 5, on the role of medical discourse in the formation of HIV-related discourses, revealed a different, more obscure form in which this power/knowledge unity manifested itself. While in the past the state employed the medical profession to gather information on sexually transmitted diseases, which led to the control of sex work (see Chapter 5, p.121), in the case of HIV/AIDS there was an 'informational silence'.

The absence of adequate and reliable data gathered through the health system, and the obstacles in front of collaborative relationships between the medical profession and state institutions, prevented the medical profession from obtaining and interpreting epidemiological data. Therefore, the role of the medical profession in the construction of HIV-related discourses seems to be limited. I argued that, as did one of the KIs (see Chapter 5, p.127), the state's inaction in obtaining and disseminating epidemiological data is a strategy for maintaining the 'cultural immunity' discourse. Epidemiological data might reveal facts that contradict the 'cultural immunity' discourse. It might prove the 'existence' of populations and behaviours which have been denied. There would then be the requirement to address the needs of those 'deviant' people. In this case, 'informational silence' could be a better way of maintaining control. In other words, the state still maintains control over populations, not by using scientific information gathered by the medical profession as the Foucauldian approach suggests, but through an 'informational silence'. It should be stated however, that although scientific informational silence weakens the power of medical profession in the formation of HIV-related discourses, the cultural immunity discourse is reproduced by the health

professionals, through morality-based and 'fear of contagion' based discriminatory practices that are explained in Chapter 6 and 7.

Research findings on the construction of HIV-related discourses also revealed, in the eyes of participants and key informants, the overarching power of a monolithic state, a source of power which is not central to the Foucauldian conceptualisation of power, in terms of his criticism of 'state power'. According to Foucault, power is not owned by a specific group or institution, but it exists in independent, various, local social settings. His conceptualisation of power as 'dissolved' and decentralised, operating through multiple channels challenged the classic understandings of the authority and dominance of the sovereign state (Jessop, 2007). The data on the power relations between the actors in the formation and negotiation of HIV-related discourses in Turkey did not allow me to identify disaggregated agents of the state. Rather, 'the state' was perceived as occupying the dominant authority position. Both the reviewed documents and the narratives of KIs reflected the idea of a 'strong state tradition' in Turkey (Heper, 1985) and the weakness of civil society against it. Particular negotiations of rights discourses that prioritise the perpetuity of society over the rights of individuals also resonated with this historical perception of the state in Turkey: a 'sublime' authority, and a 'sacred' unity, that should be served and protected by the people. In this sense, it could be argued that macro or structural forces of power based on the state need to be considered seriously, as well as the Foucauldian conceptualisation of disaggregated power operating at multiple local levels, if we are to achieve a fuller understanding of discursive power relations in such cultural contexts.

The results presented in Chapter 6 showed that enacted stigma in the context of the family, such as being shunned by family members, was not common. While this finding from a small sample of PLHIV cannot be generalised to all PLHIV living in Turkey, it is important to note that the observations of doctors and civil society workers who were interviewed as KIs, as well as previous research (SIT, 2010), also found that acceptance from parents, spouses and other close family members was common.

Nevertheless, this does not mean that the institution of the family in Turkey was perceived by PLHIV as a source of comfort. In other words, family support did not

prevent people having to struggle with a 'tainted' or 'deviant' identity. On the contrary, strong social expectations and personal desires around familial roles, and the cultural value attributed to 'the family' in the ideal life trajectory, acted as the primary drivers of internalised and felt stigma. Getting married, having children, being a 'responsible' spouse, mother, or father are perceived as the main sources of acquiring respected and valued social identities in the society of Turkey. Consequently, the actual and potential damaging effects of HIV on one's life were evaluated by PLHIV in terms of the failures in fulfilling family-related social norms.

The role of perceived failure in fulfilling family-related roles in internalised stigma and in enacted stigma from family members was demonstrated in the general literature on HIV-related stigmatisation. However, one important difference between the cases shown in this research and the ones discussed in previous research is that the male participants of this research did not articulate their perceptions about failure in family-related roles in terms of their identities as 'breadwinners' (Wyrod, 2011). This is partially because of the sample bias, since very few participants had to stop working because of their ill health. Even those few married male participants who were unemployed at the time of the study due to their HIV status did not express their failure in terms of a failure to provide. Their narratives about 'disappointing their families' were not related to their inability of providing for the family, but were expressed in terms of putting the lives of their family members in danger and making them feel sad.

Previous research also shows that HIV might have a particular effect on men in terms of damaging their 'masculine reputation' (Siu et al., 2012:1). Feeling sick and in need, being unable to work and care for the family, a diminished 'authority' in the household and in 'sexual privileges' might contribute to the perception that HIV damages idealised masculinity (Wyrod, 2011; Siu et al., 2012). However, male participants of this research did not articulate any damage in their perceived 'masculinity' due to those factors.

This research contributes to understanding the relationships between adult HIV-positive individuals and their parents, which has received very little attention in the wider literature (Saengtienchai & Knodel, 2001; Ukokis, 2007). Research in developing countries has tended to focus on the role of parents mainly as

caregivers to their sick adult children, or as caregivers to their orphaned grandchildren (*ibid*). In other words, attention has been paid to the process after the parents and the child re-unite when the child is in need of care. However, in the context of Turkey, where the relationship between parents and adult children continues to be very close, and living together with parents is very common even in later stages of life, parental support remains as important as support from the chosen family.

The gendered nature of stigmatisation in Turkey appeared to have different dimensions to those often found in other settings of gender inequality. In contrast to the findings of other studies set in the contexts of South Asia or Southern and Eastern Africa, in which HIV-positive women are blamed for bringing HIV into the household, thrown out of their homes and/or subjected to violence (Ertürk, 2005; Ogden & Nyblade, 2005), the female participants of this research did not experience disproportionate or more violent forms of stigmatisation from their spouses or their parents. Previous research (Aşar-Brown, 2007; Kasapoğlu & Kuş, 2008) has shown, and KIs in this research argued, that married women are in an 'advantageous' position in terms of being perceived as 'victims' who, because of their 'purity' or 'innocence', could not have brought the disease and related shame onto themselves or the family. This is particularly remarkable in a cultural context where women are almost always blamed for 'dishonouring' the family. It is very well documented that in Turkey women who came back to their parental house because of domestic violence are often rejected, sent back, or face further violence from their parents. It is also well known that women who are raped, even when the perpetrator is a relative, are blamed for 'dishonouring' their family and are killed by their own fathers or brothers (Sirman, 2004; Akkoç, 2004; Ertürk, 2004). The support that HIV-positive women received from their husbands, their parents and their husbands' parents is therefore a particularly significant finding in this context.

This finding suggests that men accepted their responsibility for contracting HIV and passing it to their wives. Public perception of HIV-positive married women as 'victims' (Aşar-Brown, 2007; Kasapoğlu & Kuş, 2008) also affirmed that they find the only possible way for married women to contract HIV to be through their husbands' extra marital affair(s). This shows that the general public does not fully agree that the ideal of 'monogamy' is always upheld, or that the ideal 'Turkish family

'structure' is always seen to be present, as set out in the 'cultural immunity' discourse. The responsibility of men in the transmission of HIV is acknowledged by PLHIV and by the people around them. However, this does not mean that the cultural immunity discourse is challenged. Rather, it provides a 'scapegoat': the sex worker or another 'immoral' woman. In case the man did not acquire HIV from a sex worker, he must have contracted it from another woman - a woman to whom he did not chose to get married, a kind of woman who has sex out-of-wedlock, which makes her 'unchaste'. Therefore, the acceptance of HIV-positive married women can be explained in terms of the existence of another female who can be blamed and the existence of an 'official' discourse that approves it.

Another explanation for why HIV-positive married woman are not blamed, as they would be in the case of rape for example, stems from the fact that there is no 'other' man involved in the situation. The perception of HIV-positive women as 'victims' when they are married or when they 'appear to conform to gender roles', as one KI stated (see p.156), suggests that a woman's involvement in a relationship with a man, other than her husband, is unthinkable. It is not even regarded as a possibility. This echoes the general perception of women in Turkey, as detached from their sexualities. They are perceived as being 'modest', located in the private sphere of home, and as responsible for satisfying their husband's demands. In this sense, even though the perception of women as victims seemingly puts them in a more advantageous position in terms of facing less discrimination, it reflects patriarchal values and as such is a form of social control over women's behaviour and their sexuality.

The stigma management strategies analysed in Chapters 7 and 8 affirm the need for revisiting categorisations of stigma management strategies offered in the literature and for a more 'clear generic model of adjustment to illness' (Sharpe & Curran 2006, p.1154), which allows more space for understanding nuanced nature of experiences. PLHIV's narratives about management of identity pointed out cases in which the concepts of 'successful' adjustment, 'maladjustment' and the 'tasks' (or requirements) for successful management of HIV become blurred. For example, in terms of 'successful' self-management, the 'ideal' way of incorporating HIV into identity seemed to be a controversial issue from the standpoint of PLHIV. Some thought that accepting HIV-positive identity as a component of self was the 'ideal'

form of living with HIV and considered others who wanted to resume life as if 'nothing had happened' as weak and/or passive. On the other hand, some PLHIV criticised others who reconstructed a social identity through their HIV-positive status for not having any other valued identities in life and thus for leaning on their HIV status for giving meaning to their lives.

In terms of the 'tasks' of successful management of HIV, this research showed the cases in which the 'tasks' suggested in the literature contradicted or became obstacles to each other. For example, the ability to know about the disease and to make your own decisions about treatment are important for PLHIV, in terms of overcoming uncertainties and asserting agency and control over life. On the other hand, this 'lay expertise' was often problematic when trying to maintain a positive relationship with healthcare providers and compliance with treatment regimens, which are also other requisites for 'successful' illness management. It has been shown in this research that fulfilling those tasks simultaneously was not easy in Turkey, especially because of the authoritative nature of the doctor-patient relationship.

Management of chronic illness and its stigma was not a linear process or an 'end' of a process for this study's participants. I encountered people who were actively involved in advocacy while hiding their HIV status from their close family members. Some of the participants who have challenged HIV-stigma at a discursive level and reframed a positive illness identity were still struggling with serious depressive symptoms. Overall, their narratives did not allow polarised categorisations of management strategies and suggested that management of HIV and its stigma could be understood by paying attention to desired achievements of specific outcomes in specific contexts.

The diversity and complexity of stigma-management strategies were revealed in this research through the lens of the intersectionality approach. The above discussed variations in the stigma-management and self-management strategies reflect the effects of intersecting multiple identities and structural forces in PLHIV's lives. Different aspects of individuals affect not only their resources or capabilities, but also their desired achievements, thus play an important role in shaping the ways in which they manage HIV and its stigma. The previously mentioned varied

thoughts and outcomes about the 'ideal' ways of incorporating HIV into identity can also be understood within the framework of the intersectional approach, exploring the different values attributed by the individuals to their multiple social identities.

These findings show that the intersectional approach is useful to explore not only the intersection of race, class and gender, but also other dimensions of individuals' lives beyond those axes, without simply adding up the negative effects of different systems of inequality (as in the notions of 'double stigma' or 'intersectional discrimination') and without assuming a hierarchy between these systems. In doing so, I consider the methodological approach adopted in this research particularly beneficial. This approach was aimed at allowing the participants to identify the systems of inequality that are most important in their lives and their social locations in these systems. Intersectionality is one of the most important recent contributions of feminism to social theory and research. Yet, it still is considered to be an 'evolving project' and a 'challenge' in terms of developing effective methodological tools (Denis, 2008, p.688; Choo & Ferree, 2009). This thesis contributes to this developing body of research, by applying this approach to the investigation of the formation and experiences of HIV-related stigma, by exploring the local configurations of intersecting structural forces and by identifying them in both structure (i.e. discursive and institutional) and agency levels.

This study found that health system problems were an important aspect of the management of health when living with HIV, a problem frequently overlooked in studies conducted in middle income contexts where treatment access has been relatively secure. This suggests that, as Bernays et al.'s (2010) research also demonstrated, countries health infrastructure and treatment systems are important factors that affect the restorative effects of ART. Health system problems and the excessive amount of time and effort that PLHIV put in to overcoming these problems affirm that the 'availability' of free treatment does not mean that treatment is 'accessible' and sustainable (Cook et al., 2003). In addition, PLHIV's 'treatment needs' include not only ART but also healthcare from other health services and equal treatment in healthcare settings. The lack of knowledge about HIV and negative attitudes from healthcare providers especially in those other departments were demonstrated in this research. Overall these created additional obstacles to successful management of health. The importance of these health-system related

problems shows that management of health cannot be understood in terms of individual choices made in a system that offers adequate facilities and services.

Although conceptualisations around 'risk' and 'responsibility' were not a primary concern for this research, the results indicated particular understandings of perceived risk and responsibility that played important roles in self-management. A discourse of 'individualisation of responsibility' in relation to health behaviour was absent in both primary and secondary sources used for analysing the social construction of HIV/AIDS in Turkey. It has been argued in the literature that especially in the western medical discourse individuals are regarded as responsible for their health-related choices and for protecting themselves from risks (Gabe et al., 2006). Therefore a potential source of health-related stigma is the perception of individuals as 'irresponsible' or as 'failed' in making the right choices. However, none of the participants or documents reviewed for this research articulated 'risk taking' or 'healthy behaviours' in general in relation to HIV-stigma.

The limited presence of an 'individual responsibility' dimension to stigmatising discourses can be explained by the relatively less individualistic cultural structure of Turkey, in which illnesses in general are not always seen as individual pathology. Also, the cause of illness could be explained in spiritual terms, for example as a 'test' prepared by God as explained in Chapter 8. Another reason why contracting HIV was not perceived as a consequence of an 'irresponsible' behaviour might be the general lack of information about HIV/AIDS and safe sex practices, as exemplified in Chapter 8. Overall, the limited presence of an 'individualisation of responsibility' discourse might be seen as an advantage of this cultural context in terms of diminished self-blame and internalised stigma.

Another aspect of the understandings of 'risk taking' in the narratives of PLHIV was that the 'risk' of infecting others was not expressed in the 'modern' conceptualisation, in terms of being informed by 'facts' and making 'rational' choices. Although PLHIV knew about the ways of transmission, 'moral' concerns about violating '*kul hakki*' (see pp. 160-161) were in the forefront of decision making. This was more evident in the narratives about getting married to an HIV-negative person, getting in close contact with children and disclosing HIV-positive status to healthcare providers if there is a 'risk' of transmission.

A significant feature of this research context was that fear of the unknown' was an important component of HIV-related stigma. This idea, which was expressed by many participants, implies that more than the moral prejudices about HIV/AIDS, the absence of adequate and correct knowledge contributes to the stigmatisation of PLHIV. This idea was also taken forward by some participants who stated that if correct information were to be given to people who have no idea at all, people would not discriminate against PLHIV. This was indeed confirmed by a couple of PLHIV's narratives. As exemplified in Chapters 6, some participants' family members, who have never heard of HIV, were very supportive, once they have learned about HIV/AIDS for the very first time from a non-stigmatising professional. This might be related to the argument that ostracism is considered as 'impolite' in the culture of Turkey and that if people do not fear HIV/AIDS, there would be no perceived need or motivation for excluding PLHIV (see p.106 in Chapter 5 for the articulation of this argument by a KI).

Participants' depictions of negative attitudes towards PLHIV, along with their above mentioned ideas about fear-based and moral prejudices and how they might be reduced, necessitated including the conceptual models of prejudice in this thesis. Although the stigma models have been used extensively, the term prejudice has been much less frequently employed in the field of HIV/AIDS (Parker & Aggleton, 2003). The conceptual models of stigma and prejudice were considered in this research as complementary and the term prejudice was used when addressing the attitudinal components of stigma (Phelan et al., 2008). The analysis indicated some particular areas in which the conceptual framework of prejudice can contribute to our further understandings of how HIV-related stigma is shaped and can be reduced.

First, the prejudice models provide an appropriate framework especially when exploring the attitudes of the 'perpetrators' (*ibid*), i.e. the stereotype-based negative attitudes against 'foreign women' and sexual minorities that lie behind the cultural immunity discourse. Secondly, the 'fear-based' prejudices that the participants emphasised can be interpreted within the social psychology literature on prejudices rooted in the 'threat of infectious diseases' (Schaller & Neuberg, 2012). Although prejudices elicited from the threat of infectious diseases and prejudices rooted in moral threats are strongly intertwined in the case of HIV-related stigma, the 'threat-

based approaches' point out the importance of exploring the different types of threats behind different types of prejudices, since they might suggest distinct strategies for stigma-reduction (*ibid*). Finally, 'contact theories', explaining the reduction of prejudices through contact between in-groups and out-groups (Crisp & Turner, 2010), can offer a useful perspective to discuss the ideas about stigma-reduction expressed by the participants. The findings of this research pointed out a significant way in which contact with others can reduce prejudices. As discussed in Chapter 8 (pp.221-223), frequent contact with other PLHIV can cause individuals to recognise and tackle with their own prejudices against other 'out-group' members and contribute to the development of a positive self-perception.

3. Areas for further research and policy implications

Considering the scarcity of HIV-related social research conducted in Turkey and the context-specificity of this research, two areas for further research that could contribute to understanding of PLHIV's experiences in Turkey, or in similar contexts, are worth noting. There are at least three significant 'populations' whose perceptions and experiences related to HIV/AIDS remain poorly understood in Turkey. Firstly, in this research, and also in previous research in Turkey, the experiences of PLHIV who are not in contact with a peer-group or with a well-established infection clinic were not represented adequately. Secondly, the women who are perceived as the 'source' of HIV, the 'foreign sex workers' were not included. Thirdly, the investigation of another large population, which I had a chance to know through some online forums and from personal observations, the regular clients of sex workers who express a constant worry of being infected with HIV, could offer important insights about the unspoken cultures of sexuality.

With regards to areas for policy debate and possible interventions, this research has shown the benefits of peer-support and the need for social/psychological counselling. In the current situation, it is seen that social and psychological needs are not generally understood as 'treatment needs' form PLHIV and that some doctors undertake the responsibility of helping their patients with these problems. This creates an extra burden for the doctors, in terms of both work load and emotional burden, and was sometimes found to be inadequate by the patient. The formation of patient-groups in hospitals and the effective use of social workers in hospitals seem to be important, since the efforts of civil society organisations

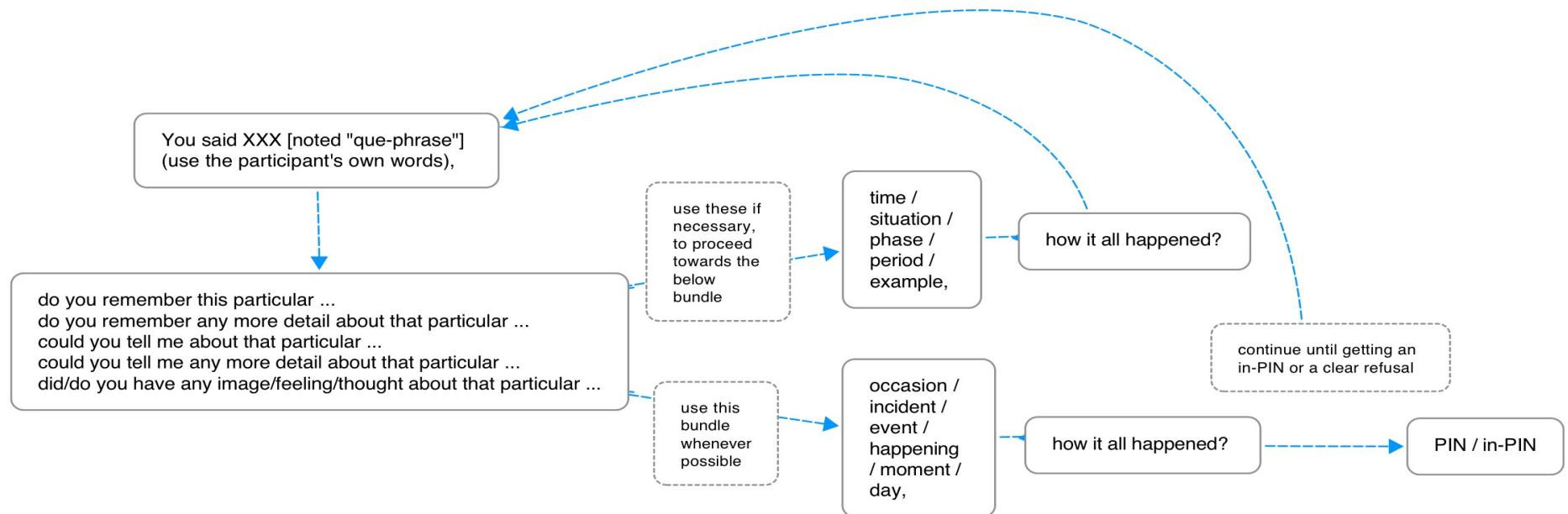
remain insufficient. High levels of stigma encountered in healthcare settings also show the importance of the inclusion of 'ethical dimensions for the healthcare profession' into the medical training curriculum, as expressed in nearly all of the civil society reports written so far. Finally, considering the role of spiritual beliefs in the formation of illness perceptions, the inclusion of religious institutions and leaders in HIV-related campaigns could have a significant impact.

4. A concluding remark

In 2004, when I first started thinking about conducting research on HIV-related stigma, my draft proposal read: 'there are 1.922 people who have been diagnosed with HIV and AIDS in Turkey, since the first reported case in 1985'. Now, this number is replaced by 5.820, meaning that in the past eight years nearly four thousand more people have been diagnosed with HIV in Turkey. Although this research was not set out to explore the causes of the rise in the epidemic, its findings suggest that the 'cultural immunity' discourse and its policy outcomes are not likely to contribute to the prevention of the disease. On the contrary, the 'alienation' of the disease leads to less voluntary testing, late diagnosis, and rejection of treatment, which then contributes to the spread of HIV.

Some characteristics of the research setting, namely, the lack of individualistic understanding of illness as 'personal responsibility', the low level of awareness about HIV/AIDS which could make people more 'open' to correct and non-prejudicial information, and the cultural and/or religious 'requirements' of 'tolerance' and 'inclusion could be seen as creating a space for stigma reduction.

Appendix 1: Formulation of "narrative-seeking questions" for generating Particular Incident Narratives (PINs) in BNIM sub-session two:



Adopted from Wengraf (2009) "Figure 23: BNIM notepad – interview blank page for use"
 Tom Wengraf . [2009]:BNIM Short Guide bound with the Detailed Manual. Version [9.12a] [724]-pages.

Appendix 2: Transcription and display of verbatim quotes from participants

Symbols and punctuations used in transcribing and displaying verbatim quotes

Symbols	Meanings
Transcription conventions	
..	a pause of less than 3 seconds
...	a pause greater than 3 seconds
word..	self-interruption / false start
X	removed (name, age, occupation, location etc.) to protect anonymity
<word>	emphasis
word	overlapping speech (the respondent and I talking at the same time)
SL	smiley voice or suppressed laughter
LL	laud laughter
HH	noticeable breathing out
C / CT	coughing / clears throat
(?)	uncertain transcription (previous word)
(???)	unintelligible
Additional symbols used when displaying quotes in text	
[explanation]	explanation derived from the respondent's speech
(explanation)	my explanation about a term or a situation
(...)	deleted sentence(s) (to shorten, to prevent repetition, or to protect anonymity)
<i>italic</i>	Turkish

Additional information on transcription of interviews with PLHIV

Pronunciation	All words, including fillers and interjections (such as 'er', 'um', etc.) have been transcribed as pronounced, and not as spelled in correct forms.
Punctuation	Full stops, commas, question marks and exclamation marks have been used as in traditional spelling, only when there was a clear intonation contour in the speech (i.e. full stop for an 'end', comma for 'continuation', question mark for an 'end of a question', exclamation mark for surprise, anger, an interjection or an imperative).
Speaking modes	Notable changes in participants' speaking mode (such as fast, slow, loud, whispering, crying, imitating etc.) have been marked in brackets.
Non-verbal expressions	Non-verbal expressions (such as facial expressions, hand gestures, and silently shedding tears) have been marked in brackets, when necessary.
Contextual events/sounds	Contextual information (such as a person entering the room or a ringing phone) has been added. Noise from outside has been marked when it might have been distracting.

Appendix 3: Invitation letter and consent form for the primary participants (PLHIV)

INVITATION LETTER AND CONSENT FORM FOR PARTICIPATION IN A RESEARCH STUDY

Hello,

My name is Pinar Öktem. I am a PhD student from the University of East Anglia in England. I am conducting a research on living with HIV and HIV/AIDS-related stigma and discrimination in Turkey. This research is for my PhD dissertation and it is not related to nor funded by any governmental or non-governmental institutions in Turkey.

I am going to give you some information about the research and after that I will invite you to participate in this study. You can keep one copy of this form and take your time to decide whether or not you wish to participate. Please feel free to ask me if there is anything you do not understand or if you request more information about the research.

Purpose of the study

The purpose of the study is to understand how people living with HIV in Turkey are affected by the perception of the society about HIV/AIDS; what their experiences are; and how they deal with the problems they face. It is aimed with this study to make the voices of people living with HIV heard in society and thus to contribute to a better understanding about their lives and social needs.

Right to refuse or end participation in the study

Your participation in this research is entirely voluntary. If you decide not to participate, the services you are receiving (or you will receive in the future) will not be affected. If you agree to participate, we can decide a time and place for our first meeting which is convenient for you. During the interviews, you have the right to refuse to answer questions or withdraw information that you have provided. If you change your mind about participation, you can withdraw from the study at any time.

What kind of research is this? / What am I expected to do?

This is not like a survey (with questionnaire) but is in a form of a face-to-face interview. I wish to make interviews with you two or three times. Questions will be related only to your experiences and opinions. They will not have any right or wrong answers and they will not require any specific knowledge. I wish to tape-record the interviews; because note taking can interrupt or slow down our interview or cause some of your statements to be missed. But still, you can refuse the interview to be tape-recorded or you can request to stop recording at any time.

The interviews will take place at a time and location of your choice. The duration of a single interview will depend on the course of interview. I would be happy to give you a copy of the written form of your interview, if you would like to review it or to keep a copy.

Confidentiality

Your name will not appear in any report of this study. Besides, the names that you mention (such as names of family members, friends, doctors, institutions, and other places) or any other facts that could identify you will not appear. You can select a name for yourself to be used in the reports.

All of your answers will be confidential. Information given by you might be shared with third persons only if it is necessary for the purpose of the study, again without any information that could identify your identity. Interview records and all other notes I take will be kept in my locked cabinet or on my computer that will be accessible only to me. Audio records of the interviews and the any other material that contains your name will be destroyed at the end of the research.

Are there any risks?

You may feel uncomfortable when talking about some topics. If this happens, you are free to change the topic or cease the interview at any time. I would like to remind you that you do not need to share anything you think that is too personal or could make you feel uncomfortable.

What are the benefits?

Participation to this study may not have a direct benefit to you. I am not able to evaluate or give advices about your physical or psychological health. But you can find it beneficial to share your opinions and experiences freely in a private environment.

I aim to share the overall findings of this study with health providers, policy makers, researchers and people living with HIV in Turkey. In this way, this study might contribute to a better understanding of the needs of people living with HIV in Turkey, to develop policies to stamp out the stigma associated with HIV, and perhaps to inspire people living with HIV.

If you have any further questions..

Could you have any further questions, at any time during this study, please ask me. My contact details are provided below. You might also want to contact Prof. Yakin Ertürk from Middle East Technical University (local contact person allocated) for your questions or complaints about the conduct of the research.

Do you want to ask me anything about the study now?

[names, affiliation, phone numbers and e-mail addresses of the researcher and of the local contact person]

Consent

The research information was read and explained to me clearly. Anything I did not understand was explained to me and all my questions were answered.

You do not need to fill the below section.

Respondent agrees to participate in the study:

Yes No

Signature of researcher: _____ Date: _____

Appendix 4: Invitation letter and consent form for the key informants

INVITATION LETTER AND CONSENT FORM FOR PARTICIPATION IN A RESEARCH STUDY

(for key informants)
<p>Introduction</p> <p>My name is Pınar Öktem. I am a PhD student in the School of International Development at the University of East Anglia in England. I am conducting a research on HIV/AIDS-related stigma in Turkey. (The research title is "Medical and Patriarchal Discourses in Shaping the Experience and Management of HIV-related Stigma in Turkey").</p> <p>This research is for my PhD dissertation and it is not conducted nor funded by any governmental or non-governmental institutions in Turkey. The research has been approved by the ethics board of the University of East Anglia.</p> <p>This form is for giving you some information about the research. After reading this form you will be asked to decide if you would like to join this study, by giving your signed consent. You can keep one copy of this form. Please feel free to ask if you request more information about the research.</p>
<p>Purpose of the study</p> <p>The purpose of the study is to understand how people living with HIV in Turkey are affected by the perception of the society about HIV/AIDS; what kind of problems they face; and how they deal with these problems. Your participation to this study is considered valuable in terms of providing an understanding of the causes and consequences of HIV-related stigma in Turkey according to your opinions and experiences.</p> <p>The findings of this research will be used to produce a PhD dissertation and academic publications. The findings will be made available also in Turkish. Thus, the study aims to provide scientific data that will contribute to the identification of urgent needs and emerging issues in research and stigma-reduction policy priorities.</p>
<p>Right to refuse or end participation in the study</p> <p>Your participation in this research is entirely voluntary. If you decide not to participate or to withdraw your consent at any time during the study, this will not affect you in any way. If you agree to participate, we can decide a time and place for the interview which is convenient for you. During the interview, you have the right to refuse to answer questions, withdraw information that you have provided or stop the interview at any time.</p>
<p>Study procedures</p> <p>I wish to visit you once to conduct an interview that will last about 30 minutes to 1 hour. The interview will be tape-recorded if you give permission. You can request to stop recording at any time. You can also request a copy of the transcription of your interview if you would like to keep or review it.</p>
<p>Confidentiality</p> <p>Your name will not appear in any report of this study. Considering your (or your institution's) unique position in the field of HIV/AIDS in Turkey, particular attention will be paid to maintain your anonymity. The names that you mention (such as names of colleagues, institutions, and other places), your position in your institution, your specific occupation or any other facts that could identify you will not be mentioned.</p> <p>All information you give will remain confidential and will not be shared with any other people. Interview records and all other notes I take will be kept in my locked cabinet or on my computer that will be accessible only to me. Audio records of the interviews and the any other material that contains your name will be destroyed at the end of the research.</p>

Risks

It is not anticipated that participation to the study will pose any risk to you. Every effort will be made to maintain your anonymity and the confidentiality of the information you provide.

Do you have any questions?

If at any time during this study you have questions you can ask me from the contact details provided below. You might also want to contact Prof. Yakın Ertürk from Middle East Technical University (local contact person allocated) for your questions or complaints about the conduct of the research.

Do you want to ask me anything about the study now?

Consent

The research information was read and explained to me clearly. Anything I did not understand was explained to me and all my questions were answered.

Respondent agrees to participate in the study:

Yes No

Signature of researcher: _____ Date: _____

Signature of the participant: _____ Date: _____

Contact information

[names, affiliation, phone numbers and e-mail addresses of the researcher and of the local contact person]

Appendix 5: Interview guide for semi-structured interviews with key informants

Starting questions:

Specific working area(s) related to HIV/AIDS (current and previous)

For how long they have been working in this area

Topic A: the general situation of the epidemic in Turkey

- 1) Current situation, its development over time, predictions about the future
 - The recently announced figures (attached to this guide), reasons for low/high figures
(Prevalence rate, the routes of transmission, number of people infected, in need of treatment, receiving treatment, died of AIDS)
 - Most-at-risk / most-affected populations
 - Evaluation of the available data (realistic, reliable, sufficient?)

Topic B: HIV/AIDS related policies and activities in Turkey

- 2) The place of HIV/AIDS in the health policies in Turkey
- 3) Civil society activities on HIV/AIDS in Turkey
- 4) What are the actors that are (and are excluded from) shaping / implementing HIV/AIDS related policies, projects and research in Turkey? (What are the roles and effectiveness of?)
 - Medical profession
 - Ministry of Health
 - International bodies
 - Governments
 - Civil society
 - People living with HIV/AIDS
- 5) Cooperation among the (mentioned) institutions/actors
- 6) Approaches and programmes for prevention
(Positive/negative aspects, causes of the problems, suggestions)
- 7) Access to treatment and care of PLHIV
(Positive/negative aspects, causes of the problems, suggestions)
- 8) Available support mechanisms for PLHIV
(Positive/negative aspects, causes of the problems, suggestions)
- 9) Scientific (medical and/or social) research on HIV/AIDS Turkey?

10) (In the specific working area of the respondent) factors / mechanisms that facilitate and obstruct the efficiency of your own work

Topic C: social perceptions of HIV/AIDS in Turkey

11) How is HIV/AIDS perceived in Turkey by the general public?
(Any variations among different parts of the society?)

12) Actors that are effective in shaping / changing the perceptions of HIV/AIDS

Related perceptions that can be mentioned:

- sexuality
- homosexuality
- religion
- healthy lifestyle / risk taking

Related actors that can be mentioned:

- health professionals
- civil society
- state institutions
- media

Topic D: HIV/AIDS related stigma in Turkey

13) According to your opinion and experiences do PLHIV face stigma/discrimination/exclusion/ labelling (wording according to the respondent: use the term used by the respondent so far)?

(When possible seek narrative / ask for examples, personally witnessed situations etc.)

- In what forms
- In which environments
- What are the factors that differentiate their experiences
- What are the main reasons
- What are the main consequences for PLHIV, their families and their social environments
- What are the strategies (and the functions of the strategies) that PLHIV develop to deal with stigma and discrimination

14) Stigma-reduction
(Works done so far, necessary steps, priority areas)

15) Stigma by association (courtesy stigma)
(Do you think that professionals working in this field also face HIV related stigma because of their association with PLHIV; did you have such an experience?)

Topics specific to the working area / institution of the respondent

Civil society sector:

- The activities of the NGO
- A profile of the members
- The level of participation of members to the activities
- The factors that affect the willingness/reluctance to be involved in activism
- The effect of involvement in activism on PLHIV (if applicable)

Doctors (and peer-counsellors when applicable):

- Any observations about meanings attributed to HIV/AIDS by PLHIV ('fighting', 'acceptance', 'denial' etc.)
- Adherence to treatment / compliance with doctors' recommendations / participation in the processes of searching and deciding treatment options
- Effects of stigma on health and health-management
- (Health sector only:) Comparison between the perceptions of health professionals and the general public opinion about HIV/AIDS
- (Health sector only:) HIV/AIDS education in the curriculum

Ministry of Health and International Bodies:

- Related departments, commissions, organizational chart, etc.
- Number and qualifications of the personnel
- Allocated budget and other sources of finance
- Related regulations, documents etc.
- Other institutions/actors in collaboration

Appendix 6: Sample Data Sheet on HIV/AIDS In Turkey released semi-annually by the Ministry of Health (MOH)

Notes:

- The original format and wording are provided, along with my own translation.
- The data sheet is not published by the MoH but is available on demand.
- The source of this particular data sheet is Pozitif Yaşam Derneği (Positive Living Association), Available at http://pozitifyasam.org/assets/files/Turkiye_verileri2011.doc [accessed 29 December 2012]

T.C. SAĞLIK BAKANLIĞI HIV/AIDS VERİ TABLOLARI (Republic of Turkey Ministry of Health HIV/AIDS Data Tables)			
01 EKİM 1985 – 31 ARALIK 2011 (01 October 1985 – 31 December 2011)			
TEMEL SAĞLIK HİZMETLERİ GENEL MÜDÜRLÜĞÜ, BULAŞICI VE SALGIN HASTALIKLARIN KONTROLÜ DAİRE BAŞKANLIĞI, ZÜHREVİ HASTALIKLAR ŞUBESİ			
(Directorate General of Primary Health Care Services Department for the Control of Infectious and Epidemic Diseases Office of Venereal Diseases)			
TÜRKİYE'DE BİLDİRİLEN AIDS VAKA VE TAŞIYICILARININ YILLARA GÖRE DAĞILIMI (Distribution of the reported AIDS cases and carriers in Turkey by year)			
YILLAR (years)	AIDS	HIV (+)	TOPLAM (total)
1985	1	1	2
1986	2	3	5
1987	7	27	34
1988	9	26	35
1989	11	20	31
1990	14	19	33
1991	17	21	38
1992	28	36	64
1993	29	45	74
1994	34	52	86
1995	34	57	91
1996	37	82	119
1997	38	105	143
1998	29	80	109
1999	28	91	119
2000	46	112	158
2001	40	144	184
2002	48	142	190
2003	52	145	197
2004	47	163	210
2005	37	295	332
2006	35	255	290
2007	24	352	376
2008	49	401	450
2009	75	453	528
2010	70	557	627
2011	80	619	699
TOPLAM	921	4.303	5.224

**TÜRKİYE'DE BİLDİRİLEN HIV/AIDS VAKALARININ,
YAŞ VE CİNSİYETE GÖRE DAĞILIMI, 2011**
(Distribution of the reported HIV/AIDS cases in Turkey by age and sex, 2011)

YAŞ GRUPLARI (age groups)	ERKEK (men)	KADIN (women)	TOPLAM (total)
0	19	7	26
1-4	11	18	28
5-9	7	11	18
10-14	6	4	10
15-19	36	43	74
20-24	282	260	502
25-29	504	299	742
30-34	632	246	811
35-39	594	158	684
40-49	795	196	868
50-59	408	131	503
60+	225	49	258
Bilinmeyen (unknown)	210	100	304
TOPLAM (total)	3.729	1.495	5.224

**TÜRKİYE'DE BİLDİRİLEN, OLASI BULAŞMA YOLUNA GÖRE HIV/AIDS
VAKALARININ, DAĞILIMI, 2011**
(Distribution of the reported HIV/AIDS cases in Turkey by the probable root of
transmission, 2011)

OLASI BULAŞMA YOLU (Probable root of transmission)	
Homo/biseksüel cinsel ilişki (Homo/bisexual intercourse)	443
Damar içi madde bağımlılığı (Intravenous drug addiction)	152
Homoseksüel/Biseksüel cinsel ilişki + Damar içi madde bağımlılığı (Homosexual/Bisexual intercourse + intravenous drug addiction)	10
Hemofili hastalığı (Haemophilia)	11
Transfüzyon (Transfusion)	57
Heteroseksüel cinsel ilişki (Heterosexual intercourse)	2.753
Anneden bebeğe geçiş (Mother-to-baby transmission)	70
Nozokomiyal bulaşma (Nosocomial transmission)	24
Bilinmeyen (Unknown)	1.704
TOPLAM (total)	5.224

Appendix 7: Stories of the two men who publicly disclosed their HIV status: Selahattin Demirer and Halil Ekerbiçer

Selahattin's story

Selahattin Demirer was the first person in Turkey who spoke to the media regarding his HIV status, to larger groups in meetings, to policy makers and who wrote a book to tell his story. I met Selahattin at an NGO meeting some years ago and later had the chance to have a long informal chat with him when I visited him at the hospital where he was receiving treatment for cancer.

His story begins in the early 90s, when he had a 'friendly small talk' with a doctor, after he had been discharged from the hospital where he had a kidney surgery. This doctor asked him whether he had ever been tested for HIV, after Selahattin told him about the two years he spent working in Romania in the late 80s as a young man in his 20s, and about 'a couple of girlfriends' he had there. Upon his return to Turkey he entered an 'arranged marriage', organised by his parents. Taking the advice of the doctor, Selahattin underwent the HIV test, subsequently being diagnosed with HIV alongside both his wife and his 40-day old daughter.

His wife's reaction was that 'they should support each other', but people in the small town where they lived in shunned them - refusing to talk to them and running away from them. Selahattin chose not to hide his HIV status, and from 1995 he began disclosing his status publicly, for example in the World AIDS Day meetings. In 1996, he spoke in person with the Minister of Health, (MoH) and asked for his intervention in securing a job. With the help of the Minister he gained employment in a hospital in his town. Selahattin and his wife's lives changed dramatically when their daughter died in 1997. According to Selahattin, her death was due to medical malpractice in an emergency situation, not due to AIDS. His wife cut herself off from the world and stopped taking her ART medication. Although he managed to convince her to restart treatment after a while, she again ceased treatment when Selahattin was sacked from his job on the basis of his HIV status. Soon after this event, his wife died.

After he lost her wife Selahattin wrote and published his book with the help of his doctors who were involved in *AIDS Savaşım Derneği* (Association for the Fight with AIDS). He started working, again with the help of MoH. He started making future plans, and hoped to marry an HIV-positive woman and have children. In early 2000s he met his second wife, who loved and supported him and who was HIV-negative. His wife learnt about HIV/AIDS from him and alongside him, assisting him in his efforts to raise public awareness, and developing supportive relationships with other PLHIV whom she got to know.

Selahattin continued to devote his life to teaching people about HIV/AIDS, and to challenge stigmatisation until he died in April 2010, at the age of 42.

Sources:

Informal personal communication, 2008-2010.

Anon., 2000, Romanya'da AIDS kaptı önce kızı, sonra eşi öldü (Caught AIDS in Romania, first his daughter, then his wife died). *Hürriyetim*, 1 December 2000, [online] Available at <http://webarsiv.hurriyet.com.tr/2000/12/01/266488.asp> [Accessed 28 December 2012].

Demirer, S., 1999. *HIV'le yaşamak* (Living with AIDS), Ankara: Güneş Kitabevi.

Demirer, S., 1999. *Interview: Bir AIDS'li Anlatıyor* (A person with AIDS narrates), Interviewed by R. Karakaş. [newspaper] *Hürriyet*, Available at <http://dosyalar.hurriyet.com.tr/dosya/aids/aidsianlatiyor.htm> [Accessed 28 December 2012].

Demirer, S., 2000. *Interview: 'HIV Positif Bir Eş Arıyorum* (I'm looking for an HIV-positive wife), Interviewed by M. Tömbekici. [newspaper] *Sabah*, 3 December 2000, Available at: <http://arsiv.sabah.com.tr/2000/12/08/z09.html> [Accessed 28 December 2012].

Demirer, S., 2006. *Interview on the Evening News*, Interviewed by O. Haksever. [television channel] *NTV*, 1 December 2006, Available at <http://arsiv.ntvmsnbc.com/news/392956.asp> [Accessed 28 December 2012].

Demirer, S., 2007. *Interview on Habere Doğru*, Interviewed by E. Murat. [television channel] *BENGÜTÜRK TV*, 1 December 2007, Available at http://www.youtube.com/watch?v=OKKaQ-yQ_M [Accessed 28 December 2012].

Demirer, S., 2008. *Interview on Sade Vatandaş*, Interviewed by O. Bayülgen. [television channel] *NTV*, 1 December 2008, Available at http://arsiv.ntvmsnbc.com/modules/habervideo/frm_video.asp?sayfa=2&NewsType=&CatID=48&VideoSearch=# [Accessed 28 December 2012].

Ekerbiçer's story:

Halil Ekerbiçer, a 58-year old man, first appeared in the media in June 2012, when he undertook an awareness-raising walk from his home town - a small city in Northern Turkey - to Greece. His intention was to attract attention to the problems experienced by PLHIV in Turkey in accessing both ART treatment, and employment. Calling his action 'the death walk', he explained that he had chosen Greece as his final destination because 'it is a European country in which he could be entitled to open a court case against Turkey in the European Court of Human Rights'.

Ekerbiçer informed the media that he left his wife and children in Turkey in 1980, working in several other countries before finally settling, in 1988, in South Africa where he lived for 20 years, intermittently visiting his wife in Turkey. He was diagnosed with HIV in 2003, after he had a 'heavy stroke'. He explained that he received good, free medical treatment and psychological support in South Africa and regained his health. With the aim of being 'a conscious patient', he 'attended trainings and seminars, followed advancements in medicine and did some HIV/AIDS related work in a church for 4 years'.

When he returned to live in Turkey in 2008, he brought with him a three-month supply of ART pills, and his medical certificate, detailing his test results and treatment regimen. He stated that this certificate was not accepted by health institutions in Turkey and that he was forced to repeat HIV tests before being issued with another certificate. Ekerbiçer's struggle with bureaucracy and 'indifference' of health professionals during the process included: very long waiting times for test results, health professionals' lack of knowledge about appropriate care and signposting when his results came back positive, confusion about his eligibility to be registered in the social security system, each institution directing him to another institution, and the lack of anyone capable of categorically informing him about access to ART within the health system in Turkey. He explained that after a year, he had failed to be registered in the social security system, and failed to obtain the required certificate, being consequently unable to access his ART medication for the duration of that year. In the meantime, his health situation deteriorated, his wife, who learned about his HIV status when he came back from South Africa, left him, he was denied access to employment due to his HIV status, and he subsequently he lived alone, and in poverty.

However, one day he saw the phone number of *Pozitif Yaşam Derneği* (*Positive Living Association*) in a newspaper and contacted them for support. The NGO helped him to register to the social security system, and to find a hospital that was able to provide treatment. Ekerbiçer still could not access his medication, because it took a month for the pharmacy in his home town to procure them on his behalf. He explained that his efforts to make legal complaints against health institutions were rejected.

In the end, he embarked upon his 'death walk' as a protest against the obstacles he had routinely encountered in the Turkish health system. During his walk, Ekerbiçer talked to members of the public in coffee houses and in the streets and informed them about HIV/AIDS. The walk lasted about 10 days - until he reached Istanbul - and was covered by some local and national newspapers. However, after the initial interest, there was no further reported news about his subsequent actions or achievements. The information that I did receive came through word of mouth, and consisted simply of assertions that he accessed treatment and he was in good health.

Sources:

Alagöz, Y., 2012, Türkiye'deki sağlık kuruluşlarını şikayet için yürüyerek Yunanistan'a gidecek. (He will walk to Greece to complain against the health institutions in Turkey), *Pusula*, 3 June 2012, [online] [Accessed 28 December 2012] Available at <http://www.pusulagazetesi.com.tr/haber.php?hayns=2&yazilim=haberler&osmanli=hdetay&aid=26171&title=26171>.

Anon., 2012, Bartınlı HIV hastasının yürüyüşü sürüyor. (The walk of the Bartın patient with HIV continues), *Cumhuriyet*, 6 June 2012, [online] Available at <http://www.cumhuriyet.com.tr/?hn=343156> [Accessed 28 December 2012].

Ekerbiçer, H., 2012, Interview: 1 Haziran'da ölüm yürüyüşü başlıyor (The death-walk starts on the 1st of June), Interviewed by A. Sağ, [newspaper] *Hergün*, 26 May 2012, Available at <http://www.bartinhergungazetesi.com/haber.php?id=652> [Accessed 28 December 2012].

Ekerbiçer, H., 2012, Interview: HIV pozitif bireyin yürüyüşü (The walk of the HIV-positive man), Interviewed by Anon. [video uploaded on YouTube], 13 June 2012, Available at <http://www.youtube.com/watch?v=CDG7pjf5dH8> (part 1) and <http://www.youtube.com/watch?v=EFworZmoXII> (part 2) [Accessed 28 December 2012].

Öğünç, P., 2012, Devlet beni bana kazandırmak zorundaydı. (The state should have 'reintegrated me back into myself [sic.]'). *Radikal*, 11 June 2012, [online] Available at <http://www.radikal.com.tr/Radikal.aspx?aType=RadikalYazar&ArticleID=1090745&CategoryID=97>.

References

Abu-Raddad, L.J., Ayodeji Akala, F., Semini, I., Riedner, G., Wilson, D. and Tawil, O., 2010. *Characterizing the HIV/AIDS epidemic in the Middle East and North Africa: time for strategic action*. [pdf] Washington: World Bank. Available at: <<https://openknowledge.worldbank.org/bitstream/handle/10986/2457/548890PUB0EPI11C10Disclosed061312010.pdf?sequence=1>> [Accessed 6 January 2013].

Adam, D.B., 1992. Sociology and people living with AIDS. In: J. Huber and B.E. Schneider, eds. *The social context of AIDS*. London: Sage Publications, pp.3-18.

Aga, F., Kylmä, J. and Nikkonen, M., 2009. The conceptions of care among family caregivers of persons living with HIV/AIDS in Addis Ababa, Ethiopia. *Journal of Transcultural Nursing*, 20(1), pp.37-50.

Akdağ, R., 2003. *Türkiye Sağlıkta Dönüşüm Programı Değerlendirme Raporu 2003-2010* (The Evaluation Report for the Programme of Transformation in Health in Turkey 2003-2010). Ankara: T.C. Sağlık Bakanlığı (The Ministry of Health of Turkish Republic).

Akkoç, N., 2004. The cultural basis of violence in the name of honour. In: S. Mojab and N. Abdo, eds. *Violence in the Name of Honour - Theoretical and political challenges*. İstanbul: Bilgi University Press. pp.113-126.

Allen, C., Mbonye, M., Seeley, J., Birungi, J., Wolff, B., Coutinho, A. and Jaffar, S., 2011. ABC for people with HIV: responses to sexual behavior recommendations among people receiving antiretroviral therapy in Jinja, Uganda. *Culture, Health and Sexuality*, 13(5), pp.529-543.

Allport, G.W., 1958. *The nature of prejudice*. Garden City, NY: Doubleday Anchor Books.

Alonzo, A.A., and Reynolds, N.R., 1995. Stigma, HIV and AIDS - an exploration and elaboration of a stigma trajectory. *Social Science & Medicine*, 41(3), pp.303-315.

Altay, E., 2010. Vicdan galip geldi, İnci hastanede! (Conscience won, İnci is at the hospital!). Kaos GL, 26 August 2010 [online] Available at: <<http://www.kaosgl.com/sayfa.php?id=5372>> [Accessed 6 January 2013].

Amnesty International, 2011. *'Not an illness nor a crime' Lesbian, gay, bisexual and transgender people in Turkey demand equality*. London: Amnesty International Ltd.

Anderson, M., Elam, G., Solarin, I., Gerver, S., Fenton, K. and Easterbrook, P., 2009. Coping with HIV: Caribbean people in the United Kingdom. *Qualitative Health Research*, 19(8), pp.1060-1075.

Aşar-Brown, S., 2007. *The effect of gender on HIV-related stigma and discrimination: cases from Turkey*. M.Sc. Gender and Women's Studies, Middle East Technical University.

Association for Women's Rights in Development (AWID), 2004. Intersectionality: a tool for gender and economic justice. *Women's Rights and Economic Change*, 9, pp.1-8.

Audulv, Å., Asplund, K. and Norbergh, K.G., 2012. The integration of chronic illness self-management. *Qualitative Health Research*, 22(3), pp.332-345.

Ay, P. and Karabey, S., 2006. Is there a "Hidden HIV/AIDS Epidemic" in Turkey? The gap between the numbers and the facts. *Marmara Medical Journal*, 19(2), pp.90-97.

Aydin, K., 2009. Statement made in the Grand National Assembly of Turkey on 1st December 2009. Available at:

<<http://www.pozitifyasam.org/index.php?contentId=531>> [Accessed 20 November 2012].

Bal, E., 2009. Türkiye'de HIV/AIDS'in sosyal boyutu – Sağlık Bakanlığı bakış açısı (The social aspects of HIV/AIDS in Turkey – the perspective of the Ministry of Health). In: *"HIV/AIDS 2009" Symposium*. Ankara, Turkey, 3-4 December 2009. Available at: <<http://www.hatam.hacettepe.edu.tr/sunum.shtml>> [Accessed 20 November 2012].

Barnes, D.B., and Murphy, S., 2009. Reproductive decisions for women with HIV: motherhood's role in envisioning a future. *Qualitative Health Research*, 19, pp.481-491.

Baumgartner, L.M., 2012. The perceived effect of time on HIV/AIDS identity incorporation. *The Qualitative Report*, 17(46), pp.1-22.

Baumgartner, L.M., and David, K.N., 2009. Accepting being poz: the incorporation of the HIV identity into the self. *Qualitative Health Research*, 19, pp.1730-1743.

Beer, L., Fagan, J.L., Garland, P., Valverde, E.E., Bolden, B., Brady, K.A., Courogen, M., Hillman, D., Neagis, A. and Bertolli, J., 2012. Medication-related barriers to entering HIV care. *AIDS Patient Care and STDs*, 26(4), pp.1-8.

Bell, E.S., 2000. Experiencing illness in/and narrative. In: C.E. Bird, P. Conrad, and A.M. Fremont, eds. *Handbook of Medical Sociology*. New Jersey: Prentice-Hall Inc., pp.184-201.

Berger, M.T., 2004. *Workable sisterhood: the political journey of stigmatized women with HIV/AIDS*. Princeton: Princeton University Press.

Berghan, S., 2007. *Lubunya: transseksüel kimlik ve beden* (“Lubunya”: transsexual identity and body). İstanbul: Metis.

Berk, E. 2009. *A general overview on data protection and privacy law in Turkey*. AdlawInternational, Available at: <<http://www.adlawinternational.com/articles/2009/data-protection-privacy-turkey.aspx>> [Accessed 9 April 2013].

Bernays, S., Rhodes, T. and Janković Teržić, K., 2010. “You should be grateful to have medicines”: continued dependence, altering stigma and the HIV treatment experience in Serbia. *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV*, 22(S1), pp.14-20.

Blaikie, N., 2007. *Approaches to social enquiry*. Cambridge: Polity Press.

Bond, V. A., 2010. “It is not an easy decision on HIV, especially in Zambia”: opting for silence, limited disclosure and implicit understanding to retain a wider identity. *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV*, 22(S1), pp.6-13.

Bozkaya, E., 1993. “İstanbul tip fakültesi ikinci ve üçüncü sınıf öğrencilerinin HIV/AIDS hakkında bilgi ve tutumları” (Knowledge and attitudes about HIV/AIDS amongst the second and third year students in İstanbul School of Medicine), *Birinci Türkiye AIDS Kongresi (First Turkey HIV/AIDS Congress)*, İstanbul, 12-15 January 1993, İstanbul: Omaş Ofset.

Brandt, A.M., 1988. AIDS and metaphor: toward the social meaning of epidemic disease. *Social Research*, 55(3), pp.413-432.

Brashers, D.E., Hsieh, E., Neidig, J.L. and Reynolds, N.R., 2006. Managing uncertainty about illness: health care providers as credible authorities. In: R.M. Dailey and B.A. Le Poire, eds. 2006. *Applied interpersonal communication matters*. New York: Peter Lang, pp.219-240.

Brashers, D.E., Neidig, J.L., Cardillo, L.W., Dobbs, L.K., Russell, J.A. and Haas, S.M., 1999. 'In an important way, I did die': uncertainty and revival in persons living with HIV or AIDS. *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV*, 11(2), pp.201-219.

Broadbent, E., Petrie, K.J., Main, J. and Weinman, J., 2006. The brief Illness Perception Questionnaire. *Journal of Psychosomatic Research*, 60, pp.631-637.

Brooks, A., 2007. Feminist standpoint epistemology: Building knowledge and empowerment through women's lived experiences. In: S.N. Hesse-Biber and P.L. Leavy, eds. *Feminist research practice*. Thousand Oaks, CA: Sage Publications, pp.53-82.

Brown, P., 1995. Popular epidemiology, toxic waste and social movements. In: J. Gabe, ed. *Medicine, health, and risk: sociological approaches*. Oxford: Blackwell, pp.91-112.

Brown, P., Zavestoski, S., McCormick, S., Mayer, B., Morello-Frosch, R. and Gasior Altman, R., 2004. Embodied health movements: new approaches to social movements in health. *Sociology of Health & Illness*, 26(1), pp.50-80.

Brown, T., Franklin, B., Mac Neil, J. and Mills, S., 2001. *Effective prevention strategies in low HIV prevalence settings*. UNAIDS Best Practice Key Materials. Virginia: Family Health International.

Bruce, J. and Clark, S., 2004. The implications of early marriage for HIV/AIDS policy. Brief based on background paper prepared for the WHO/UNFPA/Population Council Technical Consultation on Married Adolescents. New York: Population Council.

Bryman, A., 2008. *Social research methods*. Oxford: Oxford University Press.

Campbell, C. and Deacon, H., 2006. Unravelling the contexts of stigma: from internalization to resistance to change. *Journal of Community & Applied Social Psychology*, 16(6), pp.411-417.

Casier, M., 2009. Contesting the 'truth' of Turkey's human rights situation: state-association interactions in and outside the Southeast. *European Journal of Turkish Studies*, 10, pp.2-19.

Castro, A. and Farmer, P., 2005. Understanding and addressing AIDS-related stigma: from anthropological theory to clinical practice in Haiti. *American Journal of Public Health*, 95(1), pp.53-59.

Çavdar, G., 2010. Islamist moderation and the resilience of gender: Turkey's persistent paradox. *Totalitarian Movements and Political Religions*, 11(3-4), pp.341-357.

Chiu, Y.C., 2011. Probing, impelling, but not offending doctors: the role of the internet as an information source for patients' interactions with doctors. *Qualitative Health Research*, 21(12), pp.1658-1666.

Choo, H.Y. and Ferree, M.M., 2009. Practicing intersectionality in sociological research: a critical analysis of inclusions, interactions and institutions in the study of inequalities. Forthcoming paper, disseminated at CEU Summer University Course: Feminist Intersectionality and Political Discourse, July 5-9, 2010 Budapest.

Christian Aid, 2008. *Condemned, invisible and isolated: stigma and support for people living with HIV in Khartoum*. [pdf] Available at: <<http://www.christianaid.org.uk/images/stigmatisation.pdf>> [Accessed 6 January 2013].

Cinsel Eğitim Tedavi ve Araştırma Derneği (CETAD) (The Organisation for Sexual Education, Treatment and Research), 2006. *Cinsel sağlık ve üreme sağlığı araştırması. (Sexual and reproductive health research)*. İstanbul: Cinsel Eğitim Tedavi ve Araştırma Derneği.

Clark, S., Bruce, J., and Dude, A., 2006. Protecting young women from HIV/AIDS: The case against child and adolescent marriage. *International Family Planning Perspectives*, 32(2), pp.79-88.

CNNTürk, 2011. "Sana mı kaldı? Bu bizim kendi sorunumuz" ("Mind your own business? This is our own problem"), 16 May 2011 [online] Available at: <<http://www.cnnturk.com/haberdetay/Print.aspx?NewsID=616911&popup=true&time..17/06/2011Yazd%C4%B1r>> [Accessed 16 May 2011].

Cockerham, W.C., 2001. Medical sociology and sociological theory. In: W.C. Cockerham, ed. *Blackwell companion to medical sociology*. Oxford: Blackwell, pp.3-22.

Çok, F., Gray, L.A. and Ersever, H., 2001. Turkish university students' sexual behaviour, knowledge, attitudes and perceptions of risk related to HIV/AIDS. *Culture, Health & Sexuality*, 3(1), pp.81-99.

Çokar, M., 2008. Türkiye'de CYBE/HIV/AIDS alanında STK'ların rolü ve yapısal özellikleri. (The role and structural features of NGOs in the field of STDs/HIV/AIDS in Turkey). *Türk HIV AIDS Dergisi*, 9(1), pp.29-32.

Çokar, M., 2012, 'Mahremiyet ihlali kamu zararına dönüsüyor' (Breaches of confidentiality cause damages to public) (interview), Interviewed by Ç. Tahaoglu. [online] bianet, 6 July 2012, Available at: <<http://www.bianet.org/bianet/saglik/139580-mahremiyet-ihlali-kamu-zararina-donusuyor>> [Accessed 6 July 2012].

Collins, P.H., 2003. Toward a new vision: race, class, and gender as categories of analysis and connection. In: M.S. Kimmel and A.L. Ferber (eds), *Privilege: a reader*. Cambridge, MA: Westview Press. pp.331-347.

Connell, R. and Messerschmidt, J.W., 2005. Hegemonic masculinity - rethinking the concept. *Gender & Society*, 19(6), pp.829-59.

Connell, R., 1987. *Gender and power*. Stanford, CA: Stanford University Press.

Connell, R., 2005. *Masculinities*. Cambridge: Polity Press.

Cornish, F., 2006. Empowerment to participate: a case study of participation by Indian sex workers in HIV prevention. *Journal of Community & Applied Social Psychology*, 16, pp.301-315.

Cornwall, A., Corrêa, S. and Jolly, S., 2008. *Development with a body: sexuality, human rights and development*. London: Zed.

Coşar, S. and Yeğenoğlu, M., 2011. New grounds for patriarchy in Turkey? Gender policy in the age of AKP. *South European Society and Politics*, 16(4), pp.555-573.

Courtenay, W.H., 2000. Constructions of masculinity and their influence on men's well-being: a theory of gender and health. *Social Science and Medicine*, 50, pp.1385-1401.

Crenshaw, K., 1997. Intersectionality and identity politics: learning from violence against women of color. In: M.L. Shanley and U. Narayan (eds), *Reconstructing political theory. Feminist perspectives*, Cambridge: Polity Press, pp.178-193.

Crisp, R.J. and Turner, R.N., 2010. *Essential social psychology*. London: Sage.

Crocker, J., Major, B., and Steele, C., 1998. Social stigma. In: D.T. Gilbert, S.T. Fiske and G. Lindzey, eds. *The Handbook of Social Psychology*. New York: McGraw Hill, pp.504-553.

Crotty, M.J., 2003. *The foundations of social research: meaning and perspective in the research process*. London: Sage Publications.

De Bruyn, T., 1998. *HIV/AIDS and discrimination: a discussion paper*. Canadian HIV/AIDS Legal Network and Canadian AIDS Society, Montréal. [online] Available at: <<http://www.aidslaw.ca/publications/publicationsdocEN.php?ref=46>> [Accessed 21 November 2012].

De Cock, K. M., and A. M. Johnson. 1998. From exceptionalism to normalization: a reappraisal of attitudes and practice around HIV Testing. *British Medical Journal*, 316, pp.290-293.

De Fina, A., Schiffrin, D. and Bamberg, M., 2006. *Discourse and identity*. Cambridge: Cambridge University Press.

Demir, Z., 1997. *Modern ve postmodern feminizm (Modern and postmodern feminisms)*. İstanbul: İz Yayıncıları.

Denis, A., 2008. Intersectional analysis - A contribution of feminism to sociology. *International Sociology*, 23(5), pp.677-694.

Denzin, N.K., 1997. *Interpretive ethnography: ethnographic practices for the 21st century*. London: Sage Publications.

Department for International Development (DFID), 2007. *Taking action against HIV stigma and discrimination - guidance document and supporting resources*. [online] Available at: <<http://www.aidsportal.org/repos/stigma%20guidance%20doc.pdf>> [Accessed 19 December 2009].

Dibb, B. and Kamlesh, T., 2011. Exploring positive adjustment in HIV positive African women living in the UK. *AIDS Care*, 24(2), pp.143-148.

Dibb, B. and Yardley, L., 2006. How does social comparison within a self-help group influence adjustment to chronic illness? A longitudinal study. *Social Science and Medicine*, 63(6), pp.1602-1613.

Doucet, A. and Mauthner, M., 2005. Knowing responsibly: linking ethics, research practice and epistemology. In: M. Mauthner, J. Jessop, T. Miller, and M. Birch, eds. *Ethics in qualitative research*. London: Sage Publications, pp.123-145.

Dovidio, J.F., Hewstone, M., Glick, P. and Esses V.M., 2010. *The Sage handbook of prejudice stereotyping and discrimination*. London: Sage.

Duyan, V., Ağalar, F. and Sayek, I., 2001. Surgeons' attitudes toward HIV/AIDS in Turkey. *AIDS Care*, 13(2), pp.243-250.

Duyan, V. and Yıldırım, G., 2004. Life after AIDS. *HIV/AIDS Review*, 3(2), pp.48-55.

Edwards, R. & Mauthner, M., 2005. Ethics and feminist research: theory and practice. In: M. Mauthner, J. Jessop, T. Miller, and M. Birch, eds. *Ethics in qualitative research*. London: Sage Publications, pp.14-31.

Ekuklu, G., Tuğrul, H., Gül, Eskiocak M. and Saltık A., 2004. Trakya Üniversitesi Tıp Fakültesi öğrencilerinin HIV/AIDS konusundaki bilgi-tutumları ve 1996'dan bu yana değişimi. (Changes in the knowledge and attitudes of the students of Trakya University Faculty of Medicine on HIV/AIDS since 1996), Türk HIV/AIDS Tıp Dergisi, October-November-December [Online]. Available at: <http://www.buhus.org/Materyal/aids_ogrenci.pdf> [Accessed 18 June 2006].

Epstein, S., 1995. The construction of lay expertise: AIDS activism and the forgoing of credibility in the reform of clinical trials. *Science, Technology and Human Values*, 20(4), pp.408-37.

Erci, B., 2007. Attitudes towards holistic complementary and alternative medicine: a

sample of healthy people in Turkey. *Journal of Clinical Nursing*, 16, pp.761-768.

Erdoğan, R.T. (PM), 4 May 2011, public speech, Available at: <http://www.sansursuzhaber.com/dunku-basbakanin-ozel-hayat-anlayisi_48139>.

Erkaymaz, S.Y., 2011. Stigma Index Turkey survey. Positive Living Association, *International Conference on HIV/AIDS: "Improving the National Response to HIV/AIDS"*. İstanbul, Turkey, May 26-27 2011.

Ertürk, Y., 2004. Considering the role of men in gender agenda setting: conceptual and policy issues. *Feminist Review*, 78, pp.3-21.

Ertürk, Y. 2004. Violence in the name of honour within the context of international regimes. In: S. Mojab and N. Abdo, eds. *Violence in the Name of Honour - Theoretical and political challenges*. İstanbul: Bilgi University Press. pp.165-176.

Ertürk, Y., 2005. Intersections of violence against women and HIV/AIDS. Report of the Special Rapporteur on violence against women, its causes and consequences. United Nations Commission on Human Rights. [Online]. Available at: <<http://daccess-dds-ny.un.org/doc/UNDOC/GEN/G05/102/11/PDF/G0510211.pdf?OpenElement>> [Accessed 7 October 2008].

Esmer, Y., 2011, *Türkiye değerler araştırması*, Bahçeşehir Üniversitesi, Available at: <<http://smgconnected.com/2011-turkiye-degerler-arastirmasi>>.

Evered, E.Ö. and Evered, K.T., 2011. Sex and the capital city: the political framing of syphilis and prostitution in early republican Ankara. *Journal of the History of Medicine and Allied Sciences*. pp.1-34.

Evered, K.T. and Evered, E.Ö., 2012. Syphilis and prostitution in the socio-medical geographies of Turkey's early republican provinces. *Health & Place*, 18(3), pp.528-535.

Fathalla, M., 2008. *Issues in women's health and rights: International, Arab regional and Egyptian perspectives*. Cairo: International Planned Parenthood Federation, Arab World Region.

Figueiras, M.J. and Alves, N.C., 2007. Lay perceptions of serious illnesses: an adapted version of the Revised Illness Perception Questionnaire (IPQ-R) for

healthy people. *Psychology and Health*, 22(2), pp.143-158.

Finn, M. and Sarangi, S., 2009. Humanizing HIV/AIDS and its (re)stigmatizing effects: HIV public 'positive' speaking in India. *Health*, 13(1), pp.143-158.

Fiori, K.L., Hays, J.C. and Meador, K.G., 2004. Spiritual turning points and perceived control over the life course. *International Journal of Aging and Human Development*, 59(4), pp.391-420.

Folkman, S. and Moskowitz, J.T., 2000. Positive affect and the other side of coping. *American Psychologist*, 55(6), pp.647-654.

Foucault, M., 1977. *Language, counter-memory, practice: selected essays and interviews*. Translated from French by D.F. Bouchard. Oxford: Basil Blackwell.

Foucault, M., 1980. *Power/Knowledge: selected interviews and other writings, 1972-1977*. NY: Pantheon Books.

Foucault, M., 1990 [1976]. *The history of sexuality Vol. 1: the will to knowledge*. London: Penguin.

Foucault, M., 2003 [1963]. *The birth of the clinic: archaeology of medical perception*. London: Routledge.

Gabe, J., Bury, M. and Elston, M. A., 2006. *Key concepts in medical sociology*. London: Sage Publications.

GFK Turkey & Pozitif Yaşam Derneği (Positive Living Association) (GFK/PYD), 2008. *HIV farkındalık araştırması raporu* (Report on HIV awareness research). [Online]. Available at: <http://www.pozitifyasam.org/e-bulten/ocak2009/ocakbulten_2009.htm> [Accessed 20 January 2010].

Ginsberg, P.E. and D.M. Mertens, 2009. Frontiers in social research ethics: fertile ground for evolution. In: D.M. Mertens and P.E. Ginsberg., eds. *The handbook of social research ethics*. Los Angeles: Sage, pp.580-613.

Goffman, E., 1963. *Stigma: notes on the management of spoiled identity*. Englewood Cliffs, NH: Prentice-Hall Inc.

GNP+ and Positive Living Association Turkey, 2010. People Living with HIV Stigma

Index in Turkey, poster presentation at 2010 International AIDS Conference, Vienna.

Gökengin, D. et al., (forthcoming) *Analysis of HIV/AIDS-related social stigma and discrimination in Turkey*.

Gönüllü, A., 2005. *Contemporary women's activism in engendering the political agenda: a case of legal reform in Turkey*. M.Sc. Gender and Women's Studies, Middle East Technical University.

Goudge J., Ngoma, B., Manderson, L. and Schneider, H., 2009. Stigma, identity and resistance among people living with HIV in South Africa. *Journal of Social Aspects of HIV/AIDS*, 6(3), pp.94-104.

Grbich, C., 1999. *Qualitative research in health: an introduction*. London: Sage.

Grbich, C., 2007. *Qualitative data analysis: an introduction*. London: Sage.

Guba, E.G. and Lincoln, Y.S., 1994. Competing paradigms in qualitative research. In: N.K. Denzin and Y.S. Lincoln, eds. *Handbook of qualitative research*. London: Sage Publications, pp.105-117.

Hacettepe University Institute of Population Studies, 2009. *Turkey Demographic and Health Survey, 2008*. Hacettepe University Institute of Population Studies, Ministry of Health General Directorate of Mother and Child Health and Family Planning, T.R. Prime Ministry Undersecretary of State Planning Organization and TÜBİTAK, Ankara, Turkey.

Hancock, A.M., 2007. When multiplication doesn't equal quick addition: examining intersectionality as a research paradigm. *Perspectives on Politics*, 5(1), pp.63-79.

Heper, M., 1985. *The state tradition in Turkey*. Beverley: Eothen.

Herek, G.M., 1999. AIDS and stigma. *American Behavioral Scientist*, 42(7), pp.1106-1116.

Herek, G.M., 2004. Beyond homophobia: thinking about sexual stigma and prejudice in the twenty-first century. *Sexuality Research and Social Policy*, 1(2), pp.6-24.

Holliday, A., 2007. *Doing and writing qualitative research*. London: Sage.

Howarth, C., 2006. Race as stigma: positioning the stigmatized as agents, not objects. *Journal of Community & Applied Social Psychology*, 16(6), pp.442-451.

Hughes, I., 2000. How to keep a research diary. *Action Research E-Reports*, [Online]. 5, Available at: <<http://www2.fhs.usyd.edu.au/arow/arer/pdf%20e-Report%20version/005.pdf>> [Accessed 30 October 2009].

İlkkaracan, İ. and Ronge, K., 2008. Integrating sexuality into gender and human rights frameworks: a case study from Turkey. In: A. Cornwall, S. Correa and S. Jolly, eds. *Development with a body: sexuality, human rights and development*. London: Zed Books. Ch.18.

İlkkaracan, P., 1998. Exploring the context of women's sexuality in eastern Turkey. *Reproductive Health Matters*, 6(12), pp.66-75.

Independent.co.uk 'Abortions are like air strikes on civilians', 30 May 2012, Available at: <<http://www.independent.co.uk/life-style/health-and-families/health-news/abortions-are-like-air-strikes-on-civilians-turkish-pm-recep-tayyip-erdogans-rant-sparks-womens-rage-7800939.html>> [Accessed 2 June 2012].

İnsan Kaynağını Geliştirme Vakfı (İKGV), 2011. *Seks işçileri ve yasalar: Türkiye'de yasaların seks işçilerine etkisi ve öneriler* (Law and sex workers: the effects of law on sex workers in Turkey and advices). İstanbul.

International AIDS Society (IAS), 2010. *Annual Report*. [pdf] Available at: <http://www.iasociety.org/Web/WebContent/File/IAS_annual_report_2010.pdf> [Accessed 6 January 2013].

Jessop, B., 2007. From micro-powers to governmentality: Foucault's work on statehood, state formation, statecraft and state power. *Political Geography*, 26(1), pp.34-40.

Joffe, H., 1997. The relationship between representational and material perspectives. In: A. Yardley, ed. *Material discourses of health and illness*. London: Routledge, pp.132-149.

Joffe, H., 1999. Social representations and the AIDS field. *Psychology in Society*, 24, pp.21-39.

Judge, M., 2005. *The contemporary construction of the causality of HIV/AIDS: a discourse analysis and its implications for understanding national policy statements on the epidemic in South Africa*. MA. University of the Western Cape.

Kadın Adayları Destekleme Derneği (KADER) (Association for the Support of Women Candidates), 2011. Kadından Sorumlu Devlet Bakanlığının Kapatılmasına Karşıyız, press release, Available at: <<http://www.kader.org.tr/tr/basin.php?act=sayfa&id00=116&id01=81&menu=>>

Kandiyoti, D., 1988. Bargaining with patriarchy. *Gender & Society*, 2, pp.274-290.

Kaplan, S., 2008. *Türkiye ve Avrupa Birliği'nde HIV/AIDS politikaları (HIV/AIDS policies in Turkey and in European Union)*. Ankara Üniversitesi Avrupa Toplulukları Araştırma ve Uygulama Merkezi (ATAUM), Ankara.

Kapusuz, S., 2012, 'İnsan Hakları Günü' mesajı (The Message for the Day of Human Rights) Adalet ve Kalkınma Partisi (Justice and Development Party) [online] Available at: <<http://www.akparti.org.tr/site/haber/17212/insan-haklari-gunu-mesaji/baskanliklar>> [Accessed 11 December 2012].

Karataş, S. 2011. Stigma Index Turkey results, workshop presentation at *HIV in European Region - Unity and Diversity*, 25-27 May 2011, Tallinn.

Kasapoğlu, A. and Kuş, E., 2008. The role of gender in the stigmatization of people living with HIV/AIDS in Turkey. *Journal of Gender Studies*, 17(4), pp.359-368.

Keyder, Ç., Üstündağ, N., Ağartan, T. and Yoltar, Ç., 2007. *Avrupa'da ve Türkiye'de sağlık politikaları: reformlar, sorunlar, tartışmalar*. (Health policies in Europe and in Turkey: reforms, problems, debates). İstanbul: İletişim.

Koch, T., Jenkin, P. and Kralik, D., 2004. Chronic illness self-management: locating the 'self'. *Journal of Advanced Nursing*, 48(5), pp.484-492.

Kralik, D., Koch, T. and Price, K., 2004. Chronic illness self-management: taking action to create order. *Journal of Clinical Nursing*, 13(2), pp.259-267.

Kremer, H., Ironson, G. and Kaplan, L., 2009. The fork in the road: HIV as a potential positive turning point and the role of spirituality. *AIDS Care*, 21(3), pp.368-77.

Kuhlmann, E. and Babitsch, B., 2002. Bodies, health, gender-bridging feminist theories and women's health. *Women's Studies International Forum*, 25(4), pp.433-442.

Kusow, A.M., 2007. Stigma. In: G. Ritzer, ed. *Blackwell encyclopaedia of sociology*. Blackwell Publishing, 2007. [Online] Available at: <http://www.sociologyencyclopedia.com/subscriber/tocnode?id=g9781405124331_chunk_g978140512433125_ss1-264> [Accessed 13 August 2008].

Law, I. 2007. Discrimination. In: G. Ritzer, ed. *Blackwell encyclopaedia of sociology*. Blackwell Publishing, 2007. [Online] Available at: <http://www.sociologyencyclopedia.com/subscriber/tocnode?id=g9781405124331_chunk_g978140512433110_ss2-27> [Accessed 13 August 2008].

Levy, D.P., 2007. Patriarchy. In: G. Ritzer, ed. *Blackwell encyclopaedia of sociology*. Blackwell Publishing, 2007. [Online] Available at: <http://www.blackwellreference.com/public/tocnode?id=g9781405124331_chunk_g978140512433122_ss1-10> [Accessed 13 August 2008].

Link, B.G. and Phelan, J.C., 2001. Conceptualizing stigma. *Annual Review of Sociology*, 27, pp.363-85.

Livneh, H. and Martz, E., 2007. An introduction to coping theory and research. In: H. Livneh and E. Martz, eds. *Coping with chronic illness and disability, theoretical, empirical, and clinical aspects*. NY: Springer, pp.3-28.

Mağden, D., Şahin, S., Metin, F. and Akkaya F., 2003. Lise son sınıfa devam eden öğrencilerin AIDS hakkındaki bilgi düzeylerinin incelenmesi (Investigation of the level of knowledge of senior high school students on AIDS), *Eğitim ve Bilim*, 28(127), pp.31-36.

Mahajan, A.P., Sayles, J.N., Patel, V.A., Remien, R.H., Sawires, S.R., Ortiz, D.J., Szekeres, G. and Coates, T.J., 2008. Stigma in the HIV/AIDS epidemic: a review of the literature and recommendations for the way forward, *AIDS*, 22, pp.67-79.

Makoae, L.N., Portillo, C.J., Uys, L.R., Dlamini, P.S., Greeff, M., Chirwa, M., Kohi, T.W., Naidoo, J., Mullan, J., Wantland, D., Durrheim, K. and Holzemer, W.L., 2009. The impact of taking or not taking ARVs on HIV stigma as reported by persons living with HIV infection in five African countries. *Aids Care - Psychological and*

Socio-Medical Aspects of AIDS/HIV, 21(11), pp.1357-1362.

Martin, J.K., Lang, A. and Olafsdottir, S., 2008. Rethinking theoretical approaches to stigma: a framework integrating normative influences on stigma (FNIS), *Social Science and Medicine*, 67(3), pp. 431-440.

Mason, G., 2001. Body maps: envisaging homophobia, violence and safety. *Social and Legal Studies*, 10, pp.23-44.

Mason, J., 2002. *Qualitative researching*. London: Sage.

McCall, L., 2005. The complexity of intersectionality. *Journal of Women in Culture and Society*, 30(3), pp. 1771-1800.

Medimagazin, 2011. Doktorlar hastayı AIDS'li diye ameliyat etmiyor iddiası (A claim of a refusal by doctors to treat a patient with AIDS). 8 August 2011 [online] Available at: <<http://www.medimagazin.com.tr/hekim/hukuk-etik/tr-doktorlar-hastay-aidsli-diye-ameliyat-etmiyor-iddias-2-17-36673.html>> [Accessed 8 August 2011].

Miller, J.F., 1989. Patient power resources. In: J.F. Miller, ed. *Coping with chronic illness: overcoming powerlessness*. Philadelphia: F.A. Davis Company, pp.3-13.

Miller, T. and Bell, L., 2005. Consenting to what? Issues of access, gate-keeping and 'informed consent'. In: M. Mauthner et al., eds. *Ethics in qualitative research*. London: Sage, pp.53-69.

Ministry of Health of Turkey (MOH), 2006. *Data on HIV/AIDS in Turkey / 1985-2006*. Temel Sağlık Hizmetleri Genel Müdürlüğü (Directorate-General on Primary Health Care Services), Ankara.

Ministry of Health of Turkey (MOH), 2007. *Cinsel Sağlık ve Üreme Sağlığı Hizmet Standartları* (The Standards for the Service of Sexual Health and Health of Reproduction). Ankara: T.C. Sağlık Bakanlığı (The Ministry of Health of Turkish Republic).

Ministry of Health of Turkey (MOH), 2008a. *Country Progress Report to UNGASS*. [Online] Available at: <<http://www.msmgf.org/documents/NorthAfrica/Government/TurkeyMinistryfHealthCountryPrgressReprt.pdf>> [Accessed 10 March 2010].

Ministry of Health of Turkey (MOH), 2008b. *Data on HIV/AIDS in Turkey / 1985-2008*. Temel Sağlık Hizmetleri Genel Müdürlüğü (Directorate-General on Primary Health Care Services), Ankara.

Moss-Morris, R., Weinman, J., Petrie, K. J., Horne, R., Cameron, L. D. and Buick, D., 2002. The Revised Illness Perception Questionnaire (IPQ-R). *Psychology and Health*, 17(1), pp.1-16.

Mother and Child Health and Family Planing General Directorate (MCHFP) (Ana Çocuk Sağlığı ve Aile Planlaması Genel Müdürlüğü), 2005. *Cinsel sağlık ve üreme sağlığı ulusal stratejik eylem planı*. (The national strategic action plan on sexual and reproductive health). Ankara: Ana Çocuk Sağlığı ve Aile Planlaması Genel Müdürlüğü.

Mullings, L. & Schulz, A.J., 2006. Intersectionality and health: an introduction. In: A.J. Schulz & L. Mullings, eds. *Gender, race, class, and health: intersectional approaches*. USA: Jossey-Bass, pp.3-17.

Musheke, M., Bond, V. and Merten, S., 2012. Individual and contextual factors influencing patient attrition from antiretroviral therapy care in an urban community of Lusaka, Zambia. *Journal of the International AIDS Society*, 15(S1), pp.1-9.

Nadin, S. and Cassell, C., 2006. The use of a research diary as a tool for reflexive practice. *Qualitative Research in Accounting & Management*, 3(3), pp.208-217.

Namal, A., 2003. The death of a patient with AIDS in Turkey: thought on the ethical dimensions. *Nurse Ethics*, 10, pp.497-503.

NTVMSNBC, 2012. Erdoğan: Sezaryenle iki çocuktan fazla olmaz (Erdoğan: No one can have more than two kids with caesarean section), 29 May 2012. [online] Available at: <<http://www.ntvmsnbc.com/id/25353517/>> [Accessed 29 May 2012].

Official Gazette, 25 May 2010:27591, Family Medicine legislation. Available at: <http://www.ailehekimligi.gov.tr/index.php?option=com_content&view=article&id=257:aile-hekimlii-uygulama-yoynetmelii-resmi-gazete-tarih-25-mays-2010-say-27591-&catid=42:yoynetmelikler&Itemid=223> [Accessed 29 May 2012].

Ogden, J. & Nyblade, L., 2005. Common at its core: HIV-related stigma across contexts. International Center for Research on Women (ICRW) [online] Available at: <http://www.icrw.org/docs/2005_report_stigma_synthesis.pdf> [Accessed 19

September 2009].

Öğün-Boyacıoğlu, A. and Türkmen, A., 2008. Social and cultural dimensions of pregnancy and childbirth in eastern Turkey. *Culture Health & Sexuality*, 10(3), pp.277-285.

Öğuzkaya, M.A. and Güleser, G.N., 2006. Sağlık okulu öğrencilerinin HIV/AIDS, hepatit-B virüsü ve hepatit-C virüsü konusundaki bilgi düzeylerinin değerlendirilmesi (Evaluation of the level of knowledge of medical school students on HIV/AIDS, Hepatitis B and C), *Erciyes Tıp Dergisi*, 28(3), pp.125-133.

Okan, N. and İrgil, E., 1993. Sağlık personelinin AIDS konusundaki bilgi ve tutumları (Knowledge and attitudes of health workers on AIDS). In: *1st Turkey AIDS Congress*. İstanbul, Turkey, 12-15 January 1993. İstanbul: Omaş Ofset.

Öktem, K., 2008. Another struggle: sexual identity politics in unsettled Turkey. *Middle East Report*, [Online]. Available at: <http://www.merip.org/mero/interventions/oktem_interv.html> [Accessed 24 January 2009].

Öktem, P., 2008. Understanding and challenging HIV/AIDS related stigma in Turkey: perceptions and experiences of professionals working in HIV/AIDS treatment, prevention, and care programs. *ISA RC15 & CMSA Inaugural Meeting: Making Connections for Health*. McGill University, Montréal, Canada 13-16 May 2008.

Öktem, P., 2011. Interpretation of findings from PLHIV Stigma Index in Turkey. Positive Living Association, *International Conference on HIV/AIDS: "Improving the National Response to HIV/AIDS"*, İstanbul, Turkey, May 26-27 2011.

Özbek, M., 2010. The regulation of prostitution in Beyoğlu (1875–1915). *Middle Eastern Studies*, 46(4), pp.555-568.

Özçelik-Adak, N. 2002. *Sağlık sosyolojisi, kadın ve kentleşme (Sociology of health, women and urbanisation)*. İstanbul: Birey.

Özlü, A., 2012. Türkiye'de HIV/AIDS epidemiyolojisi (The HIV/AIDS epidemiology in Turkey). *Clinic HIV/AIDS Symposium*. Kapadokya, Turkey, 23-25 November 2012, Available at: <<http://hiv-aids2012.naklenkongre.com/>>.

Parker, R. and Aggleton, P., 2003. HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Social Science & Medicine*, 57(1), pp.13-24.

Paterson, B.L., 2001. The shifting perspectives model of chronic illness. *Journal of Nursing Scholarship*, 33(1), pp.21-26.

Phelan, J.C., Link, B.G. and Dovidio, J.F., 2008. Stigma and prejudice: one animal or two?, *Social Science and Medicine*, 67, pp.358-367.

Plummer, K., 2006. Rights work: constructing lesbian, gay and sexual rights in late modern times. In: L. Morris, ed. 2006. *Rights: sociological perspectives*. Oxon: Routledge, pp.152-167.

Pozitif Yaşam Derneği (Positive Living Association), 2007. Türkiye'de HIV ile Yaşayanların Yaşadıkları Hak İhlalleri Raporu. (Report on the violation of rights of people living with HIV in Turkey) Available at: <<http://www.pozitifyasam.org/index.php?contentId=185>> [Accessed November 2007].

Pozitif Yaşam Derneği (Positive Living Association), 2008. News and summary of "Türkiye'de HIV ile yaşayan insanların hassasiyet/savunmasızlık durumunun Değerlendirmesi" (Evaluation of the vulnerability situation of PLHIV in Turkey) report, Available at: <<http://www.pozitifyasam.org/index.php?contentId=228>> [Accessed January 2008].

Pozitif Yaşam Derneği (Positive Living Association), 2009. HIV ile yaşayan bireyler için destek hizmetlerinin yaygınlaştırılması projesi (Projects document - improvement of the support services for PLHIV). [Online]. Available at: <<http://www.pozitifyasam.org/publishDocument.php?id=943>> [Accessed 10 March 2010].

Pozitif Yaşam Derneği (Positive Living Association), 2010. Türkiye'de HIV ile yaşayanların yaşadıkları hak ihlalleri raporu. (Report on the violation of rights of people living with HIV in Turkey) Available at: <<http://www.pozitifyasam.org/index.php?contentId=185>> [Accessed November 2010].

Rahmati-Najarkolaei, F., Niknami, S., Aminshokravi, F., Bazargan, M., Ahmadi, F.,

Hadjizadeh, E. and Tavafian, S.S., 2010. Experiences of stigma in healthcare settings among adults living with HIV in the Islamic Republic of Iran. *Journal of the International AIDS Society*, 13(27), pp.1-11.

Rebecca J. Cook, Bernard M. Dickens, and Mahmoud F. Fathalla, 2003. *Reproductive health and human rights integrating medicine, ethics, and law*. Clarendon Press.

Reidpath, D.D. and Chan, K.Y., 2005. A method for the quantitative analysis of the layering of HIV-related stigma. *AIDS Care*, 17(4), pp.425-432.

Richards, L., 2006. *Handling qualitative data: a practical guide*. London: Sage.

Riessman, C.K., 2000. Stigma and everyday resistance practices - childless women in South India. *Gender & Society*, 14(1), pp.111-135.

Riessman, C.K., 2000. Analysis of personal narratives. In: J.F. Gubrium and J.A. Holstein, eds. *Handbook of interviewing*. London: Sage.

Robins, S., 2004. 'Long Live Zackie, Long Live': AIDS activism, science and citizenship after Apartheid. *Journal of Southern African Studies*, 30(3), pp.651-672.

Robins, S., 2005. *Rights passages from "near death" to "new life": AIDS activism and treatment testimonies in South Africa*. IDS Working Paper 251. Brighton: Institute of Development Studies.

Rose, N. and Novas, C., 2005. Biological citizenship. In: A. Ong and S. Collier, eds. *Global assemblages: technology, politics and ethics as anthropological problems*. Oxford: Blackwell, pp. 439-463.

Rose, R. & Özcan, Y. 2007. *First European quality of life survey: quality of life in Turkey*. Luxembourg: Office for Official Publications of the European Communities.

Roudi-Fahimi, F., 2007. *Time to intervene: preventing the spread of HIV/AIDS in the Middle East and North Africa*. Washington: Population Reference Bureau.

Roura, M., Urassa, M., Busza, J., Mbata, D., Wringe, A. and Zaba, B., 2009. Scaling up stigma? The effects of antiretroviral roll-out on stigma and HIV testing: early evidence from rural Tanzania. *Sexually Transmitted Infections*, 85(4), pp.308-312.

Russell, S. & Seeley, J., 2010. The transition to living with HIV as a chronic condition in rural Uganda: working to create order and control when on antiretroviral therapy. *Social Science & Medicine*, 70(3), pp.375-82.

Saengtienchai, C. and Knodel, J., 2001. Parents providing care to adult sons and daughters with HIV/AIDS in Thailand. [pdf] Geneva: UNAIDS. Available at: <<http://www.hivpolicy.org/Library/HPP000709.pdf>> [Accessed 29 December 2012].

Şahin T.K. et al., 2000. Selçuk Üniversitesi Tıp Fakültesi hastanesinde görevli hemşirelerin AIDS konusundaki bilgi ve tutumlarının değerlendirilmesi (Evaluation of knowledge and attitudes of the nurses working in Selçuk University Medical Faculty Hospital on AIDS). *Selçuk Üniversitesi Tıp Fakültesi Dergisi*, 16(3), pp.139-150.

Scambler, G., 2009. Health-related stigma. *Sociology of Health and Illness*, 31(3), pp.441-455.

Schaller, M. and Neuberg, S.L., 2012. Danger, disease, and the nature of prejudice(s). *Advances in Experimental Social Psychology*, 46, pp.1-54.

Schumaker, L.L. and Bond, V.A., 2008. Antiretroviral therapy in Zambia: colours, 'spoiling', 'talk' and the meaning of antiretrovirals. *Social Science & Medicine*, 67(2008), pp.2126–2134.

Schüssler, G., 1992. Coping strategies and individual meanings of illness. *Social Science & Medicine*, 34(4), pp.427-432.

Schwarzer, R. and Knoll, N., 2003. Positive coping: mastering demands and searching for meaning. In: S.J. Lopez and C.R. Snyder, eds. 2003. *Positive psychological assessment: a handbook of models and measures*, Washington DC: American Psychological Association, pp.393-409.

Scott-Samuel, A., Stainistreet, D. and Crawshaw, P., 2009. Hegemonic masculinity, structural violence and health inequalities. *Critical Public Health*, 19(3), pp.287-292.

Seeley, J., Grellier, R. and Barnett, T., 2004. Gender and HIV/AIDS impact mitigation in sub-Saharan Africa - recognising the constraints. *Sahara*, 1(2), pp.87-98.

Seeley, J., Russell, S., Khana, K., Ezati, E., King, R. and Bunnell, R., 2009. Sex

after ART: sexual partnerships established by HIV-infected persons taking anti-retroviral therapy in Eastern Uganda. *Culture, Health & Sexuality*, 11(7), pp.703-716.

Seeley, J., Mbonye, M., Ogunde, N., Kalanzi, I., Wolff, B. and Coutinho, A., 2011. HIV and identity: the experience of AIDS support group members who unexpectedly tested HIV negative in Uganda. *Sociology of Health and Illness*, 34(3), pp.330-344.

Seidel, G., 1993. The competing discourses of HIV/AIDS in sub-Saharan Africa: discourses of rights and empowerment vs. discourses of control and exclusion. *Social Science and Medicine*, 36(3), pp.175-194.

Seidman, S., 1988. Transfiguring sexual identity: AIDS and the contemporary construction of homosexuality. *Social Text*, 19/20(Fall), pp.187-205.

Sharpe, L. and Curran, L., 2006. Understanding the process of adjustment to illness. *Social Science & Medicine*, 62(5), pp.1153-1166.

Shih, M., 2004. Positive stigma: examining resilience and empowerment in overcoming stigma. *Annals of the American Academy of Political and Social Science*, 591, pp.175-185.

Silver, H., 2007. Social exclusion. In: G. Ritzer, ed. *Blackwell encyclopaedia of sociology*. Blackwell Publishing, 2007. [Online] Available at: <http://www.sociologyencyclopedia.com/subscriber/tocnode?id=g9781405124331_chunk_g978140512433125_ss1-150> [Accessed 13 August 2008].

Silversides, A., 2003. *AIDS activist*. Toronto: Between the Lines.

Sirman, N., 2004. Kinship, politics, and love: Honour in post-colonial contexts - the case of Turkey. In: S. Mojab and N. Abdo, eds. *Violence in the Name of Honour - Theoretical and political challenges*. İstanbul: Bilgi University Press. pp.39-56.

Siu, G., Wight, D., and Seeley, J., 2012. How a masculine work ethic and economic circumstances affect uptake of HIV treatment: experiences of men from an artisanal gold mining community in rural Eastern Uganda. *Journal of International AIDS Society*, [online] Available at: <<http://www.jiasociety.org/index.php/jias/article/view/17368>> [Accessed 22 June 2012].

Sontag, S., 2005. *Metafor olarak hastalık - AIDS ve metaforları* (Illness and Metaphors – AIDS and its metaphors) (London: Penguin, 1991), İstanbul: Agora.

Sprague, L., 2011. *HIV related stigma: late testing, late treatment*. [pdf] Available at:<<http://www.hiveurope.eu/LinkClick.aspx?fileticket=b1TcnGeKYno=&tabid=74>> [Accessed 6 January 2013].

Sprangers, M. and Schwartz, C., 1999. Integrating response shift into health-related quality of life research: a theoretical model. *Social Science & Medicine*, 48(11), pp.1507-1515.

Ssali, S.N., Atuyambe, L., Tumwine, C., Seguija, E., Nekesa, N., Nannungi, A., Ryan, G. and Wagner, G., 2010. Reasons for disclosure of HIV status by people living with HIV/AIDS and in HIV care in Uganda: an exploratory study. *AIDS Patient Care and STDs*, 24, pp.1-7.

St. George's Healthcare, 2009. NHS Trust 2009 Guidelines for HIV testing in adults policy no: Clin.5.22, Version No: 3.2.

Stacey, M., 1988. *The sociology of health and healing*. London: Unwin Hyman.

Stevens, P.E. and Hildebrandt, E., 2009. Pill taking from the perspective of HIV-infected women who are vulnerable to antiretroviral treatment failure. *Qualitative Health Research*, 19(5), pp.593-604.

Sussman, A.L., 2011. Dimming the red lights in Turkey, New York Times, [online] Available at: <http://www.nytimes.com/2011/08/21/magazine/dimming-the-red-lights-in-turkey.html?_r=0> [Accessed 29 December 2012].

Swendeman, D., Ingram, B.L., Rotheram-Borus, M.J., 2009. Common elements in self management of HIV and other chronic illnesses: an integrative framework. *AIDS Care*, 21(10), pp.1321-1334.

Taylor, B., 2001. HIV, stigma and health: integration of theoretical concepts and the lived experiences of individuals. *Journal of Advanced Nursing*, 35(5), pp.792-798.

Telford, K., Kralik, D. and Koch, T., 2006. Acceptance and denial: implications for people adapting to chronic illness: literature review. *Journal of Advance Nursing*, 55(4), pp.457-464.

The Global Fund to Fight AIDS, Tuberculosis and Malaria, 2008. *Grant Performance Report: Turkey TUR-405-G01-H* [pdf] Available at: <www.theglobalfund.org/grantDocuments/TUR-405-G01-H_GPR_0_en-2.pdf> [Accessed 6 January 2013].

The Global Fund to Fight AIDS, Tuberculosis and Malaria, 2008. *Program Grant Agreement Number TUR-405-G01-H, Grant Closure Letter*. [letter] (communication from W. Paton to R. Akdağ, Minister of Health, 3 December 2008).

The Global Fund to Fight AIDS, Tuberculosis and Malaria, 2012. *Turkey, Eastern Europe and Asia: Regional Grant Portfolio* [pdf] Available at: <<http://portfolio.theglobalfund.org/en/Country/Index/TUR>> [Accessed 6 January 2013].

The Institution of Statistics of Turkey (TUİK), 2011. *Adrese Dayali Nufus Kayıt Sistemi Sonuçları*. no: 10736.

The Social Research Association, 2003. Ethical Guidelines.

Trainor, A. and Ezer, H., 2000. Rebuilding life: the experience of living with AIDS after facing imminent death. *Qualitative Health Research*, 10, pp.646-660.

Toprak, B., 2009. *Being different in Turkey: Religion, conservatism and otherization*. İstanbul: Boğaziçi University, Open Society Foundation.

Tümer, A., 2009. HIV/AIDS epidemiyolojisi ve korunma (HIV/AIDS epidemiology and protection). HATAM. [online]. Available at: <<http://www.hatam.hacettepe.edu.tr/EpidwebAT2011.pdf>> [Accessed 10 March 2010].

Turkish Statistics Institute (TSI), 2009. Birth statistics for the year of 2001 – 2008. [Press Release] Number 180, 14 October 2009, General Directorate of Population and Citizenship Affairs [Online] Available at: <www.turkstat.gov.tr> [Accessed 17 August 2011].

Ukockis, G.L., 2007. *Informal HIV/AIDS caregivers: a study of their decision-making experiences and perspectives*. PhD. The Ohio State University.

UNAIDS, 2006a. *2006 Report on the Global AIDS epidemic: Executive Summary*. Geneva: Joint United Nations Programme on HIV/AIDS.

UNAIDS, 2006b. *Men having sex with men and human rights - the UNAIDS perspective*. Statement to ILGA World Conference by Susan Timberlake, Senior Law and Human Rights Adviser UNAIDS. Geneva, 29 March 2006. Available at: <http://data.unaids.org/pub/Speech/2006/20060508_SP_Timberlake_ILGA_en.pdf> [Accessed 6 January 2013].

UNAIDS, 2007. *Country Situation Analysis / Turkey*. [Online]. Available at: <<http://www.unaids.org/en/CountryResponses/Countries/turkey.asp>> [Accessed 10 May 2008].

UNAIDS, 2008a. *Turkey UNGASS - National Composite Policy Index (NCPI) 2007 Report*. [Online]. Available at: <http://data.unaids.org/pub/Report/2008/turkey_2008_ncpi_en.pdf> [Accessed 10 March 2010].

UNAIDS, 2008b. *UNAIDS terminology guidelines*. [Online]. Available at: <http://data.unaids.org/pub/Manual/2008/jc1336_unaids_terminology_guide_en.pdf> [Accessed 15 May 2008].

UNAIDS, 2009. *AIDS epidemic update*. [Online]. Available at: <http://data.unaids.org/pub/Report/2009/JC1700_Epi_Update_2009_en.pdf> [Accessed 24 November 2009].

UNAIDS, 2010. *Key populations*. [Online]. Available at: <<http://www.unaids.org/en/PolicyAndPractice/KeyPopulations/default.asp>> [Accessed 5 January 2010].

UNAIDS, 2010 Quarterly Update on HIV Epidemiology, 2010. *Methods for Estimating HIV Incidence*. Switzerland: UNAIDS.

UNAIDS/WHO, 2008. *Adult (15-49) HIV prevalence percent by country, 1990-2007. 2008 report on the global AIDS epidemic*. [Online]. Available at: <<http://www.unaids.org/en/KnowledgeCentre/HIVData/Epidemiology/latestEpiData.asp>> [Accessed 19 January 2010].

Ünsal, A., 1999. Eskişehir'deki sağlık kuruluşlarında çalışan hemşirelerin AIDS hakkındaki bilgi düzeyi (Level of knowledge of nurses working in health institutions in Eskişehir on AIDS). *Genel Tıp Dergisi*, 9(2), pp.53-58.

van Brakel, W., 2005. Measuring health-related stigma - a literature review. Royal 300

Tropical Institute / KIT Publications, [Online]. Available at: <<http://www.kit.nl/smartsite.shtml?id=2543>> [Accessed 16 November 2007].

van der Zee, K., Buunk, B., Sanderman, R., Botke, G. and van den Bergh, F., 2000. Social comparison and coping with cancer treatment. *Personality and Individual Differences*, 28(1), pp.17-34.

Vatan Gazetesi, 2004. Zina suç olursa AIDS olmazsınız! (If adultery is a criminal offence, you will not get AIDS!). Vatan, 11 September 2004 [online] Available at: <<http://haber.gazetevatan.com/0/35787/1/Haber>> [Accessed 6 January 2013].

Volker, D.L. and Wu, H.L., 2011. Cancer patients' preferences for control at the end of life. *Qualitative Health Research*, 21(12), pp.1618-1631.

Wamoyi, J., Mbonye, M., Seeley, J., Birungi, J. and Jaffar, S., 2011. Changes in sexual desires and behaviours of people living with HIV after initiation of ART: implications for HIV prevention and health promotion. *BMC Public Health*, 11(633), pp.1-11.

Watkins-Hayes, C., Pittman-Gay, L. and Beaman, J., 2010. 'Dying from' to 'living with': framing institutions and the coping processes of African American women living with HIV/AIDS. *Social Science & Medicine*, 74(12), pp.2028-2036.

Weber, L., 2006. Reconstructing the landscape of health disparities research: promoting dialogue and collaboration between feminist intersectional and biomedical paradigms. In: A.J. Schulz and L. Mullings, eds. *Gender, race, class, and health: intersectional approaches*. San Francisco, CA: Jossey-Bass, pp.3-17.

Weinman, J., Petrie, K.J., Moss-Morris, R. and Horne, R., 1996. The Illness Perception Questionnaire: A new method for assessing the cognitive representation of illness. *Psychology and Health*, 11, pp.431-445.

Weitz, R., 1990. Living with the stigma of AIDS. *Qualitative Sociology*, 13, pp.23-38.

Wengraf, T., 2006. *Qualitative research interviewing*. London: Sage.

Wengraf, T., 2009. BNIM short guide bound with the detailed manual. Version [9.12a] [724]-pages. [For a free updated copy, write to tom@tomwengraf.com].

West, C. and Fenstermaker, S., 1995. Doing difference. *Gender and Society*, 9(1), pp.8-37.

Whiteside, A., Barnett, T., George, G. and Niekerk, A.A., 2003. Through a glass, darkly: data and uncertainty in the AIDS debate. *Developing World Bioethics*, 3(1), pp.49-76.

Wiles, R., Crow, G., Charles, V. and Heath S., 2007. Informed consent and the research process: following rules or striking balances?, *Sociological Research Online*, 12(2). Available at: <<http://www.socresonline.org.uk/12/2/wiles.html>> [Accessed 16 November 2009]

Williams, G., 1984. The genesis of chronic illness: narrative re-construction. *Sociology of Health and Illness*, 6(2), pp.175-200.

Williams, G.H., Popay, J. and Bissell P., 1995. Public health risks in the material world: barriers to social movements in health. In: J. Gabe, ed. *Medicine, health, and risk: sociological approaches*. Oxford: Blackwell, pp.113-132.

Williams, S.J., 1999. Is anybody there? Critical realism, chronic illness and the disability debate. *Sociology of Health & Illness*, 21(6), pp.797-819.

Williams, S.J., 2006. Medical sociology and the biological body: where are we now and where do we go from here? *Health*, 10(1), pp.5-30.

Wills, T. A., 1981. Downward comparison principles in social psychology. *Psychological Bulletin*, 90, pp.245-271.

Wilton, T., 1997. *Engendering AIDS. Deconstructing sex, text and epidemics*. London: Sage.

World Health Organization (WHO), 2003. *Integrating gender into HIV/AIDS programmes: a review paper*. Department of Gender and Women's Health, Family and Community Health.

Wyrod, R., 2011. Masculinity and the persistence of AIDS stigma. *Culture, Health and Sexuality*, 13(4), pp.443-456.

Yoshioka, M.R. and Schustack, A., 2001. Disclosure of HIV status: cultural issues of Asian patients. *AIDS Patient Care and STDs*, 15(2), pp.77-82.

Zengin, A. 2011. *İktidarin mahremiyeti, İstanbul'da hayat kadınları, seks işçiliği ve şiddet. (The privacy of power. Sex workers, sex work and violence in İstanbul)*. İstanbul: Metis.

Zukoski, A.P. and Thorburn, S., 2009. Experiences of stigma and discrimination among adults living with HIV in a low HIV-prevalence context: a qualitative analysis. *AIDS Patient Care and STDs*, 23(4), pp. 267-276.