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HIV and Young People:  
Perceptions of Risk, Resilience and Dignity in an Urban Slum

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A thesis submitted for the degree of Doctor of Philosophy  
in the College of Arts, Society and Education

James Cook University

March 2019

## **Declaration**

I declare that this thesis is my own work and has not been submitted in any form for another degree or diploma at any university or other institution of tertiary education. Information derived from the published or unpublished work of others has been acknowledged in the text and a list of references is given.

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## Statement of the Contributions of Others

Nature of assistance	Contribution	Names, titles and affiliations of co-contributors
Intellectual support	<p>Advisory Team advised on study design, analysis and reporting within the remit of their roles</p> <p>Proofreading of thesis</p> <p>Qualitative and mixed research in Africa; research protocols, Kenya</p> <p>Questions and Indicators on Humiliation Studies</p>	<p>Professor Komla Tsey, James Cook University Adjunct Associate Professor Debra Graham, James Cook University Professor Johannes John-Langba, Cape Town University</p> <p>Elite Editing. Editorial intervention was restricted to Standards D and E of the Australian Standards for Editing Practice</p> <p>Jani de Kock, First Person Research, Pretoria, South Africa</p> <p>Linda Hartling, Human Dignity and Humiliation Studies</p>
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Asanteni Sana.

## **Dedication**

To family and friends lost to AIDS and those now living with HIV  
And doing so without fear or prejudice

## **For**

My father, Howell E Jones, who knew no bounds

And, my children, Benjamin and Amy, that they may live in a world free of AIDS

## **Abstract**

Young people are at the centre of the HIV pandemic. Although global incidence of HIV is diminishing, for many cohorts below the age of 24, such as slum-dwelling youth, prevalence has, overall, plateaued or increased. HIV in eastern and southern Africa, the region hit hardest by the disease, is becoming an urban phenomenon and aggregating in informal slum settings. A new genre of research is called for that provides insight into the urban evolution of HIV and identifies entry points for tackling root causes of risk and vulnerability.

This is a novel piece of research carried out in two urban slums in Nairobi, Kenya: Korogocho and Majengo. Each site was politically marginalised and inhabited mostly by young people facing a generalised HIV epidemic. In contrast to the predominant quantitative research tradition in Kenya, this is a qualitative study that seeks to understand perceptions of HIV and the processes involved in managing risk from the point of view of young people. A constructivist grounded theory methodology was adopted given its fit with the study's theoretical conception and topic of inquiry.

Two methods were used to generate primary data: first, 25 semi-structured interviews with men and women aged 18–24 years; and second, a photovoice exercise involving nine participants. During interviewing and photovoice, rich data emerged that were sorted into a progression of open, focussed and theoretical codes. The simultaneous process of data generation and analysis pointed to where the research needed to go next and formed an integral part of constructing social theory. An inductive coding approach gradually created a higher conceptual order moving from descriptive to explanatory in which core properties, dimensions and relationships pertaining to the slum universe were captured and synthesised.

Through creating a storyline, participants' experiential approach to life was brought into sharp focus as was the role of individual agency and purpose. Research conclusions were interrogated within the domains of individual, environmental and structural determinants and checked against the literature to establish the principle of knowledge generation and translation. The study constructs a theoretical model, 'HIV and the Integrity of Risk —Dignifying Resilience in Disadvantage,' which accounts for young people's action driven by the exigencies of survival and in which HIV forms part of the compendium of a life lived on the edge. Risk, as this study finds, is about the integrity to perceive advantage in the daily struggle to find sustenance, to take life on

with all its pitfalls and gain resilience within the social realm capable of managing processes at the heart of HIV.

This research calls for further inquiry that explores measures taken by young slum dwellers to dignify their lives and avoid episodes of humiliation and the impact these have on the social epidemiology of HIV. As a means of helping to control the epidemic, HIV research must continue to prioritise innovative people-centred slum-based social inquiry that highlights what matters most to the people most at risk and the people holding the key to ending AIDS.



# Table of Contents

<b>Declaration</b> .....	<b>i</b>
<b>Statement of the Contributions of Others</b> .....	<b>ii</b>
<b>Acknowledgements</b> .....	<b>iii</b>
<b>Dedication</b> .....	<b>iv</b>
<b>Abstract</b> .....	<b>v</b>
<b>Table of Contents</b> .....	<b>vii</b>
<b>List of Figures</b> .....	<b>xi</b>
<b>List of Tables</b> .....	<b>xiii</b>
<b>List of Abbreviations</b> .....	<b>xiii</b>
<b>Chapter 1: Introduction—Roots, Perspectives, Methodology</b> .....	<b>1</b>
1.1 Introduction to Chapter .....	1
1.2 Perceiving the Nexus of Vulnerability and Risk .....	3
1.3 Perceiving HIV Risk .....	4
1.4 Urban Slums, Situating Risk and Vulnerability .....	5
1.5 Social Theory and the Construction of Reality .....	6
1.6 Building an Integrative Framework .....	7
1.7 Constructing Reality and Perceiving Realities .....	8
1.8 Pragmatism, Interpretive Theory and Symbolic Interactionism .....	10
1.8.1 Pragmatism and Morality .....	11
1.8.2 Interactionist Perspectives of Gender .....	13
1.9 Constructivist Grounded Theory .....	13
1.10 Social Interaction and the Social Process .....	15
1.10.1 Social Processes and Situational Analysis .....	16
1.10.2 Identifying the Social Process .....	17
1.11 The Social Construction of Risk and Processes in Managing HIV .....	18
1.11.1 Processes of Risk Construction .....	19
1.11.2 A Situational View of Sexual Risk Taking .....	20
1.12 Slum-dwelling Young People and Heterosexual Transmission .....	21
1.13 Addressing the Research Question .....	22
1.14 Chapter Summary .....	22
<b>Chapter 2: Research Methods—The Situation of Inquiry</b> .....	<b>24</b>
2.1 Introduction to Chapter .....	24
2.2 Conceptualising Research .....	25
2.3 Methodology .....	26
2.3.1 Identifying Research Context .....	28
2.3.2 The Study Sites .....	29
2.3.3 Recruiting Participants—Purposeful and Theoretical Sampling .....	32
2.3.4 The Sample Frame .....	34
2.4 Research Team .....	37
2.4.1 Lead Researcher .....	37
2.4.2 Research Coordinator .....	38
2.4.3 Mobilisers .....	38
2.4.4 Interviewers .....	38

2.4.5 Transcribers .....	39
2.5 Ethics Protocols.....	40
2.5.1 Informed Consent of Participants .....	40
2.5.2 Language and Context .....	41
2.5.3 Gender Sensitivity .....	41
2.5.4 Participating in the Generation of Knowledge .....	42
2.5.5 Privacy and Confidentiality .....	42
2.5.6 Venue.....	42
2.5.7 Honorarium.....	43
2.5.8 HIV Status .....	43
2.5.9 Support Services .....	43
2.6 Data Generation.....	44
2.6.1 Semi-structured Interviews.....	44
2.6.2 Interviewing; Procedure and Protocol .....	44
2.6.3 Statement Cards .....	46
2.6.4 Interviews, First Round, Korogocho .....	48
2.6.5 Second Round Interviews and Key Informant Interviews.....	49
2.6.6 Third Round Interviews and Key Informant Interviews.....	50
2.7 Language, Translation and Meaning.....	52
2.7.1 Language, Culture and Context .....	53
2.7.2 Abstract Conceptualisation.....	54
2.8 Photovoice, the Expanse of Meaning and Perception .....	55
2.8.1 Technical Capacity .....	57
2.9 Personal Safety and the Security Apparatus .....	59
2.10 Chapter Summary.....	60
<b>Chapter 3: Analysis—Towards a Grounded Theory of HIV and Risk .....</b>	<b>62</b>
3.1 Introduction to Chapter .....	62
3.2 Coding and Grounded Theory.....	62
3.2.1 Reflexivity and Conceptualisation.....	63
3.3 Open Coding .....	65
3.4 Situational Analysis.....	68
3.5 Focussed Coding .....	70
3.5.1 Axial Coding.....	73
3.6 Theoretical Coding .....	76
3.6.1 Refining Concepts and the Provisional Core Category .....	78
3.7 Evaluating Approach, Findings and Analysis .....	79
3.7.1 Credibility.....	79
3.7.2 Originality.....	79
3.7.3 Resonance .....	80
3.8 Theoretical Modelling .....	81
3.8.1 Theoretical Coding and Inclusion of Basic Elements .....	81
3.9 Creating a Storyline.....	84
3.10 Checking Against the Literature .....	85
3.10.1 The International Literature.....	87
3.10.2 Key Concepts in Searching the Literature .....	88
3.10.2.1 Risk .....	88
3.10.2.2 Resilience .....	89
3.10.2.3 Dignity and Humiliation .....	89

3.10.2.4 Subjective Perception.....	89
3.11 Chapter Summary.....	89
<b>Chapter 4: Findings—Modelling HIV and Risk.....</b>	<b>91</b>
4.1 Introduction to Chapter .....	91
4.2 The Social Universe of HIV Risk.....	91
4.2.1 The Individual Domain; Knowing, Feeling and Expressing.....	94
4.2.1.1 Perceiving HIV .....	94
4.2.1.2 Conceiving HIV and Pregnancy .....	98
4.2.1.3 HIV and Self-protection; Sex, Gender and Gratification.....	101
4.2.1.4 Perceptions of Efficacy and the Realism of Resilience .....	104
4.2.2 The Environment: Social Interaction and the Navigation of HIV and Risk.....	105
4.2.2.1 Communicating and Managing HIV .....	105
4.2.2.2 Sex, Morality and Condoms.....	108
4.2.2.3 Gender and Social Organisation .....	110
4.2.2.4 The Social Organisation of HIV Care and Support .....	114
4.2.2.5 Sharing and Connecting, the Nexus of HIV Risk .....	116
4.2.3 Structural: The Social and Political Organisation of HIV.....	119
4.2.3.1 Sex and Power; the Gender Fault Lines.....	119
4.2.3.2 Agency and Morality: the Structural Drivers of Wellbeing.....	122
4.2.3.3 Social and Demographic Mobility—Demonstrations of Capacity .....	124
4.2.3.4 Dignity, Poverty and Wellbeing .....	125
4.2.3.5 Manifestations of Stigma, Discrimination and Prejudice .....	129
4.2.3.6 Sexuality, Gratification and Social Capital.....	130
4.3 Chapter Summary.....	131
<b>Chapter 5: Discussion—Managing HIV and Risk.....</b>	<b>133</b>
5.1 Introduction to Chapter .....	133
5.2 Knowing, Perceiving, Acting .....	134
5.3 Intention and Perception.....	136
5.4 Capacity and Connection .....	137
5.5 Interpreting Processes of Prevention and Risk.....	138
5.6 The Intersection of Gender .....	140
5.7 Morality and the Stigma of HIV .....	142
5.8 The Social Organisation of Sex and Relationships .....	144
5.9 Social Processes of HIV Prevention.....	145
5.10 Social Arenas of Violence and Poverty.....	147
5.11 Knowledge Assemblage and Communicating Information .....	149
5.12 Modelling HIV Risk.....	150
5.13 Study Limitations .....	154
5.14 Chapter Summary.....	155
<b>Chapter 6: What Next? —A Fitting Future for HIV and Young Slum Dwellers.....</b>	<b>158</b>
6.1 Introduction to Chapter .....	158

6.2 The Normal Professionalism .....	159
6.3 Conceptualising Health Care.....	160
6.3.1 Dignifying the Nexus of HIV Risk and Resilience .....	161
6.4 Rights, an Urban Perspective .....	161
6.5 Reconceptualising Morality, Sexuality and HIV Risk.....	162
6.6 Perceiving Resilience—The Dynamics of Age and Gender .....	163
6.7 Mobility, Space and Boundaries .....	165
6.8 The Ecology of the Slum—Intersections of Vulnerability.....	165
6.9 Urban Humanitarian Settings .....	166
6.10 The Dignity of Mobility; Social and Structural Decline .....	167
6.11 Framing a ‘New Normal’ .....	169
6.12 Reconceptualising HIV: The Politics of Ending AIDS.....	173
6.12.1 Gender; the Intersection of Vulnerability and Resilience .....	176
6.12.2 Grounding Research Priorities.....	176
6.13 Chapter Summary.....	176
References.....	178
<b>Appendices.....</b>	<b>204</b>
A. Map of Research Sites .....	205
B. Data Generation Tools .....	205
C. Situational Analysis Maps .....	205
D. The Storyline Framework .....	20621

## List of Figures

Figure 2.1. Interview Rounds.....	52
Figure 3.1. Conceptualisation of HIV risk and resilience among young people. ....	75
Figure 3.2. Theoretical model of the social process of managing risk of contracting HIV. ....	81
Figure 3.3. Theoretical model of the process of managing HIV and risk.....	83
Figure 4.1. HIV and the Integrity of Risk—Dignifying Resilience in Disadvantage.....	92
Figure 4.2. Symbol of Pride:.....	94
Figure 4.3. Vitality of Youth and Sexuality:.....	96
Figure 4.4. Embracing Life:.....	97
Figure 4.5. Children are Life.....	99
Figure 4.6. Gender-based Violence.....	100
Figure 4.7. Respecting Mothers: .....	101
Figure 4.8. Mixing and Connecting:.....	102
Figure 4.9. Sustaining Health: .....	104
Figure 4.10. Sharing Food and Stories: .....	106
Figure 4.11. Condom Use: .....	110
Figure 4.12. Sexual Violence .....	111
Figure 4.13. A Woman’s Day. ....	112
Figure 4.14. ART: .....	116
Figure 4.15. Public Eventss. ....	117
Figure 4.16. Making Money. ....	118
Figure 4.17. Religion. ....	119
Figure 4.18. Roadside Work .....	120
Figure 4.19. Cash. ....	121
Figure 4.20. Sharing Work.....	122
Figure 4.21. Gender and Work. ....	123
Figure 4.22. Scavenging .....	126
Figure 4.23. The Dirt of the Street.....	127
Figure 4.24. The Cleanliness of Homes:.....	127
Figure 4.25. Stigma of Slum Work.....	130
Figure 4.26. Perceptions of Plenty.....	132

## List of Tables

Table 1.1 <i>Ontology, Epistemology and Methodology for This Study</i> .....	9
Table 2.1 <i>Sensitising Concepts</i> .....	26
Table 2.2 <i>The Theoretical Framework</i> .....	28
Table 2.3 <i>The Sample Frame</i> .....	36
Table 2.4 <i>The Research Team</i> .....	40
Table 2.5 <i>The 16 Statement Cards</i> .....	47
Table 2.6 <i>Participants in the Research</i> .....	48
Table 2.7 <i>Key Informants</i> .....	50
Table 2.8 <i>Photovoice Participants</i> .....	56
Table 3.1 <i>Extract of Open Codes, Properties and Segments</i> .....	67
Table 3.2 <i>Extract from Open Codes and Categories</i> .....	69
Table 3.3 <i>Extract from the Frame of Reference of Major Discourses</i> .....	722
Table 3.4 <i>Extract from the Terms of Reference for Developing Focus Codes</i> .....	733
Table 3.5 <i>Extract from the Framework of Iteration of Elements and Categories</i> .....	822

## **List of Abbreviations**

ABC	Abstain Be Faithful Use a Condom
AIDS	Acquired Immune Deficiency Syndrome
APHRC	African Population Health Research Centre
AVERT	Antivirus and Vulnerability Emergency Response Team
ART	Antiretroviral therapy
CDC	Centre for Disease Control
HIV	Human Immunodeficiency Virus
IOM	International Organization for Migration
NGO	Non-governmental organisation
PEP	Post-exposure prophylaxis
PrEP	Pre-exposure prophylaxis
STI	Sexually transmitted infection
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS
UN-Habitat	United Nations Habitat
WHO	World Health Organization

# **Chapter 1: Introduction—Roots, Perspectives, Methodology**

## **1.1 Introduction to Chapter**

This research seeks to understand the process for managing the risk of HIV by young people in an urban slum. The chapter outlines the theoretical roots that conceptualise the approach, frame research assumptions and give purpose to the study. A philosophical perspective, and its practical application, provides a pathway for identifying and interpreting social processes for managing risk and HIV. Key thematic areas, grounded in theoretical antecedents—principally vulnerability, risk, resilience, dignity and humiliation—inform lines of study and are explained in the situation of inquiry.

This chapter conceptualises the moral and social worlds that simultaneously create risk and offer forms of resilience for the people at the centre of this research: young people residing in two inner-city slums in Nairobi, Kenya—Korogocho and Majengo. The young slum dwellers at each location live within a nexus of social and structural vulnerability and, as the evidence shows, are far more at risk of contracting HIV and most likely to die from an AIDS-related illness than are their rural counterparts (Kyobutungi, Ziraba, Ezeh & Yé, 2008). Even as HIV infections are diminishing globally, including in Kenya, concentrated epidemics continue; for many young slum dwellers, HIV incidence is not declining.

This study adds to the body of knowledge resulting from Kenya's long history of AIDS research. Through constructivist grounded theory, based on a qualitative methodology, it amplifies the self-perceptions of a population disempowered yet resilient within the plurality of slum life.

Drimie and Casale (2009) demonstrate the multidimensional nature of HIV but less so the puzzling face of risk itself—risk of infection or risk of managing HIV infection, risk in accessing HIV services and risk of being identified as someone living with HIV. This chapter outlines the social construction of risk within social and moral worlds. Moreover, it acknowledges that the HIV research arena is 'messy', and social processes evolve according to situation and circumstance.

The epidemic in the slums of Nairobi is driven by persistent vulnerabilities, notably among young people who are often disempowered and whose pathways to prevention and managing risk is never a straightforward matter (Jones, 2016). This chapter provides the basis for studying risk within a diverse environment through



finding processes honed by and within social and moral worlds affecting and affected by slum-dwelling youth.

True to its pragmatic and postmodern leanings, the chapter conceptualises risk and recognises the essential practicality of slum morality, youthful desire and sexuality in a crisis-prone setting. Young residents are disposed to be innovative, insightful and resilient in the face of uncertainty and threat. This research adds to new turns in urban sociology and offers an alternative explanation through an ethnographic sensibility that emphasises the necessity of people-centred research. Its integrative approach recognises the totality of risk, or, the universe of the situation, in which HIV is woven into the very fabric of slum life.

A study of moral and social worlds helps explain the totality of risk and the place of HIV. Slum-dwelling young people have among the worst health outcomes for communicable and non-communicable disease anywhere in Kenya (Kyobutungi et al., 2008). It is not just AIDS that threatens life. The environment in which these people live is characterised by episodes of exponential risk, often dangerous and life threatening. This chapter describes how, within this universe of risk, meanings are generated and re-generated and held to have moral value—at least for a given moment in time. The young people facing urban HIV epidemics, their interpretations and their self-perceptions are the focus of this study.

This chapter presents the conceptual link between perceptions of humiliation by young people and associated risk behaviour within the slum universe. It builds on cognitive and social theory in conceptualising young people's actions that seek a dignified life—connected and socially assured. This research examines the idea that individual and collective resilience does not necessarily need to be evaluated as rational or productive; there are other priorities in the cultural life of young slum dwellers. Further, their daily life is experiential and consists of innumerable forms of gratification. Each day is lived—one day at a time.

Finally, the chapter closes with attending to the key question of this study. Having presented the ideological bent of this research, the groundwork is laid for empirical inquiry into the process of managing HIV risk among young slum-dwelling populations.

## **1.2 Perceiving the Nexus of Vulnerability and Risk**

Vulnerability is a relative construct with little degree of permanence, conceptually and in its practical application. The extent of vulnerability can increase or decrease, or do both concurrently, according to personal, environmental and structural determinants. For this research, HIV vulnerability is defined as the extent to which a person is exposed to the virus. Cluver, Orkin, Boyes and Sherr (2014) demonstrate that an individual's extent of vulnerability is shaped by an interplay of social, biomedical and behavioural factors. 'Risk' is being exposed to HIV and the likelihood of infection; in having HIV and progressing towards AIDS as well as incapacity to positively affect one's wellbeing. Risk involves the presence of danger or injury that can negatively impact health and wellbeing over the short and long term. As Kahneman and Krueger (2006) state, feeling vulnerable and being at risk is largely a matter of self-perception.

Within social worlds, there is 'ritual risk', which, as Ludi and Bird (2007) state, can relate to customs such as those prescribed in peer groups and sexual networks. Although risk taking is more easily traced to personal volition, as this research holds, it is often the consequence of collective consciousness—socially generated cultural values that are inculcated on a personal level. To understand processes for managing HIV is to discern the totality of vulnerability and risk. Being vulnerable, as this research understands, is a lack of autonomy in being able to shape events that can lead to the risk of uncertain dependency.

According to Ludi and Bird (2007), the structural basis of vulnerability is informed by the extent and regularity of stress factors and lack of risk modifiers combined with personal experience in perceiving and responding to uncertainty. Chambers (1995) explains vulnerability as principally made up of external and internal factors, such as exposure to shocks, stress and risk as well as an incapacity to prevent some form of loss.

This research explores how notions of vulnerability and risk are encapsulated within social processes for managing HIV and inform young slum dwellers' health-seeking behaviour. Wellbeing, as the study examines, is perceived as both morally commendable and socially, as well as personally, advantageous. The question becomes how wellbeing and emotional health are interpreted and defined.

Self-perceived vulnerability and self-perceived risk are not, as Bradley, Tsui, Hindin, Kidanu and Gillespie (2011) point out, one and the same. Perceived risk

considers the chances of acquiring HIV drawn from existing knowledge and past behavioural experience, while perceived vulnerability considers predisposition to HIV regardless of the presence of risk factors. In line with Bradley et al. (2011), risk, vulnerability and self-perception are critical in comprehending young people's attitudes and actions towards managing HIV.

### **1.3 Perceiving HIV Risk**

Barrington, Arandi, Aguilar-Martinez and Miller (2018) describe how numerous studies on HIV and resilience take as their point of departure the erosion of resilience and the catastrophic effect on life and livelihood as individual and community capacity diminish. Resilience and HIV are all too often a matter of measuring deprivation and collapse. Noting the wholly negative effect of HIV on individuals, families, communities and nations, this research seeks to understand resilience as a way of life—a way of coping and navigating social worlds. The theoretical roots of this study inform a nuanced perspective of risk through understanding how young slum dwellers perceive and create meaning about and seek a sense of resilience against HIV; essentially on their terms.

Individual and collective resilience, as this research understands, is being able to withstand shocks and uncertainty in a volatile environment. It is as much a mindset as a way of coping. It does not assume, as Ludi and Bird (2007) explain, that individuals, assets or communities will be undamaged. Rather, it is about keeping a sense of self and maintaining a degree of self-inspection and self-protection; for example, the young person discovering that they are HIV positive but going on to make at least a modicum of rational life choices.

Lever (2010) believes that resilience is manifested over the long term and can involve drawing on critical external resources. Confronted with a challenging situation and fear of facing a humiliating experience, young people may adopt negative coping mechanisms, such as risky sexual behaviour, that work against sustaining resilience in the long term. As Degenova, Patton, Jurich and MacDermid (1994) write, these survival mechanisms are often age specific and relate to particular populations at given locations. Humiliation, as Lindner (2010) states, can now turn into a downward spiral. Luke (2005) demonstrates that adolescent sex work associated with slum residence involves a set of actions that places undue risk on the individual but provides a form of

resilience (cash) and acceptance by a peer group (status) in the short term and demonstrates a refusal to succumb to the fear of uncertainty in the here and now.

For this research, associated with resilience are the constructs of dignity and honour. Although these two constructs have much in common—notably, in conferring feelings of self-worth, as Pauketat (2013) claims—they are separate phenomena. Dignity has an inherent value that is not dependent on context or the action of others, whereas honour is dependent on others, on creating a social image that is given meaning in social worlds. Self-perception and social recognition of both dignity and honour are associated with agency; of thinking, feeling and doing in the social realm. Dignity, as with humiliation, has relational value and presupposes the importance of connection and social integration. The dignity and honour cultures of the slum have bearing on young people's processes for managing HIV.

#### **1.4 Urban Slums, Situating Risk and Vulnerability**

This study is informed by the four urban sociology classifications used by the World Health Organization (WHO) and United Nations Habitat (UN-Habitat, 2010): natural and built environment; social and economic environment; food security and quality; and emergency health management. Together, they account for the totality of slum life and persistence of poverty, disadvantage and structural decline.

In agreement with Vlahov, Freudenberg, Proietti, Ompad, Quinn, Nandi and Galea (2007), the slums of Nairobi represent the complete expression of persistent poverty. Structural factors, as shown by dilapidated health and social services, are part of the compendium of population-level patterns of morbidity and mortality. As such, and as explained by Fitzpatrick and LaGory (2002), slums such as Korogocho and Majengo are expanding spaces of urban risk. As Lindner (2012) states, exclusion and disconnection resulting from entrenched poverty provide fertile ground for resentment and humiliation. This research considers the behavioural response to feelings of being denied, of personal insecurity and finding sense in a physical environment steeped in poverty. In constructing social theory, this research is not limited to a narrow economic analysis of poverty but, in line with Chambers (1995), emphasises the abundance of slum residency and looks to indicators of felt wealth and the value of assimilation and association.

The Joint United Nations Programme on HIV/AIDS (UNAIDS, 2014a) demonstrates that 'place matters'. The place of the slum, its totality and situation, is a

major factor for HIV infection. The WHO and UN-Habitat (2010) show that places having the poorest rates of health outcomes are where the poorest people reside. Here, moral social worlds evolve, and shape lives attuned to survival. The qualitative approach of this study captures young slum dwellers' perceptions to create an account of what slum reality means to young slum residents. It explores how young slum dwellers shut out from ideas of an 'urban advantage'<sup>1</sup> perceive the vicissitudes of exclusion and strive to manage HIV risk.

This research also seeks to address an often-neglected component of life for slum dwellers: protecting self, asserting self-identity and, moreover, dignifying their interpretation of the 'urban advantage' and finding resilience in slum residency. It follows, therefore, that the young person's innovative approach to building forms of social capital becomes a research priority. Jones (2016) states that empirical enquiry concerned with conceptualising 'dignity through innovation and initiative' among young people is largely missing from accounts of young people's resilience, an omission this grounded theory seeks to address.

### **1.5 Social Theory and the Construction of Reality**

This research is conceptualised according to principles of interpretivist sociology. A qualitative research paradigm provides the foundation for this study of slum life: social worlds, relationship networks and behaviour. This interpretivist perspective informs the study's analysis of human behaviour, explains social and political morality pertaining to processes of managing HIV and formulates conclusions relating to risk and resilience. As Lindner (2010) postulates, the evolution of interpretive perspective and practice is rooted in recognising the complexity of social processes and heeds the moral assertion for a rights-based approach. This research follows in that tradition, aligned with the philosophical–sociological–methodological premise of people-centred and people-sensitive study.

This social inquiry is grounded in the pragmatic belief, as described by Leeds-Hurwitz (2009), that reality is socially constructed, and only through studying young people's subjective perception in the contexts of social worlds can an understanding be gained of HIV risk and behaviour. While premised within pragmatic tradition, this

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<sup>1</sup> Jones (2016) states, 'The concept of urban advantage holds that cities are the main setting for progress. That the urban space facilitates the advancement of political ideas and action and provides unlimited benefits for the best level of health, education and public services, like adequate supplies of water and sanitation'.

research recognises the importance of other theoretical persuasions within urban sociology and, leading on from the work of Fassin (2014), the trajectory of morality in poverty-prone communities.

The theoretical perspective that frames this inquiry sheds light on what Cole (2018) identifies as the philosophical and moral roots of urban sociology's past, present and future. In agreement with Glanz and Bishop (2010), the empirical assumptions of this study provide an evaluative framework by which to engage with an identified social setting and makes no attempt to formulate scientific law with universal application.

The link between philosophy and research methodology is well established (McLachlan & Garcia, 2015). The methodological procedure of this research is aligned to its theoretical roots and capable of generating a grounded theory of managing HIV risk. However, this grounded theory is not bounded by one specific philosophical tradition. Rather, it is informed by and grows out of it. In agreement with Crossman (2017), this sociological inquiry is based on a series of shared theoretical and working assumptions: for example, that social systems such as society and family exist and hold sway; and culture, social structure, statuses and roles are real and significant. As Crossman (2017) writes, interpretivist sociology has its own vocabulary and set of assumptions about reality that help conceptualise research themes, methodological procedure and data analysis. This work is no exception.

## **1.6 Building an Integrative Framework**

As McLachlan and Garcia (2015) postulate, the philosophical positions along the positivist–constructivist spectrum, and upon which models of health are built, all have something to offer. This research supports the assertion that a broad-based theoretical cognisance enriches an informed overview of the subject matter and highlights apparent gaps. Accordingly, the study approach, in agreement with Crossman (2017), is informed by multiple theoretical perspectives in framing research questions, design and research conduct, as well as in the analysis of results and presentation of findings. The background to this research draws on quantitative research findings, including health and economic surveys, such as the longitudinal study of urban slum life by the African Population Health Research Centre (APHRC, 2014).

Taking note of McLachlan and Garcia (2015) and Miller, Glassner and Silverman (2004), the theoretical roots of this study lean towards an inclusive theoretical framework—which is essentially anti-dualist—and benefits from a wide

birth of urban ‘wisdoms’. In this way, a holistic account of the research topic is possible and adds to a more nuanced grounded theory.

As with McLachlan and Garcia (2015), this research finds relevance in the work of critical theorists writing about urban agendas that distinguish between the ontological (realism) and the epistemological (relativism) in understanding complex social worlds of young people. The study of perception becomes the priority focus of research situated within an independent reality generated, in turn, through subjective reflection. In the same vein as House (1991), this study finds value in ‘realism’, which does not have to be absolute but conceptually relative. Moreover, set against the backdrop of the universal humanist principles of progress, dialectics and consciousness, this research conceives participants as creative thinking social agents, capable of building and reflecting on their own unique experience. It provides the means to build theory from the bottom up and grounded in the data.

### **1.7 Constructing Reality and Perceiving Realities**

To understand this complex research environment, this study is aligned to the theoretical principle of multiplicity and social intellectual diversity and acknowledges the fluidity of reality and processual nature of meaning. An interpretivist approach, as defined by this research, also recognises that the human element cannot be divorced entirely from the act of research itself; and, while striving for empirical integrity, subjectivity will have a bearing on research outcomes. As Robson (2002) states, there exists among post-positivists the belief that truth can never be found and the assumption that the researcher and person of the research cannot be independent of each other. The researcher will influence the research process through their theories, background, knowledge and values. Table 1.1 outlines the theoretical assumptions and methodological components underpinning this research.

Table 1.1

*Ontology, Epistemology and Methodology for This Study*<sup>2</sup>

<b>Ontology</b>		
<b>Working definition</b>		<b>Research principles</b>
Nature of being, becoming, existence and reality	Interpretivist Notions of ‘the real world’ are erroneous; there is no direct access to a real world	Not geared in finding universal truth, replicable with wide application
<b>Epistemology</b>		
Nature of knowledge creation; generation	Realities are multiple and relative	Relationship between interpretation of reality and subjects of research key to discerning meaning
<b>Methodology</b>		
Focus of study	Emphasis on understanding subjective perception, social interaction and interpretation of meaning	Unstructured Flexible Personal Interactive Non-judgmental Empathetic
Researcher role(s)	Researcher experiences and interprets subject and environment of study	
Researcher techniques	Focus on feeling and reason as critical factors Meaning given to phenomena considered relevant Prior knowledge and understanding of key components of research topic	
Methodology–methods package	Difference between facts and value judgements often obscure Recognises a relationship between science and personal experience Reliance on a qualitative approach	

<sup>2</sup> Adapted from Carson, Gilmore, Perry and Gronhaug (2001)



As explained by Neuman (2002), reality is not fixed but is multiple and relative. The interpretivism that underpins this research—in agreement with Carson et al. (2001) drawing on the work of Berger and Luckmann (1966)—has it that knowledge can never be objectively determined or certain but rests on perception and social construction, including that of the social researcher.

The perspective that premises this research asserts that to ascertain meaning in human interaction and discern perception(s) of reality, a methodology is required that, as Carson et al. (2001) state, must be personal and flexible and not rigid or structured. In agreement with Edirisingha (2012), it is understood that researcher(s) and individual(s) of research are interdependent and mutually interactive. As Hudson and Ozanne (1988) state, it is not possible to establish prior knowledge of context-bound social realities, given that participants may adapt and reformulate perceptions of their social world in the process of inquiry. Rather than pursuing broad generalisations to establish cause and effect, in line with Hudson and Ozanne (1988), this research seeks to understand the living interpretation of meaning within human interaction. As Table 1.1 shows, the ontology, epistemology and methodology are aligned to an interpretivist perspective that highlights the role of subjective experience and, as Neuman (2002) holds, involves a study of motives, feelings and reasons as the principal interest of study; it is time and context bound.

## **1.8 Pragmatism, Interpretive Theory and Symbolic Interactionism**

The roots of this study lie in pragmatism. This research understands that the central tenant of pragmatic thought is that philosophy and social inquiry must be practical. In agreement with Ritzer (2008), for pragmatists, there is no objective reality or permanent truth. To be ‘practical’ is to realise that there is no firm reality, as all reality is fluid and indeterminate (Binswager, 1986). In considering the plurality of social worlds and the levels of interaction within different social arenas from the perceptions of participants, this research holds to the principle that consciousness and the external world are one and the same. To discern truth is to discover what works and to evaluate outcomes for appropriateness and consequences. My memo of 16 October 2015 conceived of this postulate in the experience of the slum:

*What is objective truth? Who’s to say, me? Residents? Attitudes and opinions and what is ‘right’ change, often depending on who’s present and what new information comes to light. This could be the creed of slum life. Gender,*

*ethnicity, background, family, friendship, neighbourliness ... are constructs seemingly having their own reality and where meaning and truth is found, and acted on, which are rarely one of the same thing.*

### **1.8.1 Pragmatism and Morality**

This research explores the concept of young people's social and moral worlds as pertaining to the slums of Nairobi. The pragmatic approach adopted for this purpose sees ethics as best described as humanist. A humanist approach recognizes the connection between the individual and the collective in forming and substantiating cultural mores and conceptualizing notions of that felt to be true premised on the assumption that social values are communal values. This perspective conceives a common humanity based on individuals' ability to empathise with others and sense a common purpose to life and livelihood. Moral behaviour ultimately seeks to improve personal and collective welfare and degrees of moral autonomy are foundational to social life and collective living. Ethical behaviour is that which matters most to human beings. Therefore, in its investigation of levels of social organisation, this research holds that no ontological divide exists between facts and values, given that they each have cognitive content. Of interest to this study is the notion of a 'good reasons approach', which, as Macarthur (2008) describes, considers ethical behaviour as that which constitutes good values with good reason. As this research explores, the question of good reason is a highly subjective construct and has multiple meanings leading to an expansive response on the part of young people. The study interrogates the notion that for participants, and as Cohen (2004) claims, trust and faith probably have greater impact than practical insight in deciding what is ethically correct given the frequent unavailability, confusion or disharmony of 'truths'. My memo of 4 November 2015 speaks to this point:

*Trust, as this research is finding, is the building block for reducing risk, gaining (social) strength and altogether becoming resilient. It is when that trust is broken that things break down and uncertainty derails all attempts to make good a difficult situation. The patient must trust the confidentiality of the HIV service provider; one partner must trust the fidelity of the other ... Trust is a risk. What if the trust is broken and the vulnerability threshold increases? But without risking trust, in the collective communal world, resilience and harmony is impossible. One must risk belonging in a world of uncertainty and denial. And it*

*is also trust in the spoken word. This is an oral society and information that can be trusted is actively pursued from peers.*

Following the classical pragmatist, John Dewey, morality in this research is perceived as an experimental discipline, and values are no more than hypotheses formed from a complex array of options in discerning what actions will likely lead to desired results, which Ball and Balthazart (2008) describe as ‘consummatory experience’. In its pragmatic approach, this study examines the idea that ethics have a fallible property, as individuals are frequently unable to know what would satisfy them or be in their best interest.

In discussions with participants, and in attempts to unravel layers of meaning from the data, this research is mindful of the processual nature of meaning as elaborated by Birks and Mills (2015). In agreement with Chamberlain-Salaun, Mills and Usher (2013), the epistemological and ontological foundations of pragmatic philosophy and symbolic interactionist sociology are at the root of an evolved grounded theory and, as deployed in this research, are ably suited to social inquiry in a complex study environment.

As outlined by Welch (2011), the methodological approach adopted for this research explores through heuristic analysis how individuals experience the world and give it layers of idiosyncratic meaning to elicit the reality that matters most to them.

This conception helps explain motivations behind ‘irrational’ choices and paradoxes of young people’s behaviour, which, as McLachlan and Garcia (2015) consider, can be construed as attempts to manipulate their environment for their own benefit. In exploring young people’s perception of how to dignify their world, this research examines the relationship between objective characteristics and subjective experience. In so doing, the research is informed by behaviour economics and, as explained by Samson (2014), perceptions of reality are wholly subjective. How a young person ‘feels’ about a course of action will invariably have as much import as considerations about the ‘right thing to do’. Of interest to this research is the work of Sheldon and Lyubomirsky (2012) and the rule of ‘adaptation’ that demonstrates the distinction between an objective characteristic and an individual’s interpretation of it.

This study is grounded in the perspective that making sense of moral and social worlds occurs through constant reinterpretation. Human behaviour is based on the generation of subjective meaning, and it is this process given to objects and events that is the primary unit for the interactionist analysis of this study. This research investigates

the assumption, as elaborated by DeLamater and Hyde (1998), that the organisation and meaning of social relations are found within the 'definition of the situation'. Of note is the moral content as expressed in the symbolism of HIV and risk and contained within the definition of the situation. It follows, therefore, that this research is aware of and draws on the principles of interactionism for explaining young people's subjective definition of the situation.

### **1.8.2 Interactionist Perspectives of Gender**

In its approach to questions of gender, this research agrees with Cole (2018) that the meaning of gender for each participant lies in its social construction within their known universe. This research explores the notion that it is through interactions among young people within their social worlds that symbolic meanings of gender and risk are conveyed and negotiated, and 'truths' formed. Further, this research appreciates, along with the findings of Cole (2018) that meanings of masculinity and femininity and associated behaviours are transmitted from individual to individual and from generation to generation through a myriad of planned and unplanned, organised and disorganised forms of social interaction.

My memo of 11 February 2016 on gender talks of changing perceptions:

*These young women (slum dwellers) do not fit the 'typical stereotype'. They appear to embody the very essence of resilience and do so within an overwhelming patriarchal society. Commonly held gender expectations are not manifested in behaviour. Young women do not see themselves as the protected moral guardians keeping safe cherished notions of what it is to be good.*

Porter and Robinson (2011) state that meanings people give to what they and others do, and interpretation of that experience, is premised on codes of social interaction. While acknowledging the pervasiveness of social influence on interpretations of gender, the symbolic interactionist approach of this research explores notions of free will and independent agency as integral parts of subjective experience.

### **1.9 Constructivist Grounded Theory**

This qualitative research agrees with Mberu, Mumah, Kabiru and Brinton (2014) that subjective interpretation of a lived reality is unique to the temporal, social and physical contexts in which it is situated. Further, a qualitative approach is best suited to a study explorative in nature aimed at developing new understandings where little is known (Corbin & Strauss, 2008; Fossey, Harvey, McDermott & Davidson, 2002).

This grounded theory study is based on self-perceptions of participants. In approach, it shares much with the processes of hermeneutic phenomenology, as data collection for both perspectives, in broad terms, follows a descriptive approach. As stated by Kompa (2013), both approaches start with unstructured data that, through a process of continuous refinement, crystallise into central themes. Moreover, and in line with Kompa (2013), the grounded theory adopted for explaining perceptions of young slum residents shares a core characteristic with phenomenology: it is an emergent strategy, and the role of the researcher in developing theory is pivotal.

Barney Glaser and Anselm Strauss pioneered this approach in *The discovery of grounded theory: Strategies for qualitative research* (1967) and as a theory/method practice, is widely used by qualitative researchers (Floersch, Longhofer, Kranke & Townsend, 2010; Neuman, 2012). It can be summarised as an inductive process by which a researcher develops theory from empirical data (Floersch et.al., 2010; Leedy & Ormrod, 2013).

This research understands that in building substantial theory from the data, an approach is called for that is ‘flexible and open to helpful criticism’ (Strauss & Corbin, 1998, p. 5), while portraying ‘appropriateness, authenticity, credibility, intuitiveness, receptivity, reciprocity, and sensitivity’ (Strauss & Corbin, 1998, p. 6). Grounded theory demands a creativity from the researcher as well as proximity to participants (and their claims), the field of inquiry and the capability to understand and reflect on participant discourse (Strauss & Corbin, 1998). The logic of grounded theory, and as conceived by this research, is the centrality it affords to empirical data.

In line with its social constructionist<sup>3</sup> roots, this study’s conceptual design does not attempt a search for foundational truth. Constructivism purports that the social world is made up of multiple subjective realities. As purported by Berger and Luckmann (1966), this social inquiry investigates the intricate relationship between social worlds and human behaviour and whether the former is dependent on the latter. It is understood, and stated by Cunliffe (2004), that the product of this grounded theory results from a collaborative ‘meaning-making’ process between interviewer and interviewee. A core component of this approach is the ‘communicative contingencies’ that relate to ‘the what’ (ontology) and ‘the how’ (epistemology) and from which the individual is able to interpret experience (Miller et al., 2016).

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<sup>3</sup> Both social constructivism and social constructionism are used in the literature.

This constructivist grounded theory is formulated around the work first developed by Cathy Charmaz (Charmaz, 2006; Strauss & Corbin, 1990) and is in harmony with the principle that data generation is situated between postmodernism and positivism and relevant for 21st century qualitative research (Charmaz, 2006). This research explores the epistemological basis on which individuals construct reality and assign meaning to their social universe. Further, and as espoused by Breckenridge, Jones, Elliott and Nicol (2012), of interest to this study is the notion that meaning is created through interaction and interpretation of objects. The constructivist grounded theory of this study in seeking to find core components relating to managing HIV, as Charmaz (2006) and Clarke (2005) state, assumes numerous realities that may or may not be shared between the viewer and the viewed.

In line with constructivist inquiry, this research examines if meanings and personal and collective identity are renegotiated through social interaction and shaped by prevailing cultural norms. Participant perceptions combine with the researcher's interpretation and form the building blocks for creating knowledge that recognises the importance of both substantive and constructive aspects of data.

### **1.10 Social Interaction and the Social Process**

The study explains social processes relating to managing risk of HIV that are the building block of this social theory. Sales (2012) states that the social process is a key sociological concept, especially within the interpretivist tradition. The question becomes reckoning not the importance of the social process, which is well established, but the means of its recognition in qualitative research and in identifying core characteristics. The postmodernism of Clarke (2005) suggests there may well be multiple social processes reflecting the heterogeneity of social life. In agreement with Sales (2012), this research holds that to understand a social process is to first find clarity on the universe of human interaction in the situation of inquiry.

This research explores levels of young people's social interaction through conceiving it as a process affecting attitudes, feelings and actions, that is mutual and/or reciprocal. In building a grounded theory, this study's approach examines the many forms of interaction categorised as person-to-person, person-to-group and group-to-group. The social interactionist approach chiefly concerns 1) how symbols, including, words, gestures, facial expressions and sounds, are communicated, including within the

research situation and 2) how the roots of participant thoughts, feelings and modes of interpretation are discerned through the process of social interaction.

This research studies social processes concerned with identifying patterns and recurrent forms of interaction and depicting the particularities (idiosyncrasies) of individual responses to one another that have attained full or at least substantial stability. In keeping with constructivism, the grounded theory is built without undue influence of preconceived notions concerning theory and the nature of social processes. This research understands that knowledge of the social process, however constituted, must be generated from the study of the phenomenon in question.

In this research, the study of participant interaction informs social processes that build the core category of grounded theory. This assumption is based on the notion that social processes are the totality of social cultural expression and prevailing moral landscape. HIV infection takes place through social (sexual) interaction and within moral (judgemental) worlds that shape perception and action and define social processes.

#### **1.10.1 Social Processes and Situational Analysis**

The slum is an entity unto itself. There is much intra-slum, but far less out-of-slum, movement. This may be down to lack of resources or simply owing to personal preference and choice. Given that slum inhabitants live within a particular universe made up of interlocking social worlds, this research studies if and how this universe is manipulated for personal advantage.

The slum is no easy place to comprehend. The plethora of research into slums in Nairobi consistently suggests a complex, changing and often baffling reality. This research draws on the conceptualisation and tools of inquiry from situational analysis to help unravel this complexity. As Adele Clarke (2005), a leading proponent of situational analysis points out, the situation can appear ‘messy’, and social process, or processes, hard to depict. In agreement with Clarke, Friese and Washburn (2015), not finding a clear-cut social process is, for the postmodernism that informs this research, acceptable.

Situational analysis takes into its fold all factors of influence: actors (human elements), actants (non-human elements), structural determinants and history. In perceiving the totality of the situation, a more accurate assessment of social process(es) is possible. This research draws on the principle that social reality is characterised by discursive and digressive elements that are congruent with the social process. Young

slum dwellers are busy and innovative and their lives experiential (Chambers, 1983). This research, in its exploration of social and moral worlds, analyses if, in attempting to create a positive image among peers, young people engage in diverse and high-risk behaviour. Situational analysis helps provide clarity in this muddled universe through creating a series of maps that, as Clarke (2005) considers, demonstrates the universe of social worlds and social arenas, the prevailing and changing power dynamics of social and political life, and ‘hay-wire’ complexity in a bewildering research environment.

At various stages of the research, this study drew on the ‘method assemblage’ that gave substance to the apparent ‘messiness’ of the object of inquiry in which seeking one ‘basic social process’ often appeared illusory. The practice-oriented nature of this research is in line with basic principles of grounded theory and situational analysis as it broadens the methodology’s reach through design and scope and captures better the discursive nature that characterises social inquiry (Clarke, 2005). For this study, personal narrative and visual and historical discourse are deemed integral to building grounded social theory.

### **1.10.2 Identifying the Social Process**

This research seeks to uncover the reality of social processes of managing HIV risk through its practical consequences. In line with Charmaz (2000) and Clarke (2015), the constructivist grounded theory of this research draws on the principle that theory construction happens through active interpretation of meanings by participants themselves and reflects the ‘partialities, positionalities, complications, tenuousness, instabilities, irregularities, contradictions, heterogeneities, situatedness and fragmentation-complexities’ of their interpretation (Clarke, 2000, p. xxiv, as cited in Mathar, 2008). This echoes the experiential nature of slum life, the cultural integration and dis-integration of African cities, the politics of identity and the necessity of the ‘social expediency of youth’.

This study considers the influence of non-human elements and their power to influence discourse. Aligned to actor-network theory, and as purported by Clarke (2005), the role of non-human elements is crucial. The analysis techniques deployed to find processes in managing HIV and risk build on the principle of ‘situation focus’, in which all factors are deemed relevant and equally important. This grounded theory dismisses ideas of finding ‘social forces’. It is objects, ideas and processes that have relevance in constructing theory based on the social situation. Moreover, as purported by Carroll, Richardson and Whelan (2012), the principal goal of research is to



understand how social groupings are assembled and maintained—particularly in the context of goal achievement. This research explores notions that non-human elements are active and have influence over the life of social systems and social networks. In its analysis of findings, the ‘material-semiotic’ method is drawn on to aid discerning relations, both material (between things) and semiotic (between concepts) (Law & Hassard, 1999).

### **1.11 The Social Construction of Risk and Processes in Managing HIV**

This study accepts the conclusion of Bajos (1997) that risk is socially constructed and shaped by political, economic, social and scientific processes. These processes are grounded in human relationships within interconnected moral social worlds that give meaning to HIV and risk. Through socialisation, young people come to know these processes and become aware they can exist in harmony or in conflict (Jenkins, 2000). This study investigates the notion that processes used by slum-dwelling youth possess a distinctiveness reflecting challenges and opportunities unique to the slum environment.

As Hogan and Palmer (2005) state, ‘reservoirs of information’ on managing HIV risk that inform self-perception also inform individual behaviour, made sense of with and through significant others. Unlike more ‘individualist’ approaches to comprehending risk, typically concerned with how individual risk is represented, the constructivist methodology of this study focusses more on process and perception that underpin risk construction.

Bajos’ (1997) work on the social construction of risk, informs this study’s conceptualisation of managing processes relating to HIV. Of note, participant perceptions may not be premised on scientific content and are subject to social and cultural influences. According to Bajos (1997), contracting HIV is best understood as not one but a series of risks that impact each other and on multiple levels: risk of having an HIV-positive intimate partner amplified by risk through sexual contact resulting in transmission of the virus. This study is also concerned with risks associated with young people living with HIV and managing the infection over the span of a lifetime. Therefore, managing HIV risk depends on how a sexual encounter is perceived in the context of infection. This research accepts the principle that perceptions of risk are grounded in interpreting and assimilating information, and reasoned behaviour is influenced by the sociocultural environment. Of concern to this study is how

perceptions generated and interpreted in social worlds act as filters or modifiers of information regarding HIV and risk.

This research explores how a young person perceives and assesses probabilities of a risk event; for example, unsafe sex. The question remains regarding whether health preservation is the key motivation or if other perceptions substantially drive behaviour. Psychological health behaviour models, such as the Health Belief Model, assumes that asserting one's health is the major concern, and that protecting one's health is the key factor in structuring risk-averse behaviour (Jones, 2016). While cognisant of the Health Belief Model, this research also considers social determinants of HIV risk that may not be in tune with standard AIDS risk-reduction models.

Of interest to this research is the idea that risk distribution and risks of being exposed to HIV are not random occurrences. The work of Boyer, Greenberg, Chutuape, Walker, Monte, Kirk and Ellen (2017) shows that young people are considered a group highly susceptible to HIV and have a recognisable sociodemographic profile that includes high levels of risk taking. The multiple vulnerabilities of young women are well established (Higgins, Hoffman & Dworkin, 2010). The study examines the notion of social adaptation to HIV risk among a high-risk group and its effect on sociodemographic and socio-sexual factors within the project sites. Taking lead from the sociology of Bourdieu (McFall, Du Gay & Carter, 2008), this research interrogates if young people's attitudes towards health in general, and risks of HIV specifically, are discernible in their life course and determined by the presence or absence of critical resources linked to familial, social, cultural and educational capital.

The interactionist approach of this research seeks to understand how social capital is communicated and gives a face to risk through layers of social interaction and sexual negotiation. As Okal, Luchters, Geibel, Chersich, Lango and Temmerman (2009) demonstrate, the practice of safe sex hinges on a process of sexual negotiation/interaction in which the shape of desire and intent is communicated, and it is this communication, implicitly or explicitly, that changes according to gender, age, culture and degree of intimacy.

### **1.11.1 Processes of Risk Construction**

Generating theory on the social process of managing HIV risk involves an examination of the process of risk construction. This latter process is informed by a young person's social and affective situation as well as the relational setting in which sexual intercourse, for example, takes place. For this research, factors relating to

sociodemographic characteristics of a young person take precedence. What is of direct interest to this study is the nature of interactive risk management involving social norms, values and mores in the context of young people's social worlds.

Processes of risk construction are informed by a young person's biographical makeup. Lindberg and Stensöta (2018) state that personal, social and sexual experience builds capital, and the nexus of socio-sexual capital is key to managing risk. The research takes note of the process of risk construction shaped by the nature of the relationship between people. The work of O'Sullivan, Harrison, Morrell, Monroe-Wise, and Kubeka (2006) shows that gender dynamics and sexual relationships are key in the process of negotiating safe sex—be it subvert or overt—and increase or decrease instances of risky sex. In line with constructs of gender, this research examines the notion that sexual negotiation rarely takes place between equals, and the structure and evolution of affective and sexual relationships has meaning for strategies linked to managing HIV.

This research interrogates the social and cultural context, along with idiosyncrasies of a relationship that together provide parameters of constraints and possibilities and the rules pertaining to sexuality, gender and social power. Sexual relationships, as well as the sexual act itself, are interactive processes that evolve according to dialogue between sexual partners and the nature of a relationship (Litzinger & Gordon, 2005). Of interest, therefore, is the self-perceptions of young people regarding that interactive process to discern what behaviour is personally felt as being risky to themselves and others.

Conceptualising HIV risk has to include both male and female interpretations of risk and their respective role in managing risk and, as this research explores, whether gender stereotypes predominately see women as the risk managers in sexual liaisons (Anderson, Beutel & Maughan-Brown, 2007). This assumption is laid bare through this interactionist inquiry of the symbolism of gender power differentials existing within slum patriarchy. The study examines if self-perception of masculine authority, as Ragnarsson, Onya, Thorson, Ekström and Aarø (2008) argue, leads young men into demonstrating sexual prowess through high-risk behaviour, which diminishes the chance of finding the means for successfully managing HIV risk.

### **1.11.2 A Situational View of Sexual Risk Taking**

This research does not draw on a specific epidemiological rationale concerning risk-averse activities. The subject of inquiry is how young people themselves perceive

preventing HIV infection within their social worlds. Risk of exposure to HIV, as well as prevention strategies in managing HIV, are complex matters. Managing risk does not equate to zero exposure to risk. Of interest to this study are the limits to individual responsibility in the context of understanding agency and managing risk of HIV. Conceptualising risk is to see the determining influence of social context and the capacity and willingness to practice safe sex. The interpretivist lens of this study understands that it is the social context that frames risk management and notions of individual responsibility. This constructivist approach seeks to explain diversity of risk and resilience, and perceptions honed by the influence of socio-sexual life courses.

### **1.12 Slum-dwelling Young People and Heterosexual Transmission**

This research is about young people living on the margins of society and facing exponential risk of acquiring HIV and managing infection. Participants are males and females ages 18–24 years and classified as late adolescents. Young women are far more affected by HIV but given that the predominant route of infection is unprotected sex between men and women, the inclusion of men in this research is vital (UNAIDS, 2015).

The evidence shows that in Kenya the primary mode of HIV infection is heterosexual transmission. Whereas infection also takes place through other routes, such as contaminated blood, this study focusses on risks associated with heterosexual sex among young people. If a dent is to be made into the epidemic, this thesis holds, then it is among young slum-dwelling heterosexual couples.

Research was carried out at two project sites in the Kenya capital, Nairobi: Korogocho and Majengo. Each project site is a designated slum area and home to teeming populations of young people eking out an existence and struggling to survive. Each location has something different to offer: Korogocho is a long-established settlement away from the city centre; Majengo is much smaller and located in the heart of the city. Each site possesses both short- and long-term residents who are mobile within and between neighbourhoods and have great ethnic diversity. Among them are young residents who have been uprooted and displaced through conflict, instability, slum clearance, violence, and disease and illness who share accounts of loss and exclusion as well as sharing in a sense of pride in making it this far. Capturing this sense of resilience, its interpretation, meaning and how it relates to managing HIV, is the essence of this study.

### **1.13 Addressing the Research Question**

This study seeks to provide an account of the meaning and construction of HIV and risk through constructivist grounded theory and lay the foundation for addressing the research question regarding ‘the process used by young people living in an urban slum in Kenya to manage the risk of contracting HIV’. Through an exploration of essential themes and ‘sensitising concepts’ at the heart of social processes, this chapter deals with research objectives of understanding the interplay between self-perceived vulnerability, risk and resilience to HIV and different levels of influence that shape the organisation and meaning of social relationships for young slum inhabitants, and whether multiple moral worlds exist concerning HIV, dignity and humiliation.

### **1.14 Chapter Summary**

This chapter introduces the study’s conceptual basis and lines of inquiry. Interpretation of the research question lies within a theoretical perspective that shapes definition, design and approach. To understand its methodology is to first comprehend a theoretical tradition that gives substance to tools of inquiry and explains the intent of such study. Rooted in pragmatism and postmodernism, and understood through the application of symbolic interactionism, this is a social study of subjective perception and role of agency critical to the process of managing HIV risk.

Slum life contains multitudes and exists within a complex socio-political environment. This research is premised on the contention that only through a holistic approach, which sees the ‘definition of the situation’ and can account for a social universe of risk, can processes be construed as existing within entwined moral and social worlds.

As shown, this research is organised through qualitative methodology that asserts the primacy of participant perception and the exploratory nature of inquiry in generating meaning and forming opinions—for both the researcher and the participant. A qualitative approach fits well with its theoretical antecedent, which recognises the plurality of interpretation and meanings generated in the course of proactive and exploratory fact finding and analysis.

This is a constructivist grounded theory of HIV risk. It follows in the Straussian tradition and takes heed of the work of Charmaz (2006) in stepping away from any notion of finding a priori truth. The situational analysis of Clarke (2005) that pushes this grounded theory round the ‘postmodern turn’ (Birks & Mills, 2015) informs

interpretation of data generated notably in analysis of relational components of actors and actants.

The chapter defines themes critical to design and conceptualisation and presents a discourse on their meaning in the context of and as relating to this study. Key to understanding processes of risk is the construct of dignity and honour, and its nemesis humiliation, as well as resilience, vulnerability and strength. This study explores how these themes, and as they are ‘felt’ by slum-dwelling youth, can exert influence on thought, perception and action and serve to accelerate or diminish attempts to manage HIV.

In line with pragmatic principles—that the act of research must have a practical basis—this work is carried out in two slums in Nairobi, Kenya with high HIV prevalence: Korogocho and Majengo. Each site provides a rich representation of the diversity of slum life and livelihoods. This is about young people, the group at most risk of contracting HIV and dying from an AIDS-related illness.

The research question is addressed in data generation, analysis and ultimately through constructing a grounded theory of HIV and risk. This chapter presents the theoretical roots adopted by the study that guide the process of answering the question of this research. A comprehensive overview of its theoretical heritage that provides the starting point for this study, its direction and flow, makes it possible to arrive at social theory that is as coherent as it is systematic.

## **Chapter 2: Research Methods—The Situation of Inquiry**

### **2.1 Introduction to Chapter**

This constructivist grounded theory study is based on the perceptions of young people. Aligned to its theoretical roots and drawing on the work of Bryant and Charmaz (2007), data were generated, not collected, and captured through two principal tools: semi-structured interviews and photovoice. Observations were made of the data generation process and captured in a series of memos.

This chapter details how data were generated on participant perceptions towards HIV and risk. It was a task of grasping and explaining nuances of meaning within participant discourse. Using the combined techniques of interview and photovoice gave added assurance that the worldview of participants would be accurately conveyed. The literature shows that these tools of data generation are effective in qualitative research and the practice of grounded theory (Pink, 2013).

This research depended on capturing the expansive and complex world of slum-dwelling youth. Grounded theory depends on empirical data and assuring integrity of these data was crucial. As the chapter shows, extensive steps were taken to ensure the authenticity of data generation. This was an environment in which English was known but was not the lingua franca, which was Kiswahili and/or one of the two dominant ethnic languages.

A research team was identified to fill the critical roles of field research. This was not, nor could it ever be, a one-person study; the environment disallowed any notion of it being so. This chapter outlines the skills required of members of the team and how together competencies complemented each other and gave a sharpness, indeed direction, to data generation.

The constructivist grounded theory adopted was forging a new pathway of slum-based research. As the chapter demonstrates, the sensitising concepts and study design, along with tools of inquiry, were revisited and amended where necessary. This social theory is dependent on young peoples' perceptions; they are the universe of this study. All efforts, therefore, needed to be taken to respect the integrity of their opinion. Ethical protocols were followed, which not only protected but dignified the space young people occupied in this study. Protocols are dealt with in this chapter, which shows how this approach is aligned to a qualitative grounded theory able to empower and enlighten participants in the study.

The intent and purpose of the research was known, so too was the sort of information required and from whom. On this basis, the chapter discusses the process of identifying project sites and the sample frame, and participant selection. An iterative approach was adopted for each aspect of this research. This chapter presents personal memos written at different stages of data generation that highlight, from the point of view of the researcher, conceptualisations and research priorities, and provide an audit trail of how and in which way decisions were made and for what purpose.

## **2.2 Conceptualising Research**

Informed by the work of Eriksson and Emmelin (2013), carried out in an urban setting, the method assemblage of situational analysis helped structure the sensitising concepts and map the mosaic of relationships emerging in the data. Sensitising concepts that indicate core lines of inquiry were established and organised according to Blumer's (1973) work in qualitative discourse, which as Clarke et al. (2015) points out is a key tool of interactionist inquiry. Sensitising concepts had both theoretical and practical significance—namely, design of the thematic *Discussion Guide(s)*—and were a key resource for interviewers and photovoice participants. The social capital of participants consistently informed the practice of conceptualisation through 'networks, reciprocity norms, trust, and collective efficacy' (Eriksson & Emmelin, 2013, p. 113).

As shown in Table 2.1, with these sensitising concepts, initial lines of inquiry were established and informed each stage of the research.



Table 2.1

*Sensitising Concepts*

Reference	Sensitising concept	Comment
1	Young people	Being and feeling young; means of expression
2	Status	Socioeconomic standing in the community; means of public recognition
3	Social media	As a medium for conveying and interpreting messages on sexuality, health and status
4	Neighbourhood	Access to social services
5	Crime and violence	Impact on daily life; personal experiences
6	Sexuality	Relationships both temporary and permanent
7	Childbearing	Pregnancy, abortion and single motherhood
8	HIV and AIDS	Knowledge and practice; treatment uptake: antiretroviral therapy (ART), pre-exposure prophylaxis (PrEP) and post-exposure prophylaxis (PEP); stigma and discrimination
9	Dignity and humiliation	Means of expression, individually and collectively
10	Vulnerability, risk and resilience	Self-perception and interface with HIV, gender and environment

### 2.3 Methodology

This research is in line with ethnographic tradition. Ethnography as defined by Brewer (2000) is the systematic study of peoples and cultures, which, for this research, yielded data on participant self-perception that were captured through interview, observational field notes and photovoice. As Ember (2006) states, as an empirically based discipline, ethnography is in harmony with the fundamental principles of grounded theory. This study provides a holistic account of the totality of the participants' universe, including human and non-human elements, structural determinants and habitat.

During the course of simultaneous data generation and analysis, key themes emerged on physical and social mobility and personal and collective status dignifying life and livelihood; avoidance of humiliating experiences; the materiality of success; interpretation of risk, resilience and behaviour; communication literacies; and moralities of emotional wellbeing. Sensitising concepts proved an invaluable tool for emerging topics such as these to be tested for their authenticity, their properties and value to

emerging provisional core categories. Within an ethnographic perspective meaning was found from participants' responses on the amorphous complexity found within the interconnectedness of urban social worlds. According to Brown (2006), the grounded theory method, as an evolving process, helps in exploring themes of an ongoing experience based solely on participants' worldviews, expressed in their own words and understood through their own frame of reference.

As an empirical social science, symbolic interactionism is well suited for the study of human group life and human behaviour and provides direction for data generation. The integrity of this grounded theory informed by interactionism is established and, as Mills and Birks (2014) state, given shape through a coherent set of methodological sequences. The pillars of grounded theory heuristics centre on data collation, memoing, sorting and diagramming, theoretical sampling, and coding and categorisation along multiple dimensions and based on constant comparison (Charmaz, 2006; Strauss, 1987).

Selection of data generation tools is strategic as, with the methodology, these tools reflect the purpose of study and form part of what Clarke (2005) describes as the 'package' of key components linked conceptually and practically. As demonstrated in Table 2.2, I saw the 'methodology–methods package' as an evolving relationship reflecting interconnectedness of parts including the relationship between participant and researcher. Study methods needed to be justified by the methodology and vice-versa. The study approach was shaped by research questions and in response to study objectives. In agreement with Clough and Nutbrown (2012), choosing study methods involved a degree of value judgement on the part of the researcher.

Table 2.2

*The Theoretical Framework*

<b>Research paradigm</b>	<b>Data analysis</b>	<b>Methods</b>	<b>Themes</b>	<b>Research subjects</b>
Primary Interpretive	Inductive	Informal interview	Dignity Humiliation	18–24-year-old Participants
Secondary Critical	Qualitative Constructivist	Photovoice Literature review	Risk Resilience	Marginalised High rates of HIV/AIDS
Post-structural	Hermeneutic		Morality and Ethics Social Capital	

**2.3.1 Identifying Research Context**

In keeping with ethnographic procedure, I spent over a year visiting Nairobi slums before fieldwork commenced.<sup>4</sup> This was complemented by extensive reading on matters relating to study themes. This reading and real-time observation was pivotal in helping me see the situation first hand and to understand the nuances of knowledge creation among young urban populations. Being immersed in the local culture proved immensely beneficial. I spent several months observing and engaging in conversation (informal and unstructured but keeping notes) with residents to gain an overall sense of how to ground the study and select the most appropriate study methods. This early interaction at project sites was helpful in the conceptual development of themes to be covered in both the interview and photovoice. My memo of 25 November 2014, observes:

*I spent the day at the Korogocho Liverpool Voluntary Counselling and Testing (VCT) conversing with staff, volunteers and users of the health services. Talking about HIV, sex and relationships appears to come easily. Talking about HIV opened windows concerning intimacy, dignity and resilience. In inquiring with a member of staff on HIV and sex, I was told that ‘here’ sex is the social currency. Later, I chatted with a 12-year-old girl, already a mother and expecting her next*

<sup>4</sup> I was a frequent visitor to the Kabira, Korogocho, Majengo and Kawangwari slums, and to geographical areas situated close by: notably, Kariobangi, Race Course and Pangani

*... I noticed the distinct absence of men at the centre and was informed by staff this is quite normal.*

I wrote another memo written following a visit to the same site on 15 August 2016:

*I was asked to give a few words of encouragement in advance of an HIV testing event for around 20 young women. The pre-test counselling was excellent and carried out by a 15-year-old girl. I was told that many will likely test positive and just as likely as a result of sexual violence.*

### **2.3.2 The Study Sites**

For this grounded theory to stand, I had to be certain there was a sufficiently strong foundation on which to make my claims and form my conclusions. It is never easy to draw the line between enough and not enough, particularly in qualitative research. This was made clear in the complex and challenging nature of researching in the inner-city slum. My memo of 25 October 2014 raises this concern:

*I know that 'place matters' in understanding the nuances of HIV transmission. I need to find the best place to do this. Although, after a fashion, district boundaries exist, they are fluid and inextricably linked; it is a web of dependent parts. To build theory on the perceived and lived experience of young people, I need to be cognisant of the fact that where people live and work will likely influence their worldview, especially so over a life span, which impacts levels of risk and vulnerability.*

The choice of locations was based on my expanding knowledge of Nairobi and the nature of urban risk. My principal sources, from both quantitative and qualitative studies, that influenced choice of research sites included the cross-sectional surveys of the APHRC (2002, 2014), the *Kenya AIDS Indicator Survey* (Ministry of Health, 2012), the *Kenya AIDS Strategic Framework 2014/2015–2015/2019* (Ministry of Health, 2014), the *National AIDS Control Council Agenda, 2015–2018* (National AIDS Control Council, 2015), studies on migrant health in Nairobi (International Organization for Migration [IOM], 2013), the *Global AIDS Progress Report* (UNAIDS, 2014b) and the *Fast Track to End AIDS* (UNAIDS, 2015). Having studied these and other seminal texts, and aided by the tools of thematic analysis, I established criteria to guide my choice of location:

- high HIV prevalence
- officially designated slum settlement
- mixture of short and long stay residents
- distance to commercial corridors, less than 1 kilometre
- distance to sites of commerce, less than 1 kilometre
- estimated number of young residents in the area
- existence of basic information on slum settlement
- non-hindered access to project sites
- practicality of using the two principal methodologies: photovoice and in-depth interviews
- availability of HIV and trauma services, less than 2 kilometres.

There are an estimated 200 settlements in Nairobi, and around 19 officially recognised slums (Kenya National Bureau of Statistics, 2009). There is much debate on the accuracy of these figures, and I learned early on they are indicative rather than factual. Many of these sites partially met the criteria, but few, it appeared, provided sufficient depth or scope to meet all requirements. As I studied the landscape further, I was drawn to the notion of using not one but two project sites. I needed rich data and the thought of two separate sites became appealing. I travelled to numerous sites, in particular ‘Kibera’, said to be Africa’s largest slum. In an informal capacity I spent time visiting and observing HIV services and health clinics, schools and ‘drop-in centres’, and held discussions with service providers situated within the communities. I spoke with fellow researchers well versed in Nairobi and identified the ‘gap areas’ and spaces of information deficit. As much as I could, I investigated local cultural settings, built networks of key informants and made many new contacts that helped shape my own worldview of Nairobi urban slum research.

Although not part of site selection criteria, another element proved pertinent in my search for the right location(s); that is, the quest for originality. Although grounded theory analysis was novel within the research community in Kenya, some of these areas, notably Kibera, are well traversed and social life well documented. Kibera would have been the most accessible and met all the selection criteria but given its familiarity to the research community, through both quantitative and qualitative study, it became less appealing; I did not want to limit the significance of my contribution to the body of knowledge.

My selection was finally made after months of deliberation. From the information available, coupled with my own observations, I decided on two project sites: Korogocho and Majengo. Both are inner-city slums, and where one was wanting in meeting terms of the criteria, it was more than made up for by the other. Together they provided commonality and a distinct identity. They both have, for example, a runaway HIV epidemic among young people, and in each setting the bulk of the population is young. Both locations are steeped in poverty. There is far more available information on Korogocho than Majengo, which, in the case of Majengo, only served to draw me to the area; what information did exist pointed to the urgent need for qualitative study. The challenge of researching in Majengo, which was described by one informant as a ‘dangerous and difficult place’, also held the potential to reveal rich insight and credible data. Korogocho, with more empirical evidence to draw on, could help provide the backdrop to slum residency relevant for each location. The two sites are approximately 10 km apart in the city of Nairobi (see Appendix A).

There are also notable differences regarding patterns of residence and ethnicity in the two sites. Korogocho is primarily inhabited by long-term residents, whereas Majengo is known for its new arrivals and migrant population (although later, during fieldwork this was more accurately described as inter- and intra-slum mobility). Majengo has a far greater ethnic mix and fluidity than Korogocho and in terms of population size and geographic spread, it is smaller than Korogocho. Swathes of the population in both locations are considered as living in abject poverty with high rates of unemployment and seeking sustenance through an unregulated informal sector with very little job security. Jobs, money and opportunities are scarce at each site, which lack even the most basic services including Antiretroviral therapy (ART) distribution points. Further, Majengo was described by one participant as the slums’ ‘red light’ district.

I was confident that construction of theory would be strengthened by data generated from two sites. However, it was not my intention to conduct a comparative study. My goal was to delve deeply to answer questions asked in this research in information-rich settings, and to crystallise theoretical conceptions. That said, a record was kept of participants’ locations and any significant data differences between the sites were recorded. My aim was to produce one grounded theory relevant to both locations, not one for each site. If significant differences emerged, then this would be captured in coding and analytic processes.

For the sake of efficiency as well as expediency, I decided that data generation should first proceed in Korogocho and then move to Majengo, while continuing, if need be, in Korogocho. From there and directed by principles of theoretical sampling and theoretical sensitivity, further data generation would continue in either Korogocho or Majengo depending on the process and status of developing social theory.

### **2.3.3 Recruiting Participants—Purposeful and Theoretical Sampling**

The purpose of this study was not to test hypotheses or identify predictors of behaviour change as is typical of quantitative analysis; it was to elicit perceptions that lay hidden behind statistics and provide fresh insight into issues concerning infection in HIV hotspots. While it was believed this study would be of benefit to the communities in question, it was not structured as ‘implementation research’ that draws on and produces probability analysis applicable to all Nairobi settlements.

As Clarke et al (2015) points out, the objective of research methodology is intrinsically linked to research goals and methods for generating information that is both relevant and current. The aims and assumptions of the sampling approach must remain consistent with the conceptual paradigm. Aligned to the work of Creswell and Plano Clarke (2017), for this research, the sampling strategy was derived from the conceptual framework and research questions to be addressed. Creswell and Plano Clarke (2017) draw attention to the need in qualitative research to find participants who are knowledgeable and experienced in an identified setting. Bernard (2002) highlights the importance of finding participants able and willing to share their knowledge and experience in a helpful and constructive way that adds to the validity of findings.

Given the need to find a representative group of young people, the premise for participant recruitment was, as per Birks and Mills (2015), the accepted grounded theory practice of purposeful sampling. A purposeful sample is a non-probability sample that is chosen owing to shared characteristics of a subpopulation. Suri (2011) demonstrates the success of purposeful sampling in information-rich settings related to the phenomenon of interest. In the literature, purposeful sampling is also termed ‘judgemental’, ‘selective’, or ‘subjective’ sampling. ‘Judgemental sampling’ is an interesting turn of phrase as it correctly denotes the involvement of the researcher in a critical stage of the research project.

Purposeful sampling proved a useful method in reaching a targeted population; sampling for proportionality was never the concern. Of the different types of purposeful sampling, viz. expert; homogeneous; maximum variation/heterogeneous; total

population; critical case; typical case; and extreme/deviant case, the technique of homogenous sampling was selected. According to Crossman (2017), homogenous purposeful sampling is a strategy that reduces variation, narrows focus of analysis and facilitates interviewing. This sampling strategy, as Cole (2018) states, compares and contrasts and identifies inconsistencies in lines of discourse as well as shedding light on identities, core properties and dimensions. Shortcomings of the purposeful sampling method were noted especially in regard to the possibility of a 'heavy hand' from the researcher. Yet despite this critique, and no tool is faultless, it was still felt that homogenous purposeful sampling was the most appropriate.

Despite a plethora of research on HIV and youth, the interlinking themes of dignity and humiliation and risk and resilience are largely untouched and the range of variation—a key determinant in sampling—remains inconclusive. Aware of the continuing debate in setting the parameters for HIV urban research, this study is based on an iterative approach towards sampling that continues until a point of saturation occurs and theory emerges. In considering alternatives, in agreement with Bernard (2002), a drawback with forms of 'systematic' or 'realist' sampling is the purported link with positivist postulates and approaches to the conceptualisation of factual evidence. Purposive sampling was the first stepping stone in understanding, trusting and respecting participant-generated data premising subsequent analysis.

This research broadly followed a 'funnel approach' of first sampling for variation (breadth) proceeding to sample for commonalities (depth). This method is known for its compatibility with semi-structured interviewing and fits with the classical grounded theory approach (Glaser, 1978). Data generation commences with a broad view of the topic and gradually narrows to specific elements pertaining to the emerging core category. As the full range of variation was not known at the start, sampling and analysis had to be iterative with each stage informing theoretical sampling and accommodating unforeseen opportunities and constraints.

Following the first round of purposeful sampling, I adhered to the methodological imperative of theoretical sampling. Breckenridge et al. (2012) state that theoretical sampling is an active and ongoing process that directs collection of data and formation of theoretical insights and provides the bedrock for an analytic abstraction of theory. For this inductive approach, theory gradually emerged from the process of data collection in which the relevance of a data source could not be predicted in advance. In agreement with Horsburgh (2003), selection of participants for this research, and the



reason for that selection, evolved with the theoretical needs of study. Therefore, sampling was guided by emerging theory pointing where to sample next and for what theoretical purpose (Breckenridge et al., 2012). As discussed by Walker and Myrick (2006), researcher conceptions of HIV in slum settings contributed to theoretical development, notably at the outset, by providing a point of departure and raising the first round of questions. In line with Breckenridge et al. (2012) while descriptive demographic and social characteristics provided a point of departure for data collection, prior knowledge was only of relevance if it was validated in the formulation of emerging theory.

### **2.3.4 The Sample Frame**

Research precedents helped guide my crafting of a sample frame including participant characteristics thought appropriate for the generation of data relevant to the needs of this study. A ‘criterion sample’ was created that was made up of a 16-point criterion of eligibility principally divided between males and females.<sup>5</sup> Formulating a sample frame was much influenced by sensitising conceptions; as well as knowledge of ‘evidence-based practices’ demonstrating vertical relationships; HIV practice from county to local level; and horizontal links between slum-based HIV programming and local institutions. The concern was not generalisability but identifying individuals who, as Rolfe (2006) states, were in the best position to interpret the lived reality under study. Morse (2010) makes clear that this approach focusses on an initial set of individuals whose social worlds interlock; the nature of these connections, in and of themselves, provide a valuable source of information.

I had to consider the size of the initial sample. Guetterman (2015) considered the 10 most cited studies employing grounded theory in education and health research and found that sample sizes ranged from 6 to 147. Mason (2010) cites 20–50 as a guide to sample sizes for grounded theory studies. However, grounded theory is unique among qualitative approaches in its emphasis on saturation and likelihood that new data required for theoretical conceptualisation are often gained from a small subset of the envisaged sample. I chose to have a minimum of eight persons from each location possessing one or more characteristics from the sample frame, realising that in the process of theoretical sampling this number would likely increase. The first round of

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<sup>5</sup> In its original conception, I wanted to recruit members from LGBT communities (Roffee & Waling, 2017). However, only participants identifying as heterosexual became participants in the study.

interviewing aiming at eight participants would be sufficiently broad, providing a solid grounding and pointing to where and with whom I needed to sample next. A sample frame was established (see Table 2.3), identifying characteristics of participants to be recruited to the study.

In practice, the sampling frame, based on a soft quota, did not require substantial revision. There were just three areas that did require addressing as became apparent during fieldwork. First, in discerning if the participant had children was, I learned, something of a spurious undertaking. While a useful indicator, it had to be interpreted in a different light than first envisaged. That is, even if the participant did not have children of their own, they were often responsible for others' children; some had their child dependents with them, others nearby or residing with a relative, perhaps on a semi-temporary basis. Lines of distinction between these categories often became blurred. In a way, I realised it reflected my own ethnic bias in that there must be clear distinction in the concept of mother- and fatherhood. Yet culturally, such a categorisation did not hold. During our discourse I would inquire if the participant had children of their own and inquire if they were responsible as a primary caregiver for other dependents (that also included elderly and/or disabled persons) at that moment in time.

Table 2.3

*The Sample Frame*

	<b>Gender</b>	<b>Parental status</b>	<b>Employment status</b>	<b>Length of stay</b>
1.	Female	Without children	Employed	Short
2.	Female	Without children	Employed	Long
3.	Female	Without children	Unemployed	Short
4.	Female	Without children	Unemployed	Long
5.	Female	With children	Employed	Short
6.	Female	With children	Employed	Long
7.	Female	With children	Unemployed	Short
8.	Female	With children	Unemployed	Long
9.	Male	Without children	Employed	Short
10.	Male	Without children	Employed	Long
11.	Male	Without children	Unemployed	Short
12.	Male	Without children	Unemployed	Long
13.	Male	With children	Employed	Short
14.	Male	With children	Employed	Long
15.	Male	With children	Unemployed	Short
16.	Male	With children	Unemployed	Long

The second concern was unavailability of young men. The first round of purposeful sampling envisioned having an even split between male and female. In hindsight this was possibly naïve and arguably had quantitative research undertones; that is, the research was following numerical protocols. I wanted a theory grounded in data and not dependent for its success on statistics; it was quality not quantity. As the literature demonstrates, there are grounded theory studies based on uneven gender representation, and this was to be one of them.

No gender parity was achieved in the first round or thereafter. I would ask to have more men included but with little avail. On numerous occasions interviews were arranged with young men only for them to cancel at the last moment. A general unpredictability of young men was regularly mentioned by both male and female participants. However, the young men that did participate generated informative and valuable data. As data generation proceeded and points of saturation began to emerge, including data from male participants, I perceived the gender imbalance as less of a

problem and remained confident in being able to form a balanced social theory. I wrote a memo on 1 December 2016 on the matter of male engagement:

*Lack of male engagement tells a story. In the dialogue with participants, especially females, issues surrounding male irresponsibility are often raised. Not that I want to see this as a 'universal truth' but cannot help noting the similarity between perceptions and experience.*

Regarding an interview with a young man I wrote a memo on 5 December 2016: *at first putting on a 'bravado act' to show me how unconcerned he was with the interview, after probing (and humour) he opened up and let me into a world that was utterly new to me. According to him, being unpredictable is 'cool' and the social value of a non-committal attitude took on an added importance.*

The third issue was trying to achieve an even split between Korogocho and Majengo. This did not happen as most data were generated in Korogocho. At the initial planning stage an even divide in participation was envisaged between the two research sites; that is, an initial eight persons from each location. This was based on the simple notion that a grounded theory had to demonstrate evenness. It was again, arguably, an instance of preconceived ideas on building numerical strength. Certainly, both sites had much to offer—that was never in dispute—but the goal was to generate theory based not on numbers but self-perception. As the research proceeded, I realised that data being generated had far more in common from the two sites than separating them. Moreover, from the rich data generated in Korogocho, I was now more particular about who to speak to in Majengo and on what subject. The choice of participants to be interviewed in Majengo was informed by initial open coding and mapping carried out in Korogocho.

## **2.4 Research Team**

### **2.4.1 Lead Researcher**

The research was conceptualised, designed, executed and reported on by myself, in the role of lead researcher. I was responsible for the successful completion of each stage of the research and was accountable for any discrepancy or change in study protocol. This necessitated an almost constant presence at the project sites. Having spent many years working with HIV and human development in Africa this did not in itself pose any problem of note. I had a base and knew the terrain, including the research environment. From this experience, I was aware of the many emotive issues involved with HIV research, the politics of HIV prevention and the need to keep

direction in a potentially stressful study setting. This research could not be carried out alone and as shown in Table 2.4, a competent team of experts empathetic with the aims of this study and technically competent in working with HIV in a Nairobi slum was established.

#### **2.4.2 Research Coordinator**

In keeping with accepted practice for Kenya-based research, I selected a field coordinator. The appointed coordinator helped in the selection of mobilisers, interviewers and transcribers; facilitated introductions and regular liaisons with local authorities; verified accuracy of translation and transcription of interview and photovoice scripts; and assisted with safekeeping of digital cameras.

#### **2.4.3 Mobilisers**

The ‘social mobilisers’, or ‘community health volunteers’ were the point of contact with participants. Following the sampling frame, the mobilisers recruited participants and arranged the time and place for interviews. Mobilisers were selected on their knowledge and status within the local community and were registered with the Ministry of Health as bona fide professionals in their respective fields. As I was commencing with purposeful sampling, being introduced immediately to study participants who knew the area made perfect sense. Although the mobilisers would identify and introduce potential participants, it was my decision whether to proceed with interviewing. Only on two occasions were potential interviewees rejected owing to their lack of cognitive function and inability to consent.

In Korogocho, two mobilisers were selected. The purpose of the research was discussed with the mobilisers, clarifying criteria for participant selection. In Majengo, it was principally just the one mobiliser. With each mobiliser, all aspects of the research were discussed, especially selection criteria. The research team would meet at the start of each day’s interviewing for the ‘morning briefing’ in which the schedule for interviewing and respective responsibilities for mobilisers set. The mobilisers in Majengo and Korogocho remained close at hand for the duration of fieldwork. All mobilisers delivered on their task of making vital connections with participants aligned to the sample criteria.

#### **2.4.4 Interviewers**

A major concern of this research was the medium of communication with participants. A flow in the conversation and uninterrupted dialogue was critical. Given the strong likelihood of having to work in a third language, it was crucial to have a

competent team of multilingual interviewers. Through an official database, skilled interviewers were identified able to converse in local languages. A team was formed consisting of five females and one male, plus the coordinator (male)—and myself—making a total of three males. A WhatsApp group was created for the research team and used to good effect for building relationships of trust.<sup>6</sup> I encouraged constant communication and questioning of any aspect of the research by the team.

The research design had envisaged a gender balance among the interviewers. An ethical requirement was, if requested, to match the gender of the participant with that of the interviewer. The bias towards female interviewers did not prove an impediment as most participants were females. Of the female interviewers, one was a state registered nurse and the other a certified HIV counsellor. Each member of the team was fluent in Kiswahili (the lingua franca), the ethnic languages of the area and English. Interviews could now be conducted in a language of the participants choosing and be gender sensitive.

Soon into interviewing, I was confident that the interviewers had grasped the principles of this research and were performing well. At the time of the last round of interviews, a positive rapport had been established with interviewers, which aided dialogue with participants and ultimately theoretical conceptualisation.

#### **2.4.5 Transcribers**

Two suitably qualified transcribers, one male and one female, from the research team were identified. The principal skill of the transcriber was the ability to form one coherent document in English based on the audio recording in Kiswahili and notes taken in English, and to do this in a very short timeframe. Given the simultaneous process of data generation and analysis, a minimum of two transcribers was necessary. I was keen to have a gender balance so that should there be dispute in translation of meaning or intonation or manner of speech, there would be a male and female perspective. It also became the practice that one transcriber would spot check the work of the other, before handing it over to the coordinator for final inspection, and eventually myself.

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<sup>6</sup> The WhatsApp group was named 'Dignity'.

Table 2.4

*The Research Team*

Research team	Gender	
	Male	Female
Lead researcher	1	
Field coordinator	1	
Mobilisers Korogocho	0	2
Mobilisers Majengo	0	1
Transcribers	1	1
Interviewers	3	5

## 2.5 Ethics Protocols

For this research to proceed, ethics clearance was required by two boards: The Economic and Social Research Council of Kenya and the Human Research Ethics Committee of James Cook University, Australia. There was broad agreement in the requirements of both authorities, with the only differences being of a procedural nature. From the outset to its conclusion, all ethics requirements were followed to the letter. The ethical integrity of this study was assured by adoption of the following steps.

### 2.5.1 Informed Consent of Participants

At the start of each interview and photovoice, the detail of an *Informed Consent Form* was read and/or given in writing to each participant, in the language of their choosing. The *Informed Consent Form* presented aims of the research and detailed measures to be taken to assure confidentiality and respect of participant wishes. Prior consent, verbally and in writing, was sought before data generation proceeded.

For the photovoice, two forms were used: one for the participant and the other for subjects photographed. For the latter, if it was not possible to obtain written permission from the subject, then a ‘no face’ rule applied in which anyone photographed could not be identified.

It was made clear that the participant was free to leave the research at any time and with no repercussions by contacting me directly or through a third party and could do so in writing or verbally. As it happened, each participant gave their go-ahead without reservation and appeared only too pleased to be taking part; they often expressed reluctance when the interview or photovoice was over. An ambience of

respect surrounded engagements with participants and the discussion was free flowing; participants, and research team, felt safe and respected.

### **2.5.2 Language and Context**

As Ahearn (2016) states, decolonising theory highlights the subject of language and power in the research process. Accordingly, it was the participants who chose the language of discourse for all study interaction. Language is an important expression of identity, background and status. As Ahearn (2016) considers, language is embedded in culture and reflects collective patterns of behaviour, beliefs, knowledge, attitudes and values. The participant's choice of language was respected, as was their immediate cultural setting. Language and cultural context were the stepping stones in discerning the range of perceptions regarding wellbeing and demonstrated the role and influence of moral social worlds. It was not just the spoken word but also the symbolism of 'body language' and gesture. There was meaning in participant posture and modes of interpretation, which became part of the medium of communication between researcher and 'researchee', all of which were recorded in field notes and described in memos. No less than the spoken language, the physical communication of the participant was respected and responded to in an appropriate and sensitive manner.

### **2.5.3 Gender Sensitivity**

Thematic lines of inquiry involved notions of sexuality and sexual awareness that were approached in a sensitive manner and respectful of the gender of the participant. Gender is a major determinant of how questions of morality are communicated and interpreted, which, according to Mohanty (2003), can evoke deep feeling and unpredicted response. For every interview, the participant was given the option of which gender should be present in the room. If the participant was female, I would inquire whether it was appropriate for me to be present. The inevitable response was captured in a memo of 2 October 2016:

*Female participants appear quite accepting that I am present. Something unexpected has come to light. Abstaining from an interview with a female participant could signal a lack of interest on my part; a value judgement that I considered her opinion of lesser importance. My presence had a more powerful meaning than my gender. Besides, as interviews are conducted in Kiswahili, this appears to provide a cushion for the participant to raise sensitive topics out of earshot and as part of the interview is conducted by a female interviewer, the participant does not need to make eye contact with me.*



#### **2.5.4 Participating in the Generation of Knowledge**

The people of this study were perceived as participants and not subjects to be researched. As Coleman, Menikoff, Goldner and Dubler (2005) explain, these young people were participants in generating data for human subject research and able to give it meaning. Through their participation, young people were not just creating data, on their terms, but likely seeing their current circumstance in a new light. In agreement with Wilson (2001) it was an instance of emancipatory research for disadvantaged people actively participating in knowledge creation, and of direct benefit to them. Moreover, knowledge, as seen in this study, is generated through countless modes of interaction that give layers of meaning and mould individual and group consciousness. The young people in this study participated in building a grounded theory of HIV risk that fits with their social worlds and provides the basis for further active engagement within their living environment.

#### **2.5.5 Privacy and Confidentiality**

During and after the interview, a strict code of conduct was observed in which ‘anything said in the interview stayed in the interview’ and pictorial evidence from the photovoice would not be shared without participants’ prior permission. With the continuing stigmatisation of HIV and AIDS, and discourse on sexual matters, it was vital that a code of confidence was maintained for this participatory research. Krause and May (2016) have it that when trust is established, dialogue is empowered and transparent, and sheds light on situations that otherwise would remain hidden. It was precisely these ‘non-public’ moments that this research was keen to capture and could only do so if there was an ambience of trust and respect.

#### **2.5.6 Venue**

Most interviews were carried out at the participant’s residence. The research team went to the participant and not the other way around. Any inconvenience for the participant was kept to an absolute minimum. This simple act was a powerful statement of recognising the participant’s place as, in local cultural terms, it is deemed a courteous thing to do. I was the invited guest and went along with the rules of the residence. Only when it proved impractical were interviews held in another location. For Korogocho, this was the APHRC office in nearby Kariobangi; for Majengo, it was the Chief’s office. Both were near the homes of participants.

### **2.5.7 Honorarium**

A onetime out-of-pocket allowance was paid to the participant in lieu of time given to this research. The amount was just enough to compensate for lost earnings and in some cases transportation. It was made abundantly clear that this support was not intended to pay for knowledge but as an honorarium, a means of compensation for interrupting a busy daily schedule. This was no more than expected practice for research in Nairobi. In each instance this was warmly received and never was any member of the research team asked for more, as to do so would be undignifying. The honorarium was paid at the end of a dialogue and was the same amount regardless of status, age or gender of the participant, time taken in the dialogue or quality of information received. No honorarium was paid to key informants who were recognised experts on HIV and slum settlements and did not reside at the project sites; their circumstances were wholly different and not in line with standard research procedure in Kenya.

A daily payment was made to each member of the Research Team. This was based on rates commonly paid to research assistants in Nairobi and did not require negotiation. The payment for services remained the same regardless of length of time spent in the field, or the gender or age of the research assistant.

### **2.5.8 HIV Status**

Never was HIV status queried; information on personal HIV status was always only ever volunteered by the participant. When a participant did speak of their HIV status, it was met with a neutral response. As and when appropriate, I would raise the importance of having an HIV test (talking in the third person) and explain the efficacy of treatment regimens, and on three occasions offered a helping hand if that was desired. Participants' knowledge of HIV and medical services, including PrEP and PEP, was as impressive as it was accurate. Additional information on HIV was given to participants whenever requested, either directly or through a third party. I did not challenge or pursue further if, by my visual observation, a declared HIV negative status did not appear correct. It was important for the participant to feel at ease in the research situation and efforts taken to not let disclosure of HIV status be the reason for rupture in the dialogue or, worse still, lead to feelings of shame or humiliation.

### **2.5.9 Support Services**

Within the research team there was a state registered nurse and an HIV counsellor who were ready to assist if the need should arise. There was in the immediate vicinity a VCT, situated at the Chief's office in Korogocho, which had been alerted of

the study and was on standby. In two instances, I was asked to help organise an HIV test, to which I consented with the help of the HIV counsellor. In numerous interviews that involved outpourings of emotion, I suggested that the dialogue stop. However, participants, without exception, asked to continue, stating that they felt better after releasing pent-up emotion; nonetheless, the offer of trauma counselling remained. In the one year following fieldwork, no participant contacted me or any other member of the team to access trauma services.

## **2.6 Data Generation**

### **2.6.1 Semi-structured Interviews**

In building a grounded theory, the primary tool of investigation was semi-structured interviews. In-depth interviews were held with young people from the two locations and key informants selected for their knowledge on one or more aspects of this study. As Birks and Mills (2015) state, this type of interviewing works well and is common in qualitative research.

I confirmed during research the efficacy of semi-structured interviewing to unearth data that would explain the nature of the myriad forms of social interaction by providing detailed accounts that often proved very personal and deeply moving. Without exception, this approach to interviewing facilitated an open and enriching exchange. The range of open-ended questions at times diverged from the norm so that discussions could follow topical trajectories in conversation and provide a window to observe data in a new light. In agreement with Duffy, Ferguson and Watson (2004), using a semi-structured format allowed participants to construct personal narratives about their lived experiences and social relationships in a way that made sense to them and provided reliable, comparable qualitative data. As Bernard (2002) states, semi-structured interviewing with open-ended probes is appropriate in a research context such as this, not least, as some participants were interviewed more than once on emerging topics.

### **2.6.2 Interviewing; Procedure and Protocol**

Based on the sensitising concepts for this research, an initial set of questions was devised and piloted with three participants, checking for appropriateness, interpretation, reaction and relevance to the research question. The feedback was positive with the only revisions being made in the order and emphasis given to discussion points. Of note, questions relating to sex were now moved forwards in the interview as, according to the

feedback, this would not prove an issue. From the results of the pilot, the *Discussion Guide* for interviewing was prepared, as shown in Appendix B.

Interviewing began in August 2016 with eight participants in Korogocho, and continued in both Majengo and Korogocho, concluding in August 2017. All interviews were conducted in person except for one with a key informant, which was by mobile phone. For key informants, the research team was not involved as there was no challenge of language.

At the end of each day's interviewing, the research team would meet in the APHRC's Kariobangi office for Korogocho and at the chief's office for Majengo and discuss progress of the study. A part of this exercise was ensuring that for each interview there was a signed *Informed Consent Form*, audio recording and notes.

Although maximum flexibility was afforded to the interviewer and best efforts made to create a relaxed non-threatening ambience, the interview still maintained an air of formality. The rules of communication between interviewer and interviewee: question and response with no interruption from either party was established without difficulty. I wrote a memo on 30 September 2016:

*This is a piece of theatre and while we don't know how it finishes, we do know what will be happening; I know that they know that I know ... This social interaction demonstrates shared background expectancies concerning the research situation.*

Although most participants had never been interviewed before, and it was therefore a new experience, the code of 'polite conversation' premised discussions in which greetings initiated the interaction, and light conversation then commenced on subjects not necessarily relevant to the interview; there was no cross-talking; no one was judged, criticised or rebuked. Extracts from a memo of 15 November 2016 include:

*Emotion is often expressed when a participant relates a personal narrative. At this point, the 'body language' invariably changes. When one young female participant had broken into tears (and insisted that the interview continue), afterwards she had a look of contentment, a great load had been lifted from her ... We had achieved our objective of gaining rich information, but it was more, we were now trusted confidants.*

Rowley (2012) suggests that questions asked in qualitative interview are better described as probes or prompts. Bjørnholt and Farstad (2014) claim that the skill of the interviewer in probing is to allow participants to interpret and respond to questions in

their own way while keeping the participant on track. However, I did not consider that all themes should be covered in every interview; it all depended on the participant and flow of conversation and in due course, theoretical sampling. If, for example, the participant wanted to talk in depth on just one aspect still relevant to the topic, then that was acceptable. The *Discussion Guide* drawn up in advance of the study was in both English and Kiswahili and took the form of a grouping of questions organised around given topics. These questions, or probes, were often asked in different ways with different participants. The semi-structured interview gave the space for this creative interaction.

Each interview was attended by an interviewer and a note taker. Probing was primarily carried out by the interviewer (in Kiswahili) and guided by me. However, my interjections were limited as too many could spoil the flow of conversation and a ‘stop–start’ would result in lost meaning. I prioritised the interviewer establishing a meaningful rapport, which included making eye contact and watching for tell-tale signs from the participant’s ‘body language’, all of which were noted. All interviews were transcribed into English and compared with interview and observation notes in as short a time as possible by the transcriber; never more than a 5-day period.<sup>7</sup>

In the initial interview design, it was thought that each interview would last around 45 minutes. As experience showed, this was a gross underestimate. Each interview lasted 2 hours on average. Providing the timeframe was acceptable to the participant, interviews continued until they had run their course. Not untypically, the dialogue was slow at first and possibly stunted but gradually grew into a rich and very often lively discourse. In a word, if the participant wanted to keep talking then this fell within the remit of sensitive ethnography.

### **2.6.3 Statement Cards**

Drawing on the sensitising concepts, feedback from the pilot and informed by Modes of Transmission (MoT) studies as outlined by Shubber, Mishra, Vesga and Boily (2014), a series of statement cards were used in each interview. A short statement, as shown in Table 2.5, was written on each card and passed to the participant, normally towards the end of the interview. Participants were asked to rank the cards in order of importance. If the participant decided the statement was irrelevant or did not understand

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<sup>7</sup> In addition to two audio recorders, a mobile phone was used. All audio records were uploaded to the researcher’s laptop.

its meaning, the card was put aside. Once the cards had been arranged, the participant would be asked to explain, in their own words and in their own time, reasons behind the choice. In some cases, the participant found it hard to explain why they had chosen a particular card and simply said ‘it felt right’; upon which, and through sensitive probing, the participant would be helped to find words to describe that feeling. For example, as one participant said, ‘it just makes me feel wanted’.

Table 2.5

*The 16 Statement Cards*

1. Having children
2. Stable relationship
3. Living in a good area in Korogocho/Majengo
4. Abstaining from sex
5. Being attractive
6. Being young
7. Staying away from family
8. Living in a bad area in Korogocho/Majengo
9. Being HIV positive
10. Being good at sex
11. Being pregnant
12. Being from a big family background
13. Living away from your family
14. Being older
15. Having multiple sexual partners
16. Having a higher-level education

The purpose behind this initiative was multi-fold. First, it afforded autonomy to the participant and broke away from the typical interview pattern of question–answer/stimulus–response. Sorting these cards in an order that made sense to the participant meant they were responsible for the exercise and not the researcher. It was not uncommon for a participant to keep altering the ranking of a card.

Second, use of the cards provided an excellent insight into the participant’s perceptions and strengthened understanding of meanings being conveyed. In some instances, new ideas emerged and from there, lines of inquiry. Again, this encouraged the young person to participate more and become further involved in the interview and the research; I followed their lead. It was a shift in power dynamics.

Third, this exercise provided an informal check against data generated thus far and helped to illuminate any discrepancies. Even if no contradiction was noted in the

data, there was now a deeper insight into perceptions of family networks, personal space, status in the community and of personal aspirations based on what meant the most to each participant. This added knowledge helped shape the ensuing discourse. Interpreting and sorting the cards was not an exercise in finding uniformity, which could be interpreted as seeking one clearly defined social process; it was as much about seeing points of contradiction and discursive elements in the emerging grounded theory. As Mason (2010) states, in qualitative research, this is an accepted and fundamental part of inquiry. Just as interesting was the card pile of ‘don’t know’. I initially thought that these cards would have been sorted and ranked, and the fact that they were not shed light on my own interpretation of the data. This relates to what Charmaz (2002) describes as the significance of ‘silence space’.

Fourth, it was often a light-hearted exercise with much mirth between researcher and participant. I did not anticipate such a reaction; discussions of HIV rarely go with laughter... This came as something of a welcome relief if the interview had been intense. The ‘card game’, as it came to be known, was an interesting way of raising potentially difficult or sensitive subjects in a non-threatening and even jovial manner.

For each participant, as given in Table 2.6, there did not appear to be significant difference between gender and/or HIV status in the ranking of statement cards.

Table 2.6

*Participants in the Research*

<b>Participants</b>	<b>Majengo</b>		<b>Korogocho</b>	
	<b>Positive</b>	<b>Negative</b>	<b>Positive</b>	<b>Negative</b>
Male	2		4	
Female	4		11	
Total	6		15	
<b>HIV status</b>				
HIV status male	0	2	1	3
HIV status female	2	2	4	7
<b>Total HIV status</b>	2	4	5	10

#### 2.6.4 Interviews, First Round, Korogocho

Interviewing commenced in Korogocho. There was no set order to the interviews—for example, male then female; they were invariably organised on participant availability. The *Discussion Guide* (English and Swahili versions) was tested

for accuracy during these first interviews. In the presence of a ‘community minder’ and led by the mobiliser, the research team would walk from one interview to the next.

Key observations were made from the first round of interviews. I had underestimated the scope of topics under research. Any one of the themes being studied—HIV, youth, risk, behaviour, resilience, social networks and so on—could easily have dominated the entire research process. Regarding interviewing, to maintain a balance with research themes, one strategy was to note ‘linking concepts’ that could take the discussion from, for example, HIV, to being young, to risk, to dignity and humiliation. This would also entail imaginative movement around the *Discussion Guide*.

In the research design, I did not reckon on the amount of data being generated from the interviews. Some transcripts ran to 60 pages. The time originally envisaged for reading and coding transcripts was underestimated; a manuscript could take over a week to code. The process was assisted using the software NVIVO II for organising data and creating open codes. In analysing what was already becoming a vast amount of data, gaps appeared in the evidence and topics not previously considered relevant now became core components of emerging theory. Tensions arising in the analysis informed the direction of questioning and with whom for subsequent rounds of interviews. The interview process was dynamic and continued to evolve. This was the essence of theoretical sampling. Where necessary, situational analysis maps were drawn that helped with the task of organising data and keeping theoretical direction.

### **2.6.5 Second Round Interviews and Key Informant Interviews**

With the first round of interviews completed, the second round commenced in Korogocho as well as the first round of interviewing in Majengo, guided by the principle of theoretical sampling. As data was being generated in the second round, the first key informant interviews were held.

Although Payne and Payne (2004) suggest that in qualitative studies, key informant interviews generally figure early on, for this research, they were organised only when theory began to emerge. My research design included that key informant interviews followed those held with participants from the sampling frame. As I had a background in HIV, it was unnecessary to base ‘start-up’ on key informants’ input. Key informant dialogue helped to fill data gaps in theoretical sampling and provide clarity on thematic questions for which they are a recognised expert. The key informants



interviewed were selected owing to their specialist knowledge relating to ‘slum habitation,’ which strengthened the evidence of socioeconomic processes.

I heeded Payne and Payne’s (2004) assertion that key informants speak from their own perspective. It was important for me to achieve a broader overview of research topics and especially HIV policy, strategy and programming with urban youth. At times, key informants challenged my theoretical persuasions and in defence, I was forced to reconsider my analysis and, in so doing, strengthened my own knowledge of the various subject areas.

Table 2.7 demonstrates the areas of specific focus and gender relevant to each Key Informant interview.

Table 2.7

*Key Informants*

<b>Key informants</b>	
Gender	Female
Background	HIV/gender
Gender	Female
Background	Urban policy/HIV
Gender	Male
Background	Urban migration
Gender	Male
Background	Urban adolescents

The more information that was generated from each project site, the longer it took to analyse as now it was being sorted into higher-level coding and through constant comparison substantiating core categories. As part of the second round, five participants were interviewed in Majengo, and a further seven participants interviewed in Korogocho. I constantly compared data emerging from the two sites, looking for discursive elements in the discourse. As before, I noted strengths and weaknesses in data generation and, assisted by mapping, decided where the research needed to go next.

**2.6.6. Third Round Interviews and Key Informant Interviews**

In the third round, I interviewed four participants for the second time: one male and two females from Korogocho, one participant, a male, from Majengo for the first time and one female for the second time. I singled out these participants based on the quality of data coming from our first exchange and exigencies of theoretical sampling. In particular, the male participant from Korogocho had spoken of the morality of a

‘reformed life’ and the risks that came with new identity; the two female participants from Korogocho were both self-identified sex workers, yet very active in the local community and could detail well how their numerous jobs, including sex work, were given meaning and constantly renegotiated among peers. One of these females was HIV positive. The female participant from Majengo had demonstrated a very proactive approach to her HIV-positive status and gained personal resilience in the face of danger through diligent manipulation of social networks. Interviewing these four participants was productive on different levels. We already knew each other, and the interviews was a meeting of friends. We could go straight to the substance of the interview and talk openly and raise questions that probably would not have been appropriate in our first encounter.

In Majengo, interviews took place in residential area ‘4’; including one held at the Office of the Chief. For Korogocho, interviewing was carried out in Kisumu Ndogo, Korogocho A, Korogocho B, Korogocho 4, Gorgon B and Highridge, as well as at the APHRC Kariobangi office. Data generated from these areas provided a rich diversity and interviews were conducted in homes made of wattle, sack, iron sheets and concrete.

I now interviewed two more key informants and discussed areas requiring clarity. As before it was a rewarding exercise and achieved its goal. As shown in Figure 2.1, with thematic areas reaching a point of saturation, I now decided that the interviewing phase of the research could be drawn to a close and saw the time as right for moving to the next method of data generation, photovoice. I was aware of the multidimensional nature of managing HIV and risk, and greater appreciated the holistic nature of social arenas and levels of interaction.

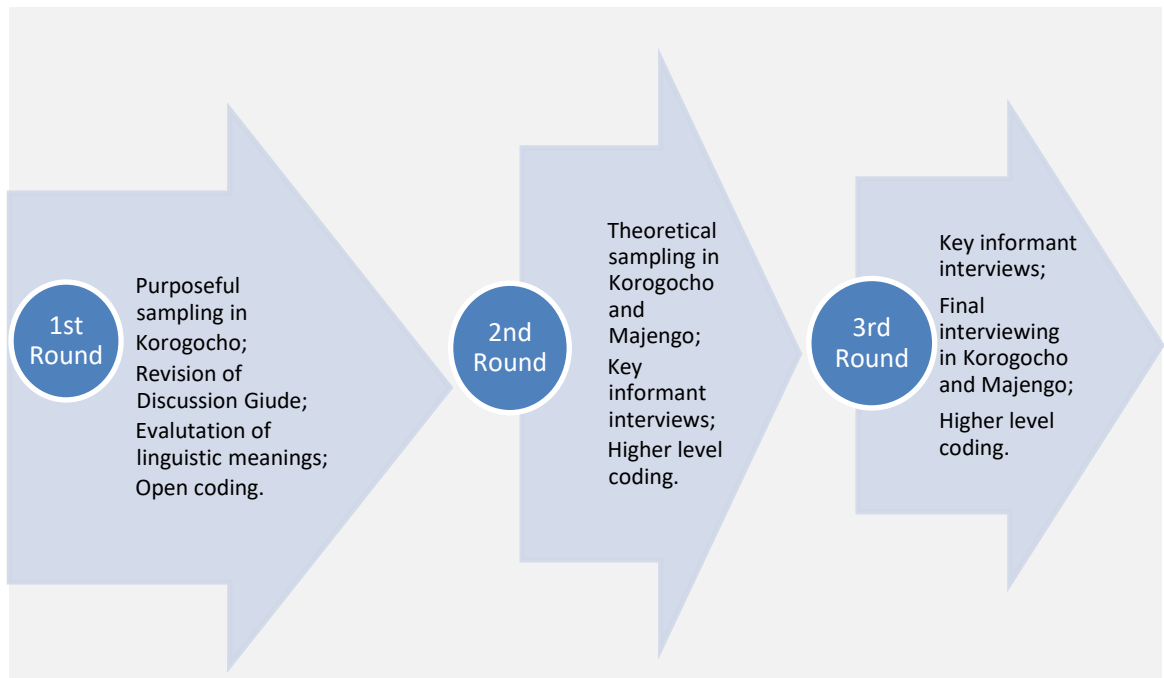


Figure 2.1. Interview Rounds

## 2.7 Language, Translation and Meaning

The lingua franca of participants was Kiswahili. Participants had knowledge of, and could use other languages, notably from their respective ethnic groups (either Dholuo or Kikuyu) and English. At the start of each interview, the participant was asked which language was preferred and invariably the response was ‘either’ (Kiswahili or English). Often, the interviews would commence in English (by me) and gradually switch to Kiswahili (by interviewers). At times, a participant would borrow words from another language to help explain or enhance a certain meaning, or resort to *sheng* (Kiswahili slang).

An interesting pattern emerged regarding language. At the start of the interview when much of the discourse was to do with establishing a rapport with the participant and the information sought was straightforward, the medium was often English. As the interview progressed and the probing concentrated more on personal experiences and perceptions, the language would switch to Kiswahili. It did not appear to be a conscious decision but happened naturally. Moreover, as an observer, as the interview would now be conducted by one of the interviewers in Kiswahili, I noted that the body language of the participant became more expressive and at times animated. At this point, it was not unusual for the participant to display deep emotion.

I wrote a memo describing and trying to understand this outpouring of emotion on 9 November 2016:

*while conversing in Kiswahili, the participant broke down, but wanted the interview to proceed, asking us—now in English and aimed at me—to listen to her story, the choice of language was interesting ... There appears to be much unresolved trauma. Many narratives are harrowing and include accounts of killings, loss of loved ones, abandonment, rejection, homelessness, extreme violence, severe hunger—and the stigma of being HIV positive. Talking about emotive subjects requires a familiarity; a sense that the interviewer knew intimately what was being said and meant. A word or a phrase could have a multitude of meanings and needed cultural interpretation. It needed the lingua franca to give voice to these deeply held feelings rich in symbolic meaning ... I wonder about the effect of carrying such trauma if it is manifested in forms of humiliation and self-defeating behaviour.*

I was cognisant of capturing exact representation of participants' perceptions. To achieve this, I followed standard grounded theory procedure: detailed field notes, audio recordings (checked against field notes) and precise transcriptions to ensure perceptions were not distorted in anyway. The 'empirical rule of thumb' was the least amount of data committed to memory the better, as attempting to recount retroactively from memory, or hearsay, could easily lead to bias; be moulded around my own perceptions; and 'increase the resistance of the phenomenon to our interpretations' (Timmermans & Tavory, 2012, p. 175).

### **2.7.1 Language, Culture and Context**

A substantial portion of data generated was in Kiswahili, characterised by use of slang and shortened grammatical structure. Given the lack of empirical study into the evolution of Swahili in the urban slum, it remains conjecture whether the language used by young people expands or restricts the boundaries of their worldview and influence on forging identity.

The role of the interviewers, translators and transcribers became pivotal. Interviewers emerged as the vital link in conveying meaning to and from participants. Before fieldwork started, several sessions were held with the interviewers, in which the *Discussion Guide* (English) was discussed (in English) and checklists made of key points to act as reference for the interviewers. Mock interviews were held with the interviewers and reviewed as a group for strengths and weaknesses, noting agreement and disagreement on meanings. Confident that the meanings contained within the

*Discussion Guide* and *Photovoice Guide* were now correctly understood in English, a translation of the *Discussion Guide* and *Recruitment Script* was compiled in Kiswahili.

The same procedure now took place regarding the Kiswahili version. Each Kiswahili word in the *Discussion Guide* was interrogated to ensure that it conveyed the desired meaning. This activity took place in organised group sessions and where any doubt was cast, alternative words were suggested, or another phrase used. It was decided that this should not be an either/or but all options to express humiliation, for instance, could be used, depending on the judgement of the interviewer and participant's grasp of the word.

### **2.7.2 Abstract Conceptualisation**

Vulnerability, risk, dignity, humiliation and resilience are polysemous abstractions and largely understood through their social and contextual construction. They are also emotive compound nouns and convey feeling. Often these words must be experienced before being truly understood, as Lindner (2009) states, humiliation is hard to understand until one is humiliated; then its impact can be devastating. This was noted as a challenge in my memo of 4 August 2017:

*There are it seems no 'perfect' words to translate 'dignity and humiliation'. There is much discussion as to what word should be used capable of carrying the full weight of meaning. I have attempted to 'personalise' the meanings they convey, for example, asking the interviewers to consider, 'how would you feel if insulted and ridiculed in front of others?' And request the felt response be described in Kiswahili. For humiliation, it is decided to use closely related terms if need be, such as, disrespect, dishonour, shame, weakness, rejection, exclusion.*

Translation did not prove a problem given the command of languages by the research team. However, some challenges persisted in conveying conceptual meanings, especially on abstract constructs of 'dignity and humiliation'. Participants, it appeared, were unfamiliar with abstract conceptions. For some participants, conveying clear and precise meanings for these terms proved an issue. Of note, conceptualising HIV risk through risky sexual practice and staying healthy in the event of HIV infection were grasped with relative ease and allowed free-flowing discussions. In comprehending a word or a term, conveying a 'sense of meaning' is just as important. Even if precise words could not be used, through various media, a sense of 'what was meant' could be conveyed. If the participant could not grasp the exact meaning of a word (even if given in Kiswahili) this was noted; not necessarily as a drawback but as a window into their

worldview—it was a case of the silence speaking loudly. I captured the issue of abstraction in a memo, dated 17 July 2017:

*it is of interest to try and comprehend the role of conceptual abstraction in participants' lives. It appears that participants do not deal especially well with abstract constructions. Given the severity of life and making ends meet through real-time non-stop networking involving a multiplicity of social worlds—is there the time and would it be relevant to their lives?*

## **2.8 Photovoice, the Expanse of Meaning and Perception**

Haque and Eng (2011) and Vavrova (2014) show that pictorial evidence yields rich data and proves a valuable addition to conversation-based methodologies. A weakness of grounded theory, it is purported, is that it can be reductive in its search for general patterns, especially in diverse settings. Aware of the complexity of the research topic, I was concerned that the selective coding process may not do justice to a gamut of influencing factors, such as urbanisation, mobility, poverty, gender and HIV, and did not want this study to be reductivist. Photovoice provided an innovative method of data generation and enriched selective coding processes, providing a fuller context for analysis and conceptualisation. Noting the importance of ‘areas of silence’, photovoice, as an auto-ethnographic tool, produced a narrative giving voice where there may have been none.

Selected participants, as given in Table 2.8 were asked to take photographs of any aspects of their lives considered pertinent to the research themes. This exercise was to be as accessible as possible with the minimum of requirements. This was a new initiative for participants, and it was important not to create unrealistic expectations. Participants were invited to take photographs individually or in groups and on whatever they felt related to the topic of research and do so without mediation. The goal was to offer a new dimension of communication and highlight the nuances of their social worlds and the processes of interpretation, symbolism and construction of meaning.

In the original project design, I considered each participant interviewed as automatically part of the photovoice; it was a logical assumption. I also set the number of photographs each participant had to produce at 20. The aim was to enable cross-comparisons between photographers and photographs. From there I could construct a matrix and draw conclusions. However, following the first round of interviews and becoming increasingly wise as to how to proceed with this project, the photovoice

protocols were revised. I did not now set a limit on the number of photographs and left it open for participants to decide how many was enough. Having a fixed number might not lead to any better photographs or clarity of understanding. The following memo of 25 May 2016 explains:

*The principles of theoretical sampling, reflexivity and theoretical integration are to be applied to photovoice. A participant's photographs can reveal new lines of enquiry and support the coding process. I am dropping the idea of selecting best photographs and, who decides which is best, whose knowledge counts...?*

A total of nine people participated in the photovoice. Of these, six had been interviewed. An additional three people from Korogocho were also invited to participate on the grounds that they were not available at the time of interviewing but had since shown a keen interest in the research. These 'new' participants all met the requirements of the sample frame.

Table 2.8

*Photovoice Participants*

Location	Gender		Age group (years)	HIV status	HIV status	
	Male	Female			Male	Female
Korogocho	Male	Female	18–24		Male	Female
	4	4	8	Positive	1	2
				Negative/unknown	3	2
Majengo	Male	Female	18–24		Male	Female
		1	1	Positive	0	1
				Negative/unknown	0	0

Although it could have been possible to invite each participant interviewed, as originally envisaged, some 2 months into the interviewing I decided that this would not be feasible. Although interviews were conducted throughout the fieldwork, the photovoice only began when the first open codes had been created and the first semblance of theoretical categories emerged. Following each interview, I had an impression of the level of conceptual understanding of the participant and made a value call on who was likely to best deliver on study topics. Although each participant had demonstrated an understanding of the process for managing risk of HIV, some grasped study topics quickly and took the dialogue in exciting and unexpected directions. It was to this latter group I turned for the photovoice.

I drew up criteria to help in the selection of photovoice participants:

- available for the duration of the photovoice
- current resident of Korogocho and/or Majengo
- satisfies the sample criteria
- demonstration of understanding research topics and able to engage in their elaboration
- willing to work with the research team in creating a narrative
- commitment to using *Informed Consent Forms*
- willing to sign for and return camera.

### **2.8.1 Technical Capacity**

Not all participants selected had a working knowledge of photography. Assuming this to be the case, in the project design, training in use of digital cameras had been included as a component of photovoice. I would meet with participants individually and advise on how to use one of the two cameras at my disposal. This familiarisation would involve a practical session in which participants would take photographs of people, places, buildings and books, all of which were thought relevant to the research. The content of each photograph would be discussed, and an explanation requested on their meaning. If necessary, further technical advice would be provided, normally on use of the camera flash and zoom. Participant interpretation of how to capture abstract images of dignity and risk and resilience in most cases did not prove a problem in contrast with the experience from interviewing.

A *Photovoice Guide* was prepared, partly as a technical aid and partly to help deliver on the thematic topics of study. This guide was organised around sensitising concepts and statement cards, and as before, the participant was given freedom to follow it verbatim or concentrate on one or two subject areas. The guide also provided space for handwritten notes by the participant and to capture the ensuing narrative. If the participant preferred, then they could write the narrative and present it to me upon completion; the choice was theirs.

The participant would sign for a camera, collect multiple copies of the *Photovoice Guide* and *Informed Consent Form*, and agree on a date and time for the next meeting to view photographs and create their narrative. The time the camera stayed with the participant ranged from 1–10 days; rarely did the participant keep to the agreed meeting time. I would ensure that the participant had my or a team member's mobile



number to call, for whatever reason and we remained on standby for the duration of the photovoice, day and night. When a meeting did take place, the narrative was matched with pictorial creations. These photographs illustrated social worlds and participants' place within those worlds. I wrote a memo on 12 December 2016 after having jointly created a narrative with one female photovoice participant from Korogocho:

*Nearly every picture is taken from her mother's shop, or the shop next to her mother's place. In most photographs, it is the one person standing still looking head on at the camera. Taken on face value they are tedious and uneventful. But I looked beyond the first impression. In the narrative, Sharon,<sup>8</sup> told me that her mother was 'dignity' as she brought the family food and thereby had status in the community; her mother was resilience. The limits of her world were the shop; there was nothing beyond.*

Some two weeks into the photovoice in Korogocho, a few issues became apparent regarding the use of digital cameras.<sup>9</sup> These were very practical matters: temporary loss of the camera case and battery charger; the large amount of time to charge the camera battery coupled with intermittent supply of electricity; and fear of the camera being stolen. Although in each instance the problem was resolved it did add an inordinate amount of time to completion of the exercise and was not conducive to the participants' living environment. It was proposed that participants could use mobile phones to take pictures and the narrative was created directly from the mobile phone. Further, if preferred, these could be sent to me via the WhatsApp group. Participants seemed to be more at ease in using a mobile phone and did not require training in its functions. This fell into the theoretical stance of empowerment; the participant could use the means they preferred and obtain the results they wanted. The question of time, however, was not resolved. As some participants did not own a mobile phone, they would contact a friend or relative, which could prove time consuming. I wrote a memo on the dynamics of obtaining a phone, dated 12 December 2016:

*To have a mobile is to enjoy a certain economic status, phones cost money and phone credit is expensive. But phones are equally shared among small 'tight' groups of friends and relatives. I get the impression that if someone has a phone then it is lent out with regularity. What does this mean? Trust between friends*

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<sup>8</sup> Pseudonyms are used for all participants.

<sup>9</sup> Two digital cameras were used: a Canon IXUS 145 and Panasonic LUMIX DMC-SZ7. Both cameras were easy to use, pocketsize and capable of producing quality photographs.

*and mutual support; the cultural imperative of sharing; little concern over privacy as SMS messages are not deleted from one user to the next. This is an economy of interchange.*

A laptop was used for creating narratives from the photographs. As this entailed sitting next to the participant, it was a shifting in power dynamics; now we sat next to each other, not opposite. Preparing photovoice narratives became a symbol of equal sharing between the researcher and participant, and people in the photograph.

Finally, the narratives were thematically coded and viewed alongside existing codes from the interviews; reshaping codes and giving further depth to their dimensions and properties. The photovoice proved a useful ethnographic tool in conveying a sense of time and place that transcended language and spoke through ‘sensory exchange’ between researcher and participant.

## **2.9 Personal Safety and the Security Apparatus**

Personal security for the research team was a priority concern. This highlighted the everyday danger of living in a slum. Everyone is at risk. This violence was intimate and omnipresent. A memo of 8 August 2016, explains:

*Often when I use my mobile phone to take a photograph, I am told ‘people are watching and will kill you for it...’.*

Majengo proved a more difficult area in which to work, for reasons that at times included insecurity. On more than one occasion the team was forced to ‘lay low’ while the threat of insecurity passed.<sup>10</sup> Further, there was no secured and fenced office space in Majengo as there was in Korogocho. However, despite the many visits to Korogocho and Majengo, no harm ever came to anyone connected with this research, although the limitations caused by this violence were real. I would have wanted to move about far more in both project sites but this was considered too risky given levels of random violence and organised crime in the area. It was decided that all interviews and photovoice narratives would be held only in daylight and at least with a modicum of protection.

The Office of the Chief in both Korogocho and Majengo helped provide security. Courtesy calls were paid to the respective chiefs and their entourage early in the research and throughout the study. In Majengo, following an official visit to the

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<sup>10</sup> Majengo is said to be a recruiting ground for a terrorist cell (‘Al Shabaab’). In addition to ‘popular knowledge’ two participants referred to this fact.

deputy commissioner, I was asked to prepare a written description of the study, the estimated time to be spent in the area and what level of security was required. These formal visits were in line with cultural and professional practice; it would be out of keeping for me not to introduce myself, a stranger to the area and who might call on them for assistance. It was important to gain the chiefs' approval for the research to proceed in the area of their jurisdiction. Despite the frenetic movement of people in and out of the area, especially in Majengo, a close eye is kept by the authorities on all new arrivals.

The chiefs' offices and community elders in both locations stayed on top of the research and genuinely appeared interested in all its aspects. Sharing the progress and findings with community leaders became part of the research experience. In both Korogocho and Majengo, authorities gave their unequivocal support and were keen to see information generated on HIV that could lead to its demise. They—like everyone concerned—were only too aware of the devastating impact of AIDS on young people. They, like I, wanted this research to be a force for good.

## **2.10 Chapter Summary**

A theoretical perspective provided the frame by which a methodology–methods package was developed. My approach demanded coherence, an interconnectedness, between theory and practice. Research objectives were the benchmark for the generation of data and provided direction for interviews and photovoice.

If data were to be credible, then they must be quality assured through accurately capturing the perceptions of young people. The fieldwork was a journey, the success of which depended on the rapport and trust established between participants and me.

I had formed an original plan on how to arrive at the data required to build social theory. Although the paradigm held fast, it was necessary to make revisions where appropriate. Much of this revision was based on 'learning from doing'. Not all could be known in advance and, especially regarding grounded theory, previous examples drawn from a Nairobi slum setting were lacking. This was a novel approach to qualitative work at the project sites and being able to make revisions was key to its success.

The tools deployed delivered the type of information required for constructing social theory. Many unexpected turns appeared in the course of interaction with participants, which was rewarding for conceptualising and entering a world unbeknown to me. The photovoice allowed an insight into participants' social worlds that was

fascinating as it was illustrative of their daily lives. The anticipated and the unanticipated all fed into a rich description of a multiplicity of participant social worlds and forced me to face my own preconceived conceptions of slum life.

The fieldwork could be judged a success if for no other reason than that it generated sufficient information on which to build social theory. Successive rounds of interviewing and photovoice provided the basis for building codes and pointing me where I needed to go to augment the growing volume of data. Probing for information constantly opened new lines of inquiry and as theory emerged, I became increasingly aware of the holistic nature of key thematic areas; so many parts of these social worlds/arenas appeared inextricably linked and interconnected. The processes of theoretical sampling and theoretical reflexivity ensured integrity of data. In qualitative research it is often a difficult decision when to stop amassing data. I made the decision when a point of saturation had been reached and no new data were being generated. This is, however, unavoidably a judgement call given the baffling complexity of social interaction and never-ending fluidity of social reality.

## **Chapter 3: Analysis—Towards a Grounded Theory of HIV and Risk**

### **3.1 Introduction to Chapter**

This chapter details the process towards a grounded theory on managing risk of HIV. The process was inclusive and followed the established logic of building theory grounded in the data. Theoretical roots of this study informed the approach to and conceptualisation of provisional core categories.

Coding, as the chapter shows, is the backbone of grounded theory. Generations of grounded theorists concur that this multifaceted process is long and by its very nature, recursive. The iterative approach to coding is based on the grounded theory method of simultaneous data generation and analysis; as themes emerge new light is shed on existing dimensions and enriches the process of coding. The chapter shows how the process moves from open to focussed and, finally, theoretical codes through synthesis of concepts and de-limiting data. Although the coding strategy of Charmaz (2006) is adopted for this study, as shown, the approach also draws on other techniques to add depth, clarity and sense of purpose.

The essence of coding presented in the chapter is in gradually discovering a core category and related sub-core categories. The chapter outlines how various grounded theory models were constructed and reconstructed as new evidence came to light as part of the process of an evolving hierarchy of themes.

In line with constructivist tradition, a thorough review of the literature was carried out. This systematic review approached the topic at different levels and demonstrated current thought on risk behaviour, the role of HIV and the structural confines of the slum environment. A storyline was created that re-emphasised the flow of the coding process and identified benchmarks in the gradual emergence of an informed model depicting HIV risk and a theory with explanatory power.

The subject of processes involved in contracting HIV is vast. The path of theorising taken systematically analysed the views, attitudes, perceptions and opinions of young slum-dwelling youth concerning a key concern in their lives—HIV and AIDS.

### **3.2 Coding and Grounded Theory**

A well-organised system of coding is pivotal in grounded theory. Strauss (1987) exhorts that, ‘the excellence of the research rests in large part on the excellence of the coding’ (p. 27). Establishing a transparent system of codes that authentically reflects the

data is, as described by Glaser (1978), a ‘delayed action phenomenon’ (p. 18). This research was no different and finding, naming and classifying codes took many months of review and adaptation. Slowly advancing through prescribed stages, and where necessary drawing on mapping techniques of situational analysis with memoing as the bedrock, a system of codes was constructed, revised, collapsed and re-ordered until a core category began to emerge.

The process of building theory demanded I ‘let go’. That is, there could be no controlling of the data—its pace, flow or direction—as this would counter the fundamental principle of natural emergence. Natural emergence, as described by Russell (2014) demands a ‘theoretical pacing’ requiring clarity of purpose, creativity, imagination and conscious effort in staying close to the data. Laying a foundation of codes and building theoretical models demands critical scrutiny; it was a forwards and backwards, never one directional or to be assumed but simply trusted for its integrity.

Following the lead of Russell (2014), I constantly questioned the authenticity of open, focussed and theoretical codes moving slowly from descriptive to more thematic conceptualisation. I compared and re-examined substantive codes for purpose and flexibility, a process that facilitated theoretical sensitivity, abstraction and theoretical integration.

### **3.2.1 Reflexivity and Conceptualisation**

It was imperative from the outset that the question of theoretical reflexivity was addressed, and emerging theory was grounded solely in the data. In this process, described as ‘reflexing and owning’ (Russell, 2014), I was conscious of previous personal experiences and the possibility that this may unduly influence the outcome of the coding process.

I have a long history of working with HIV and AIDS in Africa. From this experience, I became aware of the many strengths of ongoing AIDS research as well as the gaps, and where evidence needed strengthening. While this prior knowledge helped in drafting the conceptual design of the study, its scope and purpose, I was also keen to see where and how this experience might influence my conclusions from this study.

In the process of conceptualising the research, I took heed of Hurd’s (1988) assertion that the practice of reflexing on significant events is essentially a feminist concept in highlighting instances of patriarchal power and structure. Having a working knowledge of HIV, I was alert to the fact that I may, unknowingly, draw on this background in the formation of theory. However, I was committed to the ‘coding

method' of a qualitative researcher and being able to address perceived bias. Through embracing the principle of researcher reflexivity, I noted Glaser's (1978) prompt for the researcher to simply 'remain open to what is actually happening' (p. 3). Discerning what the data were saying I would check if there was apparent bias in my interpretation and critique the process of arriving at that interpretation. It was a case, no less, of upholding researcher integrity.

I took note of Charmaz (2006) who states that the reflexive theorist can successfully counter the sway of predetermined ideas. Given the richness of data arising from this study, much of which was new to me, I acknowledged early on that my previous endeavours in AIDS research were only of partial relevance. I created an audit trail of memos regarding my conceptualising and ensuring all theoretical postulates were based on empirical fact and not personal opinion.

The grounded theory approach of simultaneous data collection, interpretation and analysis provided the basis for rounds of theoretical sampling. Through interviewing and photovoice, data being generated had reached a point of saturation. I needed to ensure that abstract conceptualisations were crystallised from day-to-day experiences and aligned to an ethnographic approach to qualitative research. I would memo my impressions from observing young slum dwellers at the project sites and compare them with data generated from interviewing and photovoice. I was aware of the risk of forcing the data or drawing personal conclusions that could impact the process of theorising. I wrote one memo on 12 October 2016, following a conversation with a resident of Majengo:

*I was told that here people chase money. They don't know where it is coming from or where they need to go or what they have to do to get it. This was described as 'the hunt'. This is the essence of experiential existence; seeking, negotiating, searching. It is a hunt and, in the hunt, lies pride and prestige; there is recognition for a successful hunt, someone who finds the prize.*

The metaphor of waves held resonance given the recursive nature of my approach to data generation: advancing, withdrawing and returning but never exactly from the same place. Through data generation, an important insight emerged: it was the fluidity of participants' self-perception linked to the ever-changing shape of their social worlds. It was a knock-on effect; a change in one's social world held the potential to redefine perception and participant reflection. Very little appeared to have permanence—with the exception of the pursuit of material wealth. In such an

unpredictable world, I was cognisant of the danger in drawing away from the participants' universe and constructing a reality of my own, one that was more ordered and predictable. To that end I took steps to establish congruence between abstract analysis and actual perception of a participant.

### **3.3 Open Coding**

My first step in formulating a grounded theory was to create a system of open codes. I was guided by Charmaz (2006), who exhorts the researcher to stay open, concise and close to the data; to reflect a sense of motion and move swiftly through analysis. I fragmented the data and compared incident to incident, seeking patterns, frequency and points of variance. Making field notes, writing memos and diagramming aided the process. Content analysis helped to conceptualise underlying issues among 'the noise' of the data (Allan, 2006). My coding commenced at the time of receiving the first transcript from the first interview. I compared data within each transcript and between transcripts, which came to include photovoice narratives. Codes produced after the first transcript held faint resemblance to the set of codes formulated as I moved to abstractive analysis. Using the last round of coding as the basis for the next, I would proceed to add and revise according to the ongoing analysis.

As shown in Table 3.1, to help ensure authenticity, I used 'in vivo' coding of participants' terms to code the data. That is, participants' own words became the pith of the coding exercise and remained so for the research project. Each code was assigned a label describing the meaning behind various segments that made up the code and organised through a commonality of characteristics. As guided by Birks and Mills (2015), these labels were revised in the face of emerging data using simple one- or two-word descriptions expressed as gerunds (noun verbs) (Charmaz, 2006). Using gerunds conveyed a sense of action denoting something that was continuing; an action unfinished. Moreover, I found that gerunds were more in tune with a heuristic understanding of the fluency of social interaction and generation of meaning. Finding the right words for gerunds involved no small amount of searching, especially as I wanted to capture a code's conceptual properties in no more than three words.<sup>11</sup> In agreement with Russell (2014), I found gerunds perfectly suited to fit the experiential nature of grounded theory reflecting researcher action and the process of iteration in the conceptualisation of categories. Simply put, action is implicit and underpins gerunds.

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<sup>11</sup> I would often use an online thesaurus (<http://www.thesaurus.com/>) to assist in choosing gerund titles.



Transcripts were uploaded directly into the software, NVIVO II. This software greatly assisted in data management, notably, regarding coding, storage, data search and retrieval. NVIVO is well suited to open coding and enabled me to move quickly in isolating segments line by line, drawing meaning and comparing data; as well as identifying points of discussion. However, using NVIVO was not without incident and, owing to malfunction in the software, necessitated three attempts to finalise a node report. Frustrating as this stop–start was with NVIVO, it did prompt a thorough review of the coding and provided a valuable opportunity to reconsider my assumptions on three separate occasions. This review at times resulted in collapsing codes and renaming assigned labels that became less descriptive, more imaginative and increasingly abstract. For example, two early codes, ‘Looking for Work’ and ‘Seeking Employment’ in my first node report were combined and became ‘Securing Resources’ in the third and final node report. Based on the node report(s), I drew a matrix consisting of three columns: segments, codes and properties. I took the columns for ‘segments’ and ‘codes’ directly from the node reports, whereas I manually created the column for ‘properties’. NVIVO was very useful in open coding and creating the first line of labels; however, as Crowley, Harré and Tagg (2002) state, software does not analyse data or move them to a higher conceptual level. In creating categories and moving towards focussed coding I therefore preferred to do this without the help of software.

I wrote memos throughout the coding exercise. Memoing helped in conceptualising data, acting as a point of reference for my expanding perception of meanings underlying assigned codes and ‘lifting’ data to a higher theoretical level. I also discovered that a segment could be interpreted in a number of ways and fit a number of codes: for example, the code ‘Finding Moral Support’. When in doubt, I would include the same segment in more than one code and sort as the process proceeded. The point was made early on that there were more similarities than differences between codes.

Table 3.1

*Extract of Open Codes, Properties and Segments*

<b>Open code</b>	<b>Properties</b>	<b>Examples of participants' words</b>
Accessing HIV Services	Lack of health services; poor infrastructure; poverty	<i>in Koch, there are no hospitals</i>
Learning about HIV	Importance of peer group, social networking; attitude to health professionals	<i>I go for advice from other people, friends mostly</i>
Fearing Disclosure of HIV+ Status	Hiding HIV status; lack of supportive relationships; genders	<i>Most ladies here are single because of stress and their HIV+ statuses</i>
Maintaining Treatment	Multidimensional nature of treatment; food and nutrition; toxicity of ART	<i>drugs require one to eat well and they also cause dizziness</i>

As Charmaz (2006) and Corbin and Strauss (1990) suggest, through memoing, I could effectively develop hypotheses of about data properties and their inter-relationships. The process was akin to hypothesising about the apparent shape of a slowly forming mosaic with an underlying thread of patterns. As this study was a systematic generation of theory from data, I did not formulate hypotheses prior to fieldwork. However, I did increasingly hypothesise on the properties of social phenomena emerging from the data, which Corbin and Strauss (1990) note is a core component of grounded theory. This hypothesising assisted in formulating the first line of categories.

At the end of interviewing and photovoice I had classified data under 41 provisional codes and nine categories (see Table 3.2). Categories of codes were principally organised around recurring themes, although I did not attempt to create a hierarchy of themes as this, according to my research design, would proceed during the stage of focus coding. Further, I found that categorising gave an insight into the processual nature of theoretical integration. As I formed and named codes and built categories I reviewed my personal judgements. I raised this in a memo dated 2 February 2017:

*I can approach pregnancy on different levels. How I label 'pregnancy' reveals a moral bias. 'Falling pregnant', 'falling from grace' (as one female participant*

*put it) and 'becoming pregnant' each denotes a certain moral position. Pregnancy in the slum is not just a biological happening but also a complex social issue. I could equally code pregnancy: 'status seeking' and/or 'losing support'. Again, I must keep my own moral position in check. I have chosen to use the most neutral term I can find: 'being pregnant'. Although this arguably does not do justice to the weight of emotion, I feel confident that my own bias has not intruded.*

I printed out the final node report and cut out each segment, line by line. I then aligned each cutting under a particular category depicted on a card. More as a memory jogger, on the flip side of the card I wrote pointers highlighting evident gaps in the data—dimensions, variations and emerging conceptual properties—which proved useful in subsequent sampling and pointing me to where I needed to go next.

### **3.4 Situational Analysis**

In creating open codes, I turned to 'mapping' to strengthen ongoing analysis. Diagramming helped in discerning what the data were saying from a novel perspective. Through situational analysis I gained better insight relating to participants' agency within a complexity of structures and relationships.

Mapping became a part of my approach to reflexivity, especially in regard to developing theoretical sensitivity and helping me see where and how pragmatic leanings informed interpretation and analysis. This was important as I would draw on these perspectives in the course of coding given their position in framing a complex and often confusing social reality. I was aware of the interactionist theories embedded within situational analysis, which helped highlight the symbolic content of participants' perceptions about HIV.

Table 3.2

*Extract from Open Codes and Categories*

<b>Neighbourhood</b>	<b>Moral / Social Worlds</b>	<b>Income</b>	<b>Violence &amp; Threat</b>	<b>Child Bearing</b>
Overcrowding	Having and building faith	Working with sex	Living with violence	Fearing rejection & ridicule
Fleeing insecurity	Navigating uncertain arenas	Searching for income	Policing slums	Deepening dependency
Finding safety	Sanctioning behaviour	Protecting assets	Blaming law enforcement	Accepting risk
Choosing residential areas	Reforming behaviour	Avoiding poverty	Fearing men	Networking and asking
Building networks			Organizing crime	Being pregnant
			Facing the night	
			Sexualizing violence	

Through mapping, I was able to see more clearly human and non-human elements contained within the data. Data generated from interview and expressed further in pictorial form pointed to a myriad of contextual influences on contracting HIV. I needed to organise the place and the relationship of all actors (individual or collective) and actants (elements, bodies, discourses) to do with location, community

and habitation. Moreover, situational mapping helped me cope with the noise of the data (see Appendix C).

### **3.5 Focus Coding**

Numerous strategies are deployed within grounded theory for moving analysis to higher levels of abstraction and arriving at a core category (Birks & Mills, 2015). Choice in large part depends on theoretical bent of the grounded theorist and whether the adopted approach aligns to a Glaserian or Straussian perspective. Much of the debate revolves around the principle of theoretical emergence. I was set on keeping to my original research design premised on constructivism within the Straussian paradigm of knowledge creation and essentially guided by the work of Charmaz (2006).

Focus coding involved a gradual synthesis of data, sorting now according to conceptual properties. In establishing 'conceptual significance', I identified major themes and built a hierarchy of main concerns key to the process of theoretical integration. In focussed coding, the next stage in the strategy of Charmaz (2006), my intent was to achieve integration of substantial codes and shed light on provisional core categories. This involved testing various dimensions of data coded and categorised checking for congruence within and between theoretical constructs and noting points of variance. As Dey (2007) writes, in discerning commonalities, themes and conceptualisations, 'empirical relationships (and not just superficial regularities) *(are)* identified within the data' (p. 177). Moreover, Glaser and Strauss (1967) highlight the need for the grounded theorist to ensure that conceptualisation of data was always analytical and sensitising. My treatment of concepts had to be sufficiently broad in generalisation yet still able to capture specificity of elements' diverse characteristics; ensuring that sensitising concepts could still demonstrate the richness of the situation. This, I reasoned, could only be achieved through adopting a fully holistic and non-exclusionary approach to focus coding. Seeing my analysis as both analytical and sensitising involved a personal value statement; but one, I felt, that could be defended and supported through a series of transparent memos.

As prompted by Ryan and Bernard (2003), I explored links between expressions and identified concepts and themes emerging in the data. Based on the repetition of variables, I established central and general themes relevant to data synthesis and theoretical integration. To complete this exercise, my analysis now involved a degree of abductive as well as inductive reasoning to be sure to capture fully the utility of themes

identified. In examining the conceptual properties of codes, categories and themes, I constructed a frame of reference to help identify major discourses that spoke directly to the process of managing HIV and risk; subjective perceptions of HIV; the uncertain vitality of youth; fragility of youth services; and the exclusion of slum-dwelling people from social development. This frame of reference highlighted structural as well as social determinants pertaining to the situation under study. Working within the constructivist paradigm proposed by Bryant and Charmaz (2007), I began writing theoretical memos that helped crystallise my coding strategies and theoretical integration.

The frame of reference for major discourses (see Table 3.3) guided focussed coding involving construction–deconstruction–reconstruction of codes and categories. This table proved invaluable in data management, indicating points of saturation and identifying topics requiring further elaboration. I wanted to ensure that my analysis did justice to oppositional intents found within the data, which, according to Clarke (2005) are critical in grasping the complexity of the situation. The table included points of discussion and reflected the ‘messiness’ of the field of research.

Integral to focus coding is the principle of ‘delimiting’. I needed parameters to ensure greater focus in selection of core variables. Delimiting prompted me to see incidents of codes; recurring themes and their relative significance in building theory. As the process went on, I increasingly focussed on developing the logic of the emerging theory, even if it did appear incoherent, through aligning inter-related concepts and categories. Delimiting helped clarify both areas of cohesion conducive to the social process and points of tension seemingly at odds with that same social process. In delimiting the data through this analysis, I reduced the number of categories from the initial number of nine to five; and codes from 41 to 12.

Table 3.3

*Extract from the Frame of Reference of Major Discourses*

<b>Topic</b>	<b>Concept</b>	<b>Properties</b>
HIV	Perceptions of transmission and prevention	Invulnerability of youth; sexual and social networks; reinforcing messages and changing perception; dignity; rites of passage; risk and resilience
HIV & discrimination	Perceptions of stigma	Humiliation and shame; self-worth; other forms of stigma—poverty and exclusion and link with HIV; disempowerment
Social services	Perceptions of public health	Availability of and access to services; sex worker-friendly/youth-friendly services; neglect by authorities; involvement in urban planning and functionality of infrastructure
Habitation	Perceptions of community	Neighbourhood; location; mobility; sense of identity; resilience
Moralism	Perceptions of ‘being moral’	Social definition of standing and respectability; faith-based messaging and religious interpretation; notions of right and wrong; moral obligation; influence of local necessity

As shown in Table 3.4, it was critical to ensure that focus codes contained all essential elements relating to the subjective perception of HIV risk. In so doing, the focus codes became sufficiently abstract, reflecting the rich array of dimensions of each segment of data and enabling me, as Birks and Mills (2015) state, to begin formulating a provisional core category. This would entail seeing all other categories in regard to their relationship with the core variable. In a final review of focus codes, principally discerning aspects of inter-relationships, I created a frame of reference to help analyse pivotal concepts, areas of commonality, variance and points of saturation.

Table 3.4

*Extract from the Terms of Reference for Developing Focus Codes*

<b>Category</b>	<b>Inter-related concepts</b>	<b>Dimensions</b>	<b>Challenges</b>	<b>Contradictions</b>
Finding status and standing in community	Recognition in community Socioeconomic status Social capital Residence and habitation	Social profile; moral overtones and sanctions for types of work; family standing; conspicuous wealth; mother and father hood; HIV+ and sustaining status and facing low status	Inclusion of HIV Hiding HIV+ status Changes in living and family arrangements	Creating risk in establishing position in community; Avoiding humiliation through risk taking leading to humiliation

### 3.5.1 Axial Coding

Alternative coding frameworks can be traced to the two founding fathers of grounded theory. Glaser provides for 18 coding families drawing from diverse theoretical persuasions to pinpoint the relationship between substantive codes in building an integrated theory. As Glaser writes, this approach helps a researcher ‘conceptualize how the substantive codes may relate to each other as hypotheses to be integrated into a theory’ (1978, p. 72). Strauss (1987) provided an alternative approach based on a single axial coding framework, which, he argued, was more in line with the theoretical roots of pragmatism and social interactionism. There are six paradigm variables in axial coding, which ‘function as a reminder to code data for relevance to whatever phenomenon is referenced by a given category’ (Strauss, 1987, p. 27). As per Dey (2007), choice of framework was critical as it charts the path to the formation of theoretical models through identifying likely associations between substantive codes.

I followed the guidance of Strauss and Corbin (1994) in turning to axial coding to strengthen conceptualisation of the relationships within and between the five categories of codes. To feel confident in finding a core category, it was imperative I fully understood all aspects of its properties and dimensions, especially as they related to the interconnectivity of variables within participants’ social worlds. I had by now realised the paramouncy of relationships all of which appeared complex, entwined and



consisting of innumerable dimensions and interpretations. While attempting to be innovative in my coding assumptions, my strategy was nevertheless premised on established practice. Although axial coding is not included in the Charmaz strategy, as long as my analysis was theoretically coherent, I did not see choice of coding methodology as an either/or option. Accordingly, in the process of theory development I now drew on the work of Strauss and Corbin (1994) and axial coding.

As Böhm (2004) states, a key part of developing axial codes is seeing the temporal and spatial nature of relationships including cause–effect and means–ends characteristics. Developing relationships within and between categories was the centre piece of theory formation involving both an inductive and abductive approach. To that end I re-examined the hypothetical relationships among all axial codes. Within the coding paradigm of Strauss (1987) I was particularly drawn to the notion of social action, which I aimed to capture by highlighting the dynamic nature of the relationships within the various categories shaped by social worlds. Axial coding required a balance between constructivist epistemology as proposed by Charmaz (2006) and the pragmatic and social interactionist perspective of Strauss (1987) to determine relationships between respective categories. This I found more akin to my research design than the approach espoused by Glaser (1992), which sees the roots of emergence stemming from a purely inductive analysis.

In strengthening connections between categories and a hierarchy of themes, guided by the paradigm of Strauss and Corbin (1990), I organised categories by the six axial paradigm variables:

Causal conditions ➡ central phenomenon ➡ context intervening ➡ conditions  
action/interaction ➡ strategies ➡ consequences

Axial coding helped in keeping focus on the key issues at the heart of managing risk of HIV by young people. The research field is vast with a bewildering array of topics, all of which are arguably pertinent to comprehending the properties of the social process of HIV risk. Axial coding helped highlight those categories fundamental to developing social theory and determining the reach of this research. Axial coding helped me see an HIV status for slum-dwelling young people equally as process, event and fact. In understanding how social action is captured within the data, I could better see the relationships between process, event and fact, role of personal agency and levels of social organisation between people and institutions. I had to distinguish between the

subjective perceptions of the participant and my view as the researcher, especially when it came to questions of individual and collective action. It would be all too easy for me to find an action in one situation, and assume it had general applicability.

In agreement with Böhm (2004) that social action can only truly be understood through seeing levels of social influence and social organisation, I had to identify conditions that contributed to or limited the possibilities for action and interaction—and inaction. Actions, as Böhm (2004) states, are goal-oriented and not to be confused with conscious intention carried out for specific reasons that involve interactional strategies. As shown in Figure 3.1, using young people and HIV as the axial category and fear of an HIV-positive status, I framed the major concerns according to my coding paradigm.

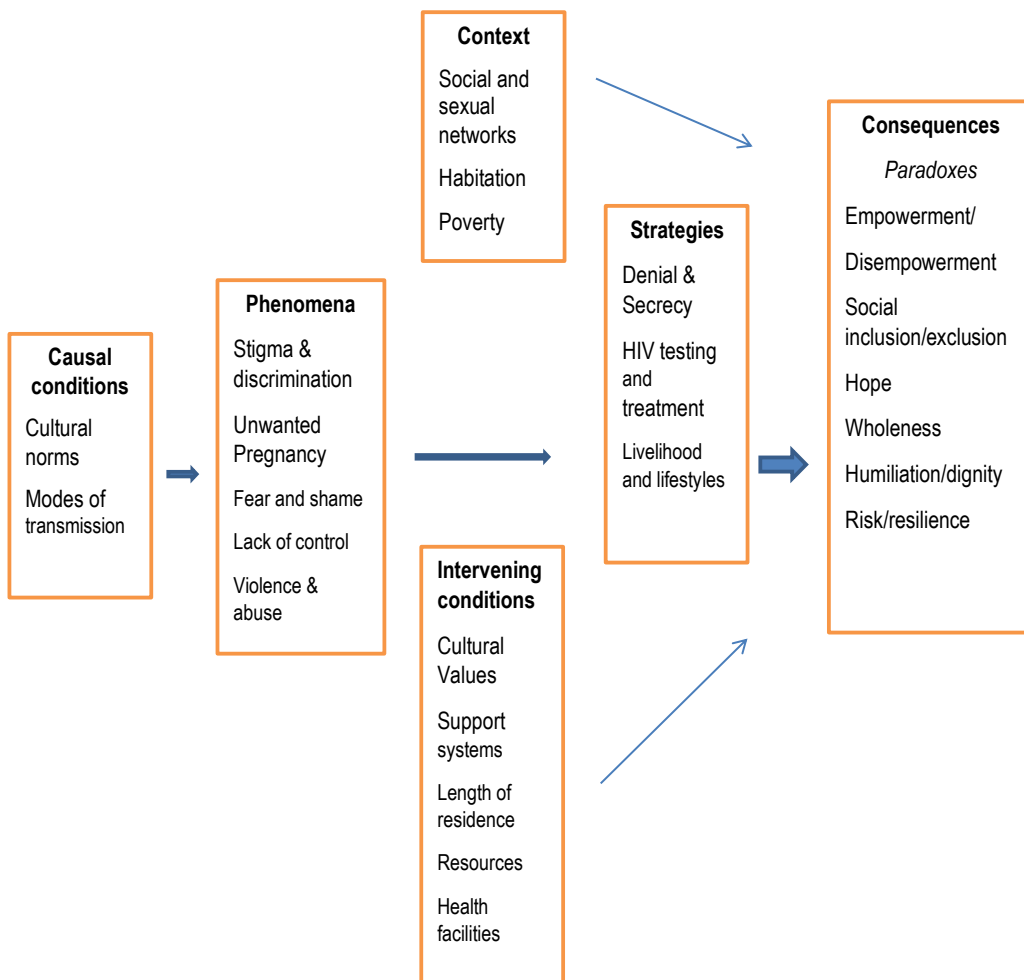


Figure 3.1. Conceptualisation of HIV risk and resilience among young people.

### 3.6 Theoretical Coding

The final stage in Charmaz's (2006) strategy is theoretical coding. To arrive at a core category able to depict the social process of managing HIV, I had to ensure my 'conceptual elaboration' was grounded in the data. For this, I had to trust in the logic of emergent theory. As per Glaser and Strauss (1967), this exercise involved hypothesising on how focus codes relate to each other and form an integrated theoretical framework.

As advised by Holton (2007) the practice of writing theoretical memos becomes an integral part of the coding process. Theoretical memos brought to light central concepts relating to the main concern. Memoing helped me further develop a theoretical sensitivity and strengthen a theoretical reflexivity. I found that memoing also helped in seeing areas of tension within and between theoretical codes.

This process was not easy, and I was often challenged in attempting to bring together hypothetical strands into one coherent whole. Arriving at a core category was pivotal in the final stages of theory development and I had to get it right. Strauss (1987) comments on the complexity of theoretical integration, pointing out that the process demands much scrutiny, soul searching, time and patience. I took heed of Holton's (2007) position that theoretical coding is a process of integrating elements found within the social world and that a grounded theorist needs to make this observation and see it reflected in the development of theory. Accordingly, I tested my postulates in real-time experiences, which included sharing with young slum dwellers. I found resonance with Glaser's (2005) point that the grounded theorist must be cognisant of integrative patterns observed in nature, society and relationships in proposing theories of social behaviour. In grounding theory in the here and now, I again used the metaphor of a mosaic; the undertones were becoming sharper and instead of distracting, brought the picture alive and gave it depth of meaning.

Through the process of theoretical coding, I feared that a social theory based on 'real-world' experiences would appear just 'more of the same' in the greater genre of AIDS research. However, I remained committed to grounding theory in the data, letting my theory speak for itself and not risk forcing conclusions in any direction.

In determining a cohesive central theoretical framework, I needed to ensure that categories really were theoretical and not descriptive summations. Moreover, as Strauss (1987) explains, logical alignment of theoretical categories allows the grounded theorist to establish the core category around which social theory develops and captures the

complexity and variance of human behaviour in diverse settings. Another aspect of theorising was to ensure that my basic unit of analysis was correct. In exploring the connection between HIV and risk among slum-dwelling young people, it was imperative that these two pivotal elements were not confused and approached as separate constructs. This would have great impact, *inter alia*, on deciphering the social process. At the beginning of this study, HIV and AIDS was perceived as the unit of analysis but as the research proceeded, I switched to seeing young people now as the focal point. The centrality of youth and youth culture—late adolescent perceptions, fears, wants and desires—provides the bedrock for understanding and responding to HIV. It was clear that HIV is just as much a social as a medical condition. It was the social process that related to young people that held the key to understanding the vexing question of managing HIV risk in the slum, and not vice-versa. It was a confused research environment, but the process of theoretical coding helped me see the young person as the centre of their universe impacted by a multitude of social and structural determinants.

I needed to ensure that the question of agency was resolved in the theoretical codes. I felt it would be erroneous to draw conclusions from the data that suggest a recklessness or impulsivity of young people towards HIV, at odds with what Payne (2011) describes as the principle of conscious resilience. I needed a core category to reflect a sense of autonomy by the young person and logic of agency regarding risk taking. The logic of my analysis showed that through personal empowerment considerable risks are taken, resulting very often in an HIV-positive status, but bringing short-term social recognition and acceptance of someone to be respected if not feared. These conceptual elements did not easily fit a neat social process but were crucial in developing a theoretical framework.

This study is premised on the worldview of young people. Theorising, therefore, is based on hypothesising about the conceptual qualities of that worldview. This was never to be an easy task. Mapping, modelling and self-reflection proved vital for the analysis. Further, to bring together often disparate perceptions from diverse social groups proved a challenge. As reasoned in theoretical memos, if I concentrated on seeing underlying processes that might appear illogical, and took steps not to lose focus on the criticality of social interaction, a path of conceptual integration could be discerned. The voice of the young person therefore remained the pith of my theorising and did not involve evaluating how these perceptions stand up to scientific fact.

### 3.6.1 Refining Concepts and the Provisional Core Category

I concurred with Sbaraini, Carter, Evans and Blinkhorn (2011) that synergising focus codes involved identifying events that gave them meaning, finding key thematic messages within the code and how its various dimensions shaped other codes. During the process of theoretical coding I was confident that my analysis had reached a point of saturation in that all core conceptualisations had been identified and adequately addressed. This did not mean that the process of testing the validity of theoretical codes stopped as new interpretations of the codes' main message(s) continued. In the course of integrating theoretical concerns, I reverted to segments from participants' discourse to assure an exactness with each link in the chain—from participant input to abstract conceptualisation.

I was now able to classify a provisional core category on the process of managing HIV and risk. I approached this core category as provisional given I still wished to pursue a storyline to ensure logic and flow and check against the literature for relevance and authenticity. The provisional core category, I felt, would capture the critical elements and allow a specificity regarding the core category and subcategories.

#### ***Provisional Core Category:***

#### *Sustaining Resilience Against HIV Through Navigation of Moral and Social Worlds*

From theoretical coding and construction of a theoretical model with the provisional core category as centre, I identified 11 key thematic areas whose properties held resonance and had demonstrable high frequency within the data. Further, I was confident that each of these elements was reflected in the provisional core category.

These were:

1. navigating spaces of vulnerability
2. building social intelligence
3. manipulating channels of communication and knowledge
4. responding to social plagues of stigma and social exclusion
5. accessing social services including HIV prevention and treatment
6. coping with shame and humiliation
7. conceiving of invincibility of youth and belittling sexual risk taking
8. legitimising deviations from 'ideal' morality
9. enforcing social mores justifying multiple and concurrent sexual liaisons as symbols of masculinity

10. inculcating fear of HIV infection from moral gatekeepers
11. using the logic of risk taking to build resilience.

### **3.7 Evaluating Approach, Findings and Analysis**

Having established a provisional core category, I needed to evaluate my approach according to the rigours of qualitative research. It was important to ensure that in developing the provisional core category my conclusions were based on fact and, where necessary, innovative and imaginative; that is, that they were analytic and sensitising. As part of her constructivist methodology, in checking for essential empirical grounding, Charmaz (2006) identifies four criteria: credibility; originality; resonance; and usefulness. I now used this criterion to test my modelling thus far.

#### **3.7.1 Credibility**

From the outset, I had purposefully developed a familiarity with the research context as part of the process of evidence-based analysis. This research, I was confident, echoed the real world of the slum and suitably contextualised the nature of risk and HIV. The interview *Discussion Guide*, for example, was reshaped according to participant feedback during the many interchanges and ensured that probing was based on everyday experiences using terminology relevant to their universe. Although I strove to obtain originality, the prescribed measures for grounded theory and qualitative inquiry were upheld. Moreover, using the tools of interview and photovoice and assisted by relational mapping exercises, I was confident that my propositions rested on solid ground. I understood that a component of credibility was transparency of approach, which I aimed to achieve through memoing and participant feedback. As Henwood and Pidgeon (2006) state, ‘(it is important to make) transparent how the analysis has involved extensive efforts to work with the data’ (p. 82).

#### **3.7.2 Originality**

I was keen to produce new insight about the topic of study through a novel approach to research in Kenya. My qualitative approach using both informal interview and photovoice was a first in many regards among researchers working with HIV in the urban environment. This addressed the criterion of originality of approach and, I discerned, findings. Further, by attempting to view the phenomenon from participants’ perceptions, I was eager to show if they ‘challenge, extend, or refine current ideas, concepts, and practices’ (Charmaz, 2006, p. 182). The use of storyline as a credible tool in qualitative research is in its infancy in AIDS studies in Kenya. This is not to say that

personal accounts through storytelling have not been utilised but storytelling specifically, as Birks, Mills, Francis and Chapman (2009) write, remains underdeveloped and underutilised.

### **3.7.3 Resonance**

Charmaz (2006) prompts the grounded theorist to take steps to ensure that outcomes from the data are perceived as accurate by participants themselves. This I did by sharing in both formal and informal settings, not just with participants but with a wide array of parties engaged in this research including health professionals, law enforcement representatives and rights activists. My understanding of the research topic was captured in a book published for peer review.<sup>12</sup> Following each instance of interviewing and photovoice I would discuss with participants and the research team what I was seeing in the data and ask for honest feedback. I would memo various responses, which helped in choosing how findings were to be presented. While this was an original piece of research, in checking against the literature, I found a resonance with the findings of other qualitative researchers working in urban centres and with HIV people-centred studies globally and in Kenya.

#### **3.7.3.1 Usefulness**

Regarding usefulness, I trusted in the pragmatic principle that this research provided a means for the voice of young people to be heard and holds the potential to contribute to AIDS policy and urban planning in Kenya. It was important that participants came to understand that there was a purpose behind the research, which had the potential to affect their lives in a positive direction. This way I hoped to add to the domain of knowledge with both immediate benefits while widening the theoretical basis for AIDS research among young people. The assertion of Letherby (2002), writing in the context of feminist studies, had resonance in emphasising the consequences of researcher theorising adding to the existent body of knowledge. I was also aware that as Charmaz (2006) and Henwood and Pidgeon (2006) state, grounded theory study needs to explicate a theoretical or paradigmatic perspective to help readers of the research evaluate for themselves claims made from the findings and how they might benefit their own work in the domain. Consequently, all efforts were made to make this research as least esoteric as possible and ground it in the ordinary lives using language understood by the participants themselves.

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<sup>12</sup> *HIV and young people—risk and resilience in the urban slum* (Jones, 2016)

### 3.8 Theoretical Modelling

The evaluation of this research project demanded I scrutinise further findings and conclusions, especially the provisional core category to determine if it still genuinely offered a credible explanation reflecting all core elements of ‘the real world’ under study. I re-examined core themes and major subcategories and the step-by-step process of conceptualisation, checking for overlap between elements within and between categories. I also questioned the accuracy of terminology and phrasing used to explain the participants’ universe as it relates to HIV. I felt it important to better convey a sense of genuine purpose and agency by young people, which now led to a rewording of a more nuanced and informed provisional core category.

I was now in a position to construct a theoretical model of the provisional core category and subcategories. As shown in Figure 3.2, the provisional core category now became:

*Managing HIV risk through social integration, collective recognition & personal empowerment*

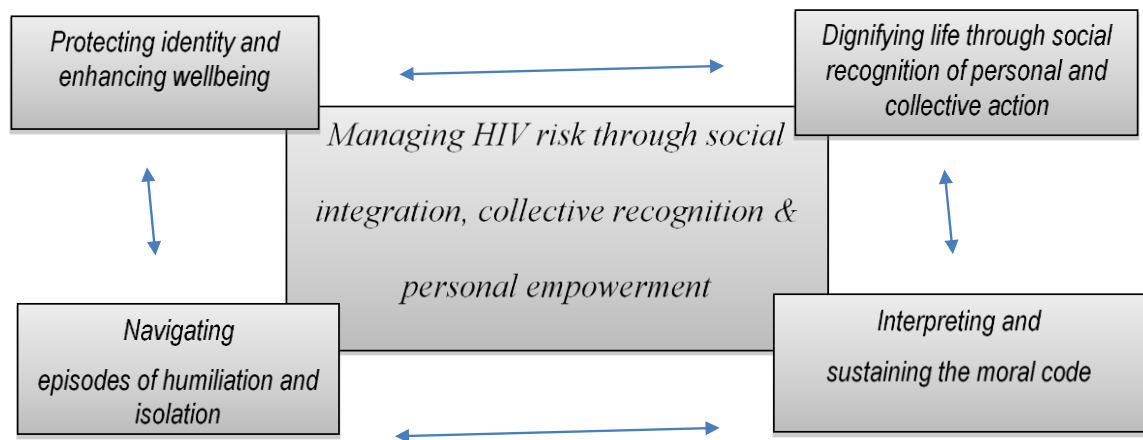


Figure 3.2. Theoretical model of the social process of managing risk of contracting HIV.

#### 3.8.1 Theoretical Coding and Inclusion of Basic Elements

For this research, it is the coding process itself that premises explanatory theory. Following the lead of Eriksson and Emmelin (2013), I constructed a framework (see Table 3.5) in which variables were organised according to ‘human, non-human, spatial, political, symbolic, historical and cultural factors’ (p. 115). It was an exercise in testing the inclusivity of the model and determining if the main concern had been fully addressed through the core categories and subcategories. What became clear was the



extensive overlap between elements having symbolic, human and non-human properties. Like Eriksson and Emmelin (2013), I discovered that elements with high symbolic content could be both human and non-human. I created a table that mapped the relationships between key elements. This involved going back to in vivo coding to make certain of the link with theoretical coding and find synergy between process and action.

Table 3.5

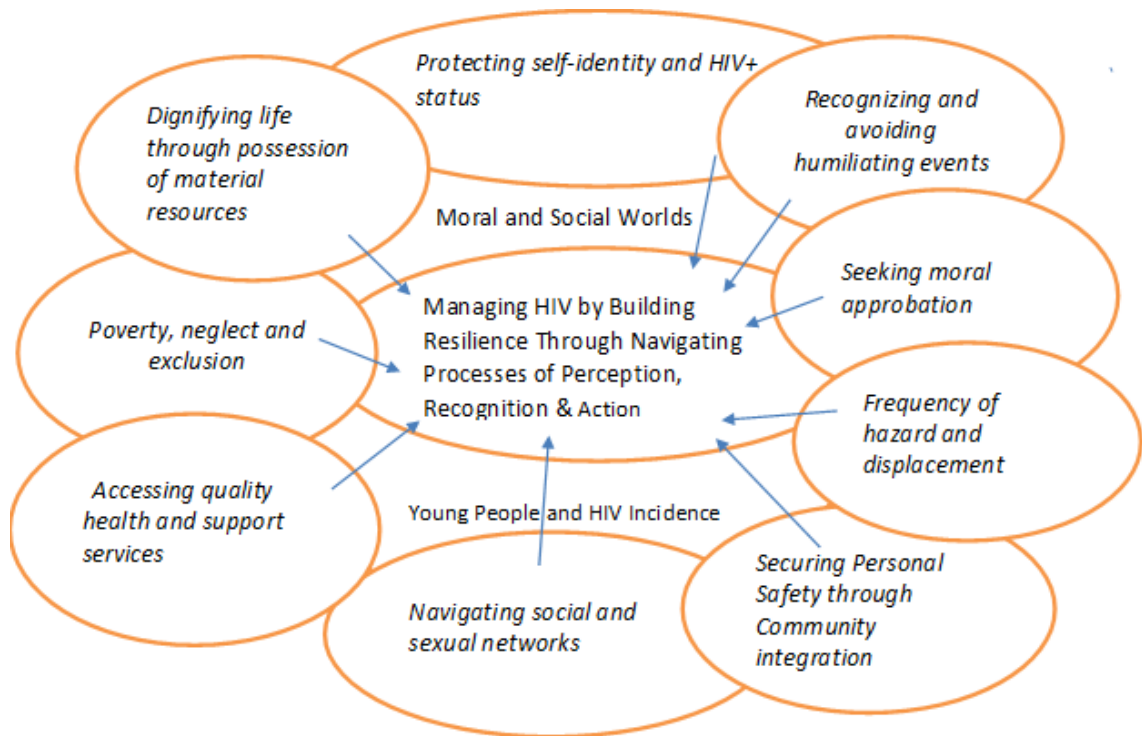
*Extract from the Framework of Iteration of Elements and Categories*

<b>Basic elements</b>	<b>Categories</b>	<b>Participants' words</b>
Human Symbolic	↔ Dignifying work and life through social engagement	↔ <i>It is important to look good and have money; people know me here and respect me for what I am</i>
Non-human Symbolic	↔ Enduring poverty, neglect and decay	↔ <i>Look at the holes in the road and state of our schools; there is nowhere here to get ART or PEP</i>
Spatial	↔ Navigating social and sexual networks	↔ <i>There are good and bad places here; some are okay but some you never go, they're too violent</i>

It was clear that I needed to reconstruct my core category for a third time. There were elements that had to be expressed, as well as commonalities and tensions in the conceptualisation. The provisional core category now became:

*Managing HIV by Building Resilience Through Navigating Processes of Perception, Recognition & Action*

As shown in Figure 3.3, I revised the theoretical model accordingly.



*Figure 3.3.* Theoretical model of the process of managing HIV and risk.

This model had to be sufficiently robust to accommodate the web of connections and tensions indicative of the nature of risk and resilience among slum-dwelling youth. Risk taking increases the chance of contracting HIV but just as likely augments a sense of cohesion among peers sanctioned by subcultural values and assumes an air of ethical virtue. Building trust within and between networks, families and institutions evokes the moral premise of making oneself vulnerable through placing trust in a situation that is uncertain and likely threatening. My theorising pointed to a reputational risk among young people in not stepping out of comfort zones and facing the cost of inaction and not seeking advantage. A social theory on HIV needed to encapsulate these compound and often counterintuitive aspects of behaviour.

It is too simplistic to assume a natural link between resilience and dignity as the two constructs are independent of each other. The path of managing HIV risk is a complex construction that does not necessarily involve dignifying self in any given situation. That is not the point. Similarly, seeking respect may not relate to creating a state of resilience but lean more to notions of conspicuous wealth.

Through developing further theoretical codes, I noted an inherent contradiction. Predominant notions of what is morally ‘right’ and ‘wrong’ in regard to a healthy and HIV free lifestyle, and promulgated in the slum by local media and religious bodies, was often in conflict with the necessities of everyday survival. This can be understood

in terms of what had to be done to find resources (cash) to feed oneself and dependents (the higher moral order); engaging in sex work and crime provide immediate and accessible options. I found it difficult to model whether AIDS was a sign of a breakdown of the moral order or of preserving the accepted moral code of the slum. What was clear is the multiplicity of moral worlds. The data showed that action is judged by its consequences; and as exemplified in strains of classic pragmatism, the end justifies the means.

### **3.9 Creating a Storyline**

Given the tenants of grounded theory, I did not enter the research with preconceived theories or hypotheses to test; the narrative from the young person provided the bedrock on which this social theory is built. Participants would eagerly narrate life stories and, in responding to probing, explain their perceptions or their interpretations; these are multifarious constructs. Participant accounts would often take the form of storytelling and, as Holloway and Freshwater (2007) show, give valuable insight into how cultural meaning is generated regarding significant life events. Data collection for this study was not intended to emanate from storytelling but the structure of an informal interview and photovoice lent itself to narration that was often heartfelt and deeply moving.

Using the techniques of storyline for developing a grounded theory was consistent with my approach to giving voice to young people. As stated by Birks et al. (2009) I turned to storyline to help assure authenticity, creativity and ‘readability’. Although my approach was not based on narrative analytic techniques, in line with the findings of Floersch et al. (2010), I found that through developing a storyline and discovering patterns, repetitions and contradictions—notably on less tangible and more emotive issues—I could appreciate more fully the multidimensional perceptions of slum-dwelling youth. I also found that following subsequent returns to studying the storyline my integrated conceptual framework was strengthened. The storyline can be described as both a means and an end, involving both process and product following an iterative methodology (Freshwater, 2009). I agreed with Freshwater (2009) that creating a storyline is essentially an intersubjective undertaking bringing together narrative evidence, data generation and analysis, discourse and variation as well as highlighting interpretation of the researcher.

I used storyline to determine if in theorising from participant narrative, all elements had been addressed in the model of HIV risk. I memoed this exercise and kept in mind the question, 'what am I hearing in this story?'. Staying close to the approach of Birks et al. (2009) I utilised the core category and subcategories as headings for writing the storyline.

For the storyline, the account had to be short and precise in dealing with the critical themes, concepts and contradictions. While mindful of the process of delimiting, however, I did not want to ride roughshod over profoundly rich participant narratives expressing the enormity of the challenge in dealing with HIV. As shown in Appendix D, the storyline demonstrated the centrality of human dignity in achieving a state of resilience and the deleterious effects of humiliation and exclusion. Slum life is about the here and now; it is experiential living that has scant regard for long-term consequences. Resilience, defined as the ability to withstand shocks and regain advantage, was only seemingly effective if built on a felt dignity that accepts and respects one's own life and livelihood embedded in moral social worlds.

### **3.10 Checking Against the Literature**

In the formative stages of this research I read widely on HIV risk, adding to my existing knowledge. This was a necessary step in ensuring a study design fitting to urban slum research. Once a research design had been established, I decided to desist from engaging further with the literature and existent theory so as not to chance constraining data collection or analysis. Impartiality, I believe, was possible through taking steps to ensure neutrality if not objectivity in the positivist sense of the word. I took caution from Ramalho, Adams, Huggard and Hoare (2015), that engaging with the literature is not just a methodological concern but also has epistemological implications. Different positions are taken within grounded theory on the question of literature review. I was clear in my 'epistemological framework' based on constructivist grounded theory, and through repeated memoing ensured that any preconceived assumptions were made explicit.

Having now arrived at a theoretical model and able to cite a provisional core category, I chose to search the literature for key works covering the gamut of HIV risk and resilience in urban settings. The idea was not to seek alignment or confirmation of my analysis but examine how other research initiatives had approached the subject matter. I also wanted to spot any incongruence in my storyline and/or gaps in perception

of the research topic. Although I aimed for inclusivity and not to be limited to a particular set of ideas or academic tradition, given the vastness of material on HIV and young people, my approach had to be strategic. I developed a five-stage approach for this task, which spoke to an identifiable theme or aspect of the research topic. I used the medium of English throughout. The approach entailed the following:

1. The literature search commenced with a review of the seminal work by Eaton, Flisher and Aarø (2003); and published and unpublished works, reports and theses from 1990 to 2000 on young people's risky sexual behaviour in South Africa. This period was largely prior to the advent of medication, when managing HIV, as Richey (2003) points out, was heavily influenced by traditional approaches to health care and AIDS as the preserve of the health professional. The work of Eaton et al. (2003) was a benchmark in AIDS research and continues to inform related studies on HIV and risk behaviour. As I read and reviewed extensively for the period 2000–15, notably on the urbanisation of HIV and the treatment agenda, there was a repeated echoing of their polemic work ( $n = 75$ ).
2. For the period 2000–15, I used databases—notably Forum: Qualitative Social Research; Proquest Social Sciences; Scopus; Medline; the Dignity and Humiliation Library—and independent searches using Google Scholar. I used the search strings “HIV and modes of transmission in young people”; “HIV vulnerability & risk/youth”; “individual and social resilience”; “dignity and humiliation”; “risk and behaviour”; “HIV and peer groups”; “HIV and urban slum settings”; “global trends in HIV”; “key populations”; “behaviour change communication”; and “modelling health”. I noted five key authors and followed up on each of their cited works. My search included reviews, reports, research and position papers ( $n = 436$ ).
3. Having gained a comprehensive oversight of the social process of managing HIV risk, I needed to examine the more policy- and development-minded research traditions. Although I did not exclude global experience, where possible I examined works concerning Nairobi, Kenya and eastern and southern Africa and the Global South. I used the following search terms: Kenya national strategic plan and Kenya national strategic frameworks on HIV; NACC research agenda, urban development/poverty eradication/slum clearance; profiling public health; urban migration; urban media. For this aspect of the literature search I

turned to the databases largely of government, the United Nations and major non-governmental organisations (NGOs); Nairobi County, Kenya; UNAIDS, WHO, UNICEF, UN-Habitat, IOM; Concern Worldwide; Refugee Women Commission; OXFAM; and APHRC ( $n = 76$ ).

4. Five studies were noted that combined at least one form of the components of HIV; risk and resilience; the urban environment; and dignity and humiliation. I compared this with my own model of HIV risk ( $n = 11$ ).
5. From the studies I identified three models of health risk and resilience that resonated with my own model of managing HIV risk and accommodated notions of morality and ethical codes as an influence over human social behaviour ( $n = 5$ ).

### **3.10.1 The International Literature**

The findings of Eaton et al. (2003) point to the complexity of researching and predicting sexual behaviour. Subsequent works further corroborate this fact (e.g., Mberu et al., 2014). Eaton et al. (2003) demonstrate from an exhaustive review of the evidence that HIV can be understood by examining three interlinked yet distinct levels of analysis: first, within the person—subjective belief and perception, disposition and interpretation; second, proximal—concerning interpersonal relationships and levels of social organisation; and, third, distal—regarding subcultural value systems and structural forces. Their review focussed on people from mid-adolescence (14 years) to mid-life (35 years). For my purposes there was enough information concerning the 18–24-year age group. Although each age cohort presented a different set of facts determining the nature and extent of risk, in each instance, the three-level typology proved insightful. My own findings from this study were principally corroborated in the literature, notably, by Marston, Beguy, Kabiru and Cleland (2013) and Mberu (2012), regarding social, psychosocial and behavioural factors influencing adolescent sexual debut and practice. As Steffenson, Pettifor, Seage, Rees and Cleary (2011) suggest, young men, in particular, may engage in multiple concurrent partnerships with minimal use of either male or female condoms during sexual liaisons. As noted by these authors, all three levels of explanations are impacted by the ubiquity of grinding poverty adversely impacting health-seeking behaviour. Further, cultural expectations, as found in the slum, reinforce gender stereotypes of women's subordination and disempowerment.

Following the work of Eaton et al. (2003), I searched the literature but failed to find any significant evolution in thought or approach to understanding HIV and risk among young people. As I searched, I drew on the framework of Eaton et al. (2003), especially in regard to levels of social organisation within moral social worlds.

The major developments in the intervening years following Eaton et al. (2003), and for which there is a considerable literature, include urbanisation of HIV and shift from a rural-based epidemic; uptake of ART, PEP and PrEP notably among key populations; risk profiling key populations in urban contexts; plateauing of infection rates among the 15–24-year age group; and exponential growth of migrant populations. Much of the literature for this period is concerned with describing risks of exposure to HIV and how they may be countered through behaviour change interventions. I did not come across work that made a radical epistemological departure in approaching the epidemic, its causes, consequences and response. If anything, under the rubric ‘place matters’ (UNAIDS, 2014a) the importance of location and population has been re-emphasised and there is a need for a tailored response, which falls in line with the Eaton et al. (2003) paradigm.

### **3.10.2 Key Concepts in Searching the Literature**

The search using key terms was informed by research objectives. Of note was perceiving the nexus of HIV risk; and different levels of influence that shape the organisation and meaning of social relations for young slum inhabitants and whether multiple moral worlds exist concerning HIV, dignity and humiliation. These conceptual themes were broken down into Risk; Resilience; Dignity and Humiliation. A focus on these three constructs provided evidence on issues relating to the multiplicity of moral social worlds and levels of social organisation and influence. This strategy fit well with the process of gradually working towards a synthesis of data and my own theoretical understanding.

#### **3.10.2.1 Risk**

In my search, I increasingly focussed on conceptualising risk, as opposed to ‘vulnerability’ or ‘risk and vulnerability’. Not that these two search items were unimportant but works of note on risk would invariably take in discussions of vulnerability, which was not necessarily the case vice-versa. Vulnerability in the literature is a rather nebulous term and is difficult to pin down in terms of specifics, whereas risk is a more ‘tangible’ concept and lends itself more readily to real-time experience. I found that while vulnerability is often expressed at a more abstract level,

risk is more to do with the here and now and immediately relevant to issues of exposure, infection, and ability to manage HIV infection and progression to AIDS. Moreover, my gradual shift in focus meant I could better address the research question of the social process of managing risk among young slum dwellers.

#### 3.10.2.2 *Resilience*

The term resilience now finds common usage in a wide range of fields and applications. For my literature search, I focussed on personal and collective resistance and instances of urban resilience. I especially sought literature that dealt with resilience as an evolving social construct and largely given shape in the social realm. In depicting the essence of resilience, as defined in this study, the word ‘relentless’ emerged as a core concept; even if lessons were not learned from repeated shocks, young people displayed the capacity to go on and on...

#### 3.10.2.3 *Dignity and Humiliation*

There is a growing body of information on these two inextricably linked terms. However, there appears to be more on dignity and less on humiliation; the latter, as a personal and social phenomenon, is still debated among academics. I began by searching dignity and humiliation as two discrete terms but became aware that in joining the terms together it was possible to discern a far richer account of the concept. I conceived how dignity and humiliation related to HIV risk and vulnerability and personal and collective resilience. I took an encompassing perspective of the constructs dignity and humiliation, and also investigated the personal and social nature of honour, respect, pride as well as shame, disgrace and embarrassment.

#### 3.10.2.4 *Subjective Perception*

The theory of self-perception is broad and can be approached on numerous levels. It was not my concern to explore the perspective from the point of view of social psychology and from there delve into questions of internal cognition and mood states. This is beyond the remit of this study. My search focussed on works that gave voice to young people’s perceptions, attitudes and opinions and the impact on social behaviour concerning HIV and risk.

### **3.11 Chapter Summary**

Arriving at a series of provisional core categories and models of HIV risk was the result of a recursive and evolving process. Participant statements were organised into segments and interpreted, analysed and delimited to the point leading to formation



of cogent, although provisional, social theory. This involved an ongoing interpretation of the data by the researcher, which moved from descriptive summary to theoretical abstraction with explanatory power. The approach was built on a system of coding within the constructivist and interpretive tradition of grounded theory.

I memored throughout and left an audit trail of my thoughts and conceptualisations. Memoing guided researcher reflexivity kept a check on deeply rooted dispositions. Guided by the principles of symbolic interactionism, I utilised, where necessary, the mapping techniques of situational analysis, which provided clarity to my coding strategy. Checking against the literature provided clarity in the interpretation of data and in theorising a model of HIV risk.

Writing a storyline highlighted the core unit of analysis as the universe of slum residence, which, through interlinking social worlds and social arenas, gives meaning to HIV infection. It is this generation of meaning affected by individual and socio-structural forces and informed by a moral imperative that holds the key to understanding risk and resilience as two inextricably linked constructs.

## **Chapter 4: Findings—Modelling HIV and Risk**

### **4.1 Introduction to Chapter**

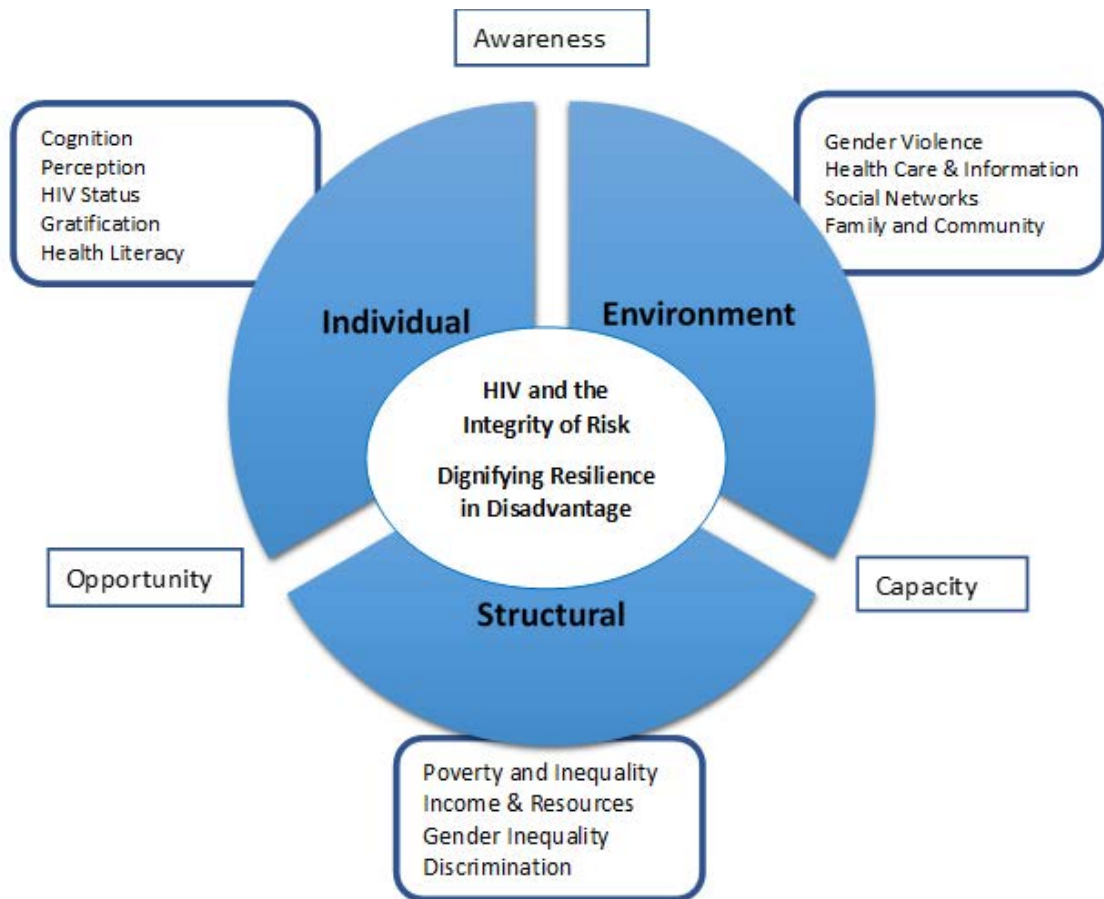
This study creates a grounded theory: HIV and the Integrity of Risk—Dignifying Resilience in Disadvantage. The social theory is made up of three interlinked domains of influence—individual, environmental and structural—with ‘awareness’, ‘capacity’ and ‘opportunity’ as cross-cutting themes. Drawing on photovoice and interviews, the model reflects a reality that is fluid and in which young people draw on multiple social processes for managing HIV. This chapter discusses the totality of the situation and presents the case that only through a holistic approach can perception and behaviour of young people be understood. It is an interrogation of strategies for surviving, finding advantage and managing risk.

This chapter draws on the study’s pragmatic roots to explore personal and social identities shaped by the intersection of gender, age and capacity. Perceptions of self are shaped through social interaction within the immediate physical environment. Symbols of youth, sexuality and personal acclaim are generated in the social realm, interpreted and internalised and, as the findings show, give meaning to health and wellbeing. This is where processes for managing HIV are grounded.

As detailed in this chapter, young people belong to social worlds that evolve and create the need for new perspectives and reinterpretation of social processes for managing HIV. The typology of individual, environmental and structural domains frames the exigencies of living in a high-HIV-prevalence setting. Inextricably linked, the three domains mirror the universe of HIV risk and resilience of young people and provide an explanation into the integrity of HIV risk.

### **4.2 The Social Universe of HIV Risk**

Depicting the totality of HIV, the progression of provisional core categories led to the emergence of social theory based on the core category: the ‘Integrity of Risk.’ This social theory, as modelled in Figure 4.1, demonstrates interconnected domains of influence within moral social worlds of young slum-dwelling people in which the kaleidoscope of risk and resilience is interpreted and played out through a multiplicity of concerns, motivations, desires and fears.



*Figure 4.1.* HIV and the Integrity of Risk—Dignifying Resilience in Disadvantage.

Given the status of social services, including health and education, income opportunity, regulated work in the formal sector, safe housing, levels of personal protection - and HIV prevalence, Korogocho and Majengo are areas of disadvantage. It was from a position of disadvantage that participants found advantage and managed processes of HIV risk; collective resilience and personal strength were given form and substance by the strictures of disadvantage. Participants knew that the slum was a high-risk environment and risk-taking, including sexual relations, was a fact of life. Yet, participants would explain how things could be different and drew on real time experiences, especially young women, in which collaborative action had resulted in tangible improvement in their lives and those around them. Conceiving where and how to find advantage and affirm personal and social achievements involved perceiving and navigating multiple layers of risk. Participants, as understood from interview and photovoice, described how finding life in the slum was never a case of mere survival, it was purposeful action reflecting a die-hard spirit that was wholly dignified; it did not require justifying or defending. Purposeful action and risk taking were, in the discourse, inseparable. Agency might seek to secure a critical connection and put at-risk long-term

health and wellbeing, but even so, it was directed at a positive social goal; it was calculated risk based on perceived reward. The hunt, as one participant put it, was a moral imperative and bestowed honour, enhanced social standing and carried the chance of personal fulfillment. Risk taking to achieve goals was the demonstration of consummatory experience, a show of values couched within participant interpretation of that which is good and socially acclaimed. Managing HIV was part of that risk and steering a path away from the risk of infection, the risk of being found to have the virus and the risk of managing a life-long regimen of treatment. HIV was just another component of risk that demanded strength of character to make good in the hunt.

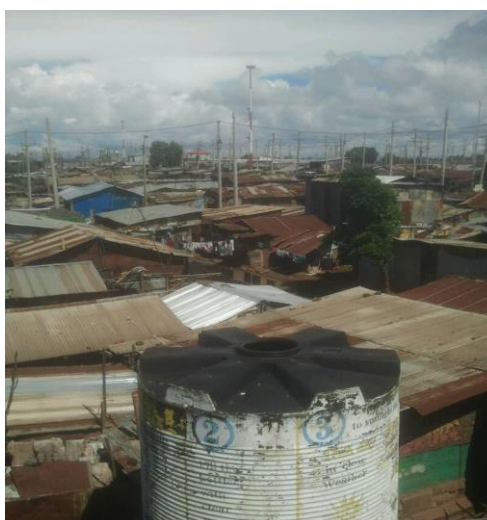
Not taking risk spelled a personal ending, a giving up, which was roundly felt as deeply humiliating and the antithesis of dignity, which participants instinctively sought to find in the here and now; taking risk provided hope for a better tomorrow, a stronger resilience. Participants demonstrated a proactive approach in discerning and securing that which mattered most to them and their dependents reflecting consistency of purpose. This, I interpreted as integrity given coherency of thought and action and was fundamentally truthful in its explicit aim of securing the trappings of life and wellness and making the best of whatever came along. Participants would speak of the interconnected world they inhabited and, as a sure way to achieve resilience, the need for certainty within themselves and cohesion within families, neighbourhoods and communities. This revealed a wholeness, a connection of parts that make up the everyday world of participants depicted in the circular model of HIV and the Integrity of Risk – Dignifying Resilience in Disadvantage and an inclusiveness of opportunity, threat and advantage involving a balancing of wants, needs and desires for the young slum dweller. Participants were keenly aware that to dignify resilience in disadvantage they had to stay within the confines of shifting moral social worlds, draw on collective strength to find solutions in tune with accepted codes of conduct which strengthened the integrity of their lives and gave it meaning over and over again.

The findings highlight the need to understand processes of managing HIV through the totality—the universe—of risk. A study of individual, environmental and structural domains, the results show, is necessary for painting the complete picture of managing risk of HIV.

As this research discovered, interpretations of gender are explained by individual perception shaped in the immediate social setting and constrained by the structural environment. Notwithstanding the place of agency, and that young slum

dwellers are proactive individuals, social and structural determinants influence behaviour, expectation and reward. The compendium of personal capacity and social structural influence that can both increase and/or diminish the presence of HIV is modelled in HIV and the Integrity of Risk-Dignifying Resilience in Disadvantage.

Factors relating to intrapersonal, interpersonal and structural concerns encompassing diversity of individual thought, action and belief demonstrate the parameters of risk and resilience for young slum dwellers. There is, perforce, much overlap between the domains: elements contained within one can be conceived as cross-cutting themes rather than autonomous phenomena; and taken together, they shape the reach and form of social processes for managing HIV. Each domain sheds light on the social, economic and political dimensions of risk and collectively elaborate the core category of this research. As shown in Figure 4.2, through the photovoice of Klara, the three domains were apparent in the successful construction of the water tank.



*Figure 4.2.* Symbol of Pride: A water tank in Korogocho was a symbol of pride and a demonstration of capacity by Klara who, aware of the dangers of contaminated water, initiated, with other women, its construction.

#### **4.2.1 The Individual Domain; Knowing, Feeling and Expressing**

##### **4.2.1.1 *Perceiving HIV***

Although it was beyond the purview of this study to test levels of AIDS knowledge, participants showed a good understanding of the sexual route of HIV and its prevention: chiefly, condoms and treatment-as-prevention. This finding held as much for 18-year-olds as it did 24-year-olds, and for short- and long-stay residents.

HIV meant something to everyone and often evoked discussion on gender, power and rights. Interview discourse on HIV often included the attitude that they ‘had the right’, to act in a certain way. Perceptions of gender, power and rights often illuminated an uncertain universe, as shown by an extract from NVIVO, capturing a discussion with Tony on HIV and gender:

Respondent: *men are in charge*

Interviewer: *What of being put down by a girl, do you fear that?*

Respondent: *Yes, almost every man fears that.*

Although participants perceived HIV as potentially fatal, depicted in the findings from the photovoice as well as interview, it was also perceived as commonplace and did not necessarily arouse an emotive response. I drew the analogy of a dangerous road; everyone knew it was there, but it did not warrant particular concern. There was a noted complacency among young people concerning HIV—it was a fact of life. Moreover, whereas the risk of not adhering to treatment was broadly understood by participants, the imperative of following a strict regimen was not emphasised in the discourse, owing, the evidence suggests, to the efficacy of ART in the short term and dismissing the urgency of continual medication. Seeking long term benefits, it appeared, was at odds with the approach of living one day at a time. As Sharon stated:

*You just use the drugs, follow the recommendations. These days it's (HIV) like common cold. If you want to die, you'll die of stress, and other things but this one doesn't kill anymore.*

The findings suggest that a commonality of perception was that threats to life, such as HIV, should not stand in the way of personal satisfaction (and young people’s sexuality was no exception); wanting to live life to its extremes and explore all it had to offer were components of what slum morality considered a healthy attitude and fitting to youth. Both Klara and Nancy referred to the necessity of youthful expression, illustrated by the following comment from Nancy and the photovoice from Klara presented in Figure 4.3:

*Why shouldn't we have fun? What's wrong with that?*



*Figure 4.3.* Vitality of Youth and Sexuality: Photovoice by Klara depicts the vitality of youth and a vibrant sexuality. Many participants echoed the feelings of Klara in explaining how young people had the right to explore and take risks.

The findings demonstrate that perceptions of HIV and one's invulnerability are not constants and will shift, especially after learning one's HIV-positive status. A 'change of heart', as described by a female participant, in being HIV positive had a potentially damaging effect on one's psyche and sense of place in the known world and, as this research discovered, experienced in a uniquely personal, and oftentimes isolating, manner. A positive test result is faced alone, no matter what support is at hand.

The findings show that perceptions differed on first learning of an HIV-positive status, but there was an equally common perception on the need to reconnect with others, including re-establishing sexual relationships. For the young people of this study, the social process of managing HIV reinfection had to be learned, interpreted and evaluated. The data demonstrate that perceptions of personal safety changed in the light of contracting HIV, as did searching for one's own resilience, moving from a refusal to face the facts to finding strength based on the facts and building a personal fortitude that overcomes. Personal capacity was nurtured through accepting an HIV-positive status, not something that came easily, but as Liz, HIV positive, said:

*It makes me strong because there are those who fear even getting tested. Being positive makes me stay away from alcohol and drugs and keeps me going. When you think you're negative you just say you don't have it and you just mess up but when you know you have it (HIV), it makes you stand strong.*

Sharon, HIV positive, similarly stated:

*If one is found to have been infected, the best thing she can do is to accept the situation, start taking medicine and continue with life.*

Sharon and Liz were learning to dignify a positive status, self-assured that their efforts were morally good and socially acceptable. Though premised on interdependence, being resilient was as much about perception as social connection. This sentiment is mirrored in Trevor's photovoice (see Figure 4.4).



*Figure 4.4.* Embracing Life: A self-identified 'reformed' character, Trevor was learning to embrace life, including his HIV-positive status.

However, the perception held by most participants was that no good came from being HIV positive and that life would take an irreversible turn for the worst. Of note, it was the fear of public shame, not the threat to one's health that mattered most. As Stephen, an HIV-positive participant explained:

*I wouldn't wish people to know of my HIV status, because they would gossip and spread rumours about it. I feel like, it's hard to say, just feel I'm alone.*

And Liz:

*Once people know you are positive, the news will spread everywhere. You won't be able to walk around with confidence. It leads to deterioration of health and loss of friends.*

As particularly expressed in the interviews, participants were aware of their own vulnerability to HIV; no one reported being immune to infection or not being at risk, though interpretations of risk differed significantly. Self-perception of risk might be offset with the need to find personal safety, which, as participants stated, was a goal worth pursuing. In the discourse with Liz she explained how having multiple partners made her strong; at risk, yes, but sexual networks were a sure way to access resources



and with resources came opportunities to effect change in one's circumstance. This response is captured in a statement from Liz extracted from NVIVO:

Interviewer: *Do many sexual partners make you strong?*

Respondent: *Yes!*

#### 4.2.1.2 *Conceiving HIV and Pregnancy*

Emotions were aroused, notably in interviews and especially among young women, concerning unwanted pregnancy. Young women appeared more concerned with getting pregnant than acquiring HIV from an episode of unprotected sex. There was a conceptual gap in connecting the risks of unprotected sex with HIV and unintended conception. The danger of unprotected sex was, first and foremost, unwanted pregnancy, as perceived by female participants. This was not to downplay the concern of HIV, but the priority was avoiding an unwanted pregnancy, in which there was no dignity to be had. As expressed by Nancy in her interview:

*It is a shame to get pregnant, people will just speak badly of you.*

Pregnancy, though not exclusively, was considered by both men and women as a sign of weakness, something blameworthy in which the female was invariably culpable. In response, and to find self-respect in a socially shaming event, conceiving was often put down to external factors that enabled a side-stepping of peer ridicule. The term 'condom baby' was used to refer to a pregnancy resulting from poor quality condoms that tear during sexual intercourse and thereby absolve a female from wrongdoing. To avoid conceiving, there was a general feeling that condoms were less reliable than hormonal contraceptives, preferred by many as a first tool of prevention. An unwanted pregnancy attracted public rebuke, whereas HIV could be controlled with the right medication. There was a gulf between dealing with a condition that was out of sight and having to answer for something that was plain for all to see. As Sharon said:

*When you're pregnant, most of your friends run away.*

There were safe-birthing options available for young women and giving birth at respected medical facilities was the norm, yet this did not reduce stigma associated with unwanted pregnancy. Despite the discourse, pregnancies among young women were not uncommon.<sup>13</sup> This presents a disconnect—the fear of becoming pregnant and the

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<sup>13</sup> It is estimated that in Nairobi County, around 17 per cent of girls aged 15–19 have begun child rearing (Ministry of Health, 2015).

regularity of pregnancy. A likely reason for pregnancies being feared so much was their pervasiveness in the local community. As Stephen remarked:

*Even young girls of 14 and 15 are pregnant, here it's normal, the young girls have already been abused. No one talks about it. Even recently four young girls were found to be pregnant.*

And Klara regarding the consequence of not being a young mother:

*The 'fashion' is now to get a kid, from 13, 14 or 15, most of them are pregnant. It's normal. If you find a girl in her 20s without a kid, you start doubting her abilities*

Childbearing and/or being responsible for children was an experience shared by all female participants. The findings suggest a collective understanding of female responsibility towards the safety and wellbeing of children. In the photovoice of Chrystal (see Figure 4.5), she explained how all children were the responsibility of every woman and that children could bring respect as well as shame.



*Figure 4.5. Children are Life: Chrystal depicted a happy scene with children and stated that the time had to be right.*

Female participants would mention abortion as an option ‘for some’, and always spoken of in the third person, creating an emotional and moral distance from themselves. Based on the body language of female participants, aborting was a shaming event and widely criticised by moral gatekeepers and medical practitioners alike, owing to unsafe practices. While the study of abortion was beyond the remit of this study, it did shed light on a potentially dangerous and humiliating event. Moreover, the findings indicate that non-clinical abortion was not uncommon.<sup>14</sup>

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<sup>14</sup> Abortion in Kenya is illegal except on the grounds of medical necessity. Paying for an abortion at a private clinic, should that be an option, would predictably be beyond the means of participants

Based on the interviews, another cause of pregnancy, according to participants' perception, was rape or some form of non-consensual sexual liaison.<sup>15</sup> An unwanted pregnancy for a young woman, in most cases, was a humiliating experience and worse still if it left her HIV positive. Female participants spoke of the difficulty in reporting incidents of sexual violence to health personnel in that it risked incurring verbal abuse and becoming another shaming event. Partly in response to the climate of mistrust, Chrystal was adamant that young women themselves had to be proactive in dealing with sexual and gender-based violence. Figure 4.6 illustrates perceptions of the role of agency among participants.



*Figure 4.6.* Gender-based Violence: Chrystal, in her photovoice, showed through a role play on gender-based violence how men and women, standing together, should not accept abuse and face the consequences—together.

Becoming pregnant, as expressed by both male and female participants, placed a heavy burden on young women, adversely affecting wellbeing and increasing levels of vulnerability often through heightened dependency on HIV-positive partners. Pregnancy, it appears, represented a downward spiral in which sustaining wellbeing became significantly more challenging. The findings demonstrate that if coerced sex was the cause of the pregnancy, the challenge in overcoming was compounded and adversely affected perceptions of who to trust and how to stay safe. Sexual coercion had immediate ramifications for processes of managing HIV and, as explained by Sharon during interview, it involved no end of soul searching in attempting to re-establish a sense of self:

*When you're abused, you just start doubting ... everything.*

And from Suzan, recounting the time she had been raped:

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<sup>15</sup> The Antivirus and Vulnerability Emergency Response Team (AVERT, 2018) states that in Kenya, an estimated 33 per cent of girls is raped by age 18, with '22 per cent of girls aged 15–19 reporting their first sexual intercourse as "forced"'.

*One weekend I went out, got drunk, and found myself in a lodging molested ... I was kicked out like a rat; this for me is humiliation.*

Findings from the photovoice demonstrate the respected status of motherhood. The interviews show that it is the preserve of older women, as female participants acclaimed their ‘modern lifestyles’ and regarded pregnancy as an impediment to achieving personal goals. Chrystal demonstrated in her photovoice (see Figure 4.7) that having children should wait until the right time, until things improve.



*Figure 4.7.* Respecting Mothers: Chrystal emphasised the importance of the mother figure in all aspects of life; a status particularly afforded to older and more established women, and that that risks of HIV changed with awareness and age.

#### **4.2.1.3 HIV and Self-protection; Sex, Gender and Gratification**

Participants spoke of the necessity to self-protect during sexual intercourse. However, the use of condoms, for example, particularly in age-disparate relationships, was described as a major challenge. Yet both male and female participants described relationships in which one partner was dependent on the other as not necessarily leading to disadvantage.

The findings in the interviews point to a tension between seeking personal safety and finding opportunity. Female participants spoke with a sense of pride in how ‘sponsors’<sup>16</sup> had paid their rent, met school fees and handed out expensive gifts. From the interviews, female participants, in particular, explained how accessing resources of an older man required a competency and was often a point of discussion among peers, especially if conspicuous expressions of wealth were involved. As Trevor stated:

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<sup>16</sup> ‘Sponsor’ is the parlance for relationships in which young women receive rewards from older men

*Young girls here (Korogocho) look up to somebody who is clean and wears nice clothes and who's smart ... they look for someone (older man) to get them things ... this is how they get respect.*

The findings were clear in that men were the providers of material gains as compensation for sexual favour and that such relationships provided the means to access material items, earn social status and gain economic empowerment. The photovoice of Sharon, shown in Figure 4.8, illustrates the places and the 'busyness' of social connection.



*Figure 4.8. Mixing and Connecting: Social interaction in public spaces was described by Sharon as 'networking'.*

However, participants were also aware that finding partners carried risk of HIV and impacted their capacity to manage that risk. Low levels of condom use possibly leading to unwanted pregnancy and HIV infection by older men was regarded more by some female participants as a 'natural hazard' that might never happen.

The photovoice, especially, demonstrates perceptions of the resource base available and opportunities for building personal capacity. Pursuing the aesthetic value of intimacy alongside acquiring tangible benefits was considered by all participants as a component of successful and dignified relationships. The risk of infection from HIV negative participants (or participants who did not know their status) often alluded to in interviews, was interpreted by male and female participants as just one facet of survival in a life-challenging environment.

Apart from two HIV-positive participants, one male and one female, both of whom had been infected at birth and shunned intimate relationships, all other participants found gratification through sexual liaisons. As stated in the interviews, sexual relationships were an important aspect of personal and social integration.

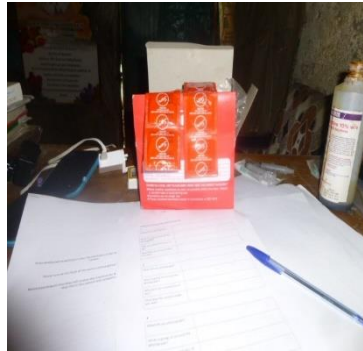
Sustained partnerships—mostly sexual but not exclusively, so the participants expressed—were something to be pursued with pride. However, at no time in the interview discourse was concern raised by HIV-positive participants about not wanting to transmit the virus through intimate partnerships; there was no virtue, in their eyes, to be had in such a course of action. Rarely was any sense of ‘altruism’ or suggestion of personal responsibility discerned from HIV-positive participants in not spreading the virus. As stated repeatedly in the interviews, no one wanted the label of ‘HIV positive’; the need to self-protect one’s standing in the community and rise above suspicions of moral laxity was always the main concern. As stated explicitly or by inference, participants did what they could to avoid risking humiliation by revealing an HIV-positive status.

Perhaps because the youngest participants were 18, in early adulthood, each participant perceived themselves as being vulnerable to HIV. Mostly from the interviews, but to an extent from photovoice, living in an environment with high HIV prevalence and having lost family and friends had given participants a keen awareness of AIDS. As summed up by Tony:

*Anyone can get HIV; no one is safe.*

Each participant understood risks associated with HIV; the question became the severity of perceived risk—that is, the subjectively constructed threshold of risk. Females felt themselves to be more at risk than males and expected that male partners would likely have numerous sexual liaisons at any one time. Males, in contrast, felt that female partners would be ‘faithful’, partly owing to fear of violent retribution if they were found ‘cheating’. The findings show that the rules of fidelity point to a very different reality for men and women.

Participants were aware of the constant threat of HIV, but there was variance in how young men and young women interpreted levels of risk and were willing to take preventative measures. Young women expressed a greater concern to do what had to be done in avoiding infection and assumed more personal responsibility for their behaviour. However, these statements were often made in the interview discourse regarding pregnancy, which may have been the primary motive behind avoiding unprotected sex, and not HIV. There was, therefore, a significant gendered response on matters of personal volition and, as shown in Figure 4.9, the wish to take affirmative action to safeguard one’s wellbeing.



*Figure 4.9.* Sustaining Health: Sharon was aware of the importance of agency in seeking a healthy lifestyle, which included monitoring treatment for HIV and sexually transmitted infections (STIs) and use of condoms.

#### 4.2.1.4 *Perceptions of Efficacy and the Realism of Resilience*

Participants spoke much in interviews about the need to take initiative and have a positive self-affirming mindset, especially in relationships in which little was known of the other partner. Participants reckoned, with variance along gender lines, how they felt empowered or disempowered depending on prior experience in a given situation that would influence if an action was considered worth it, such as use of condoms.

As shown in interview dialogues, the intent to procreate was more an immediate priority for male participants. It was, in their interpretation, a healthy life choice to make given the positive benefits of being known to be a father. Young women explained they were well aware of expectations on them to conceive; the matter was timing. Both male and female participants felt that conceiving was a sure way of declaring commitment in a relationship, yet romantic love could lead to poor choices affecting safe sex practices. Sharon stated:

*Children are good when there's love.*

The interviews illustrate that self-efficacy by both male and female participants was seen as a key component in the social process of managing HIV. Individual strength was built gradually—as interview discourses showed—on making, repeatedly, the right choice. Yet, interpretation of self-efficacy was influenced by peer group expectations of what and how far an individual must go in being effective. The findings were wanting in deciding how much is enough and when a state of resilience is obtained. It was explained by male participants on the grounds of strength of character. Mostly female participants explained in interviews how self-confidence and personal capacity were critical traits for living in the slums. The findings suggest that public

recognition of personal strength informs perceptions of self-efficacy and self-esteem. As Damien noted:

*A strong person finds solutions to problems despite the challenges; unlike a weak person who runs away.*

All participants explained that men need women and women need men as a way of showing personal worth to themselves and others. There was a need, so the interviews showed, in not wanting to appear submissive or overpowered in relationships, as evidenced by rejecting unsafe sex, while staying connected and wanted. There was little evidence in the findings of participants exclusively choosing their own paths and risking retribution from others. As repeatedly shown in interviews with young women, simply doing what a ‘woman had to do’ while risking HIV infection or risk being discovered as having HIV was necessary in pursuing personal fulfillment in relationships. Klara proudly spoke of being a ‘gender defender’ and her dedication in setting up a young women’s group based on shared history and vision; in such a collective it would be difficult to imagine how anyone not fitting the mould would benefit or even be accepted.

#### **4.2.2 The Environment: Social Interaction and the Navigation of HIV and Risk**

##### **4.2.2.1 *Communicating and Managing HIV***

As shown in the findings, social interaction underscored processes of perceiving and managing HIV. The photovoice is illustrative of a universe of interaction in which social relationships were established and information on HIV—and processes to mitigate risk—was communicated. Interview discourses constantly referred to an exchange of information, at times intense and shared through various channels. Information sharing built perceptions of social processes and, according to the findings, was as much about how it was done, by whom and whether the result of this interaction resulted in degrees of consensus or conflict. Although participants demonstrated capacity in comprehending the root of transmission, at times, in the interviews, perceptions were also moulded by misinformation and contained numerous versions of the ‘truth’. Tony, in Figure 4.10, outlined some of the many places for communicating information and building alliances of trust among like-minded peers.

Information, especially that to do with financial income, was readily shared among peers. Participants described an oral tradition in sharing information, notably to do with income generation or the opening or closing of a health clinic. Information that had an immediate practical use was prioritised by participants and, as the findings show,



HIV was oftentimes not the main concern. Information about a new construction site, for example, was spoken of by participants in interviews as more important than a new HIV-prevention technology.



*Figure 4.10.* Sharing Food and Stories: The photovoice of Tony explained it was a key aspect of everyday life.

Participants talked of the various channels in obtaining information on HIV, most of which occurred in same-sex peer groups between young people of similar age. As Suzan stated:

*In most cases our girl stories revolve around boys and things to do with sex.*

Although social media was stated as an important means for HIV information, both male and female participants explained that news was spread with probably greater alacrity by word of mouth and among same-sex peers. Participants explained how an HIV message would be heard, shared and evaluated for its relevance to the local environment. The findings demonstrate that regardless of the source of the message, it still required interpreting through a system of shared values and a common understanding of sex, risk and morality. Verbalising messages on HIV, so all participants stated, was a crucial means of building knowledge of social processes, be it based on fact or fiction. Chrystal stated:

*We can talk about HIV and how to avoid getting it and what to do if you get it.*

For these participants, nothing in and of itself was taken on face value, owing in large part, according to interview discourse, to the overall poor-quality health service in the slum with suboptimal (often counterfeit) medication, including ART, and the dubious nature of the many pharmacies doing brisk business. Trusting in the

unknown—and medicine was no exception—was explained as a risk, and minimising risk in the perception of both male and female participants, was common sense and part of the arsenal of self-defence. Liz, as part of an early cohort for roll out of PrEP for people at high risk of contracting HIV stated:

*If you're on the blue pills (PrEP), you don't need to use condoms, which no one likes.*

Participants stated, in plain terms, that the more one heard a message, the more likely it would be seen as truth. Participants explained how a public health message was shared and debated, for example, on condom use and ART, until consensus was reached on its efficacy. Participants also explained how 'the truth' could change as new information became available, which demanded an alertness to stay abreast of developments, necessitating continuous social interaction. The photovoice depicts a busy universe in which communication between peers was used as a path to dignity and resilience. Although not explicitly stated, participants alluded to processes of information assimilation in generating understanding intelligible to themselves and applicable within their social worlds. It was this interaction, as explained in interviews, that defined and shaped information relevant for managing HIV. Regarding medication, Nancy said:

*Taking medicine can be complicated, especially if it's new.*

Of note, self-identified sex workers would, more than most, proactively engage in information sharing on HIV. As stated by Klara, the seeds of this knowledge, for example on PrEP, could be planted by a local drop-in centre for sex workers and discussed until its merits was established. It was the active pursuit of knowledge through official and unofficial channels that especially characterised the universe of sex workers; as described in interviews, it was vital for their survival. Self-identified female sex workers stated there was little communication on HIV between them and their clients, short of the pros and cons of condom use. As they were part of the sex industry, it came as no surprise that talking about sex was not an issue; communicating on HIV and sexuality was far more problematic for women not self-identifying as sex workers. Communication between sexual partners (commercial or otherwise) on HIV prevention appeared limited. Building rapport between sexual partners was disadvantaged owing, so the findings suggest, to gender power dynamics in which men were expected to take the lead but may not have the skills or interest in making the first move. Chrystal explained:

*Men can talk about sex and things but sometimes they don't want to.*

The nature of the relationship, whether based on romantic love and/or transactional arrangement, was a factor in communication between intimate partners. In the discourse, it was primarily left to the participant to decide on how a relationship of long or short duration was defined. The common criteria expressed in describing a long-term union was whether the relationship lasted several months or more, if there had been some form of marriage ceremony, considerable sharing of resources and birth of a child. However, most of the participants did not talk of long-standing relationships and liaisons of short duration appeared for them to be the norm. In such situations, building dialogue in which sensitive subjects, potentially including condom use were raised, as participants explained, could prove problematic. Generally, young women had experienced repeated rejection from partners and expressed dismay that future relationships would not prove any different. However, young women also talked of finding the perfect partner in which the union is based on mutual respect. Rejection in relationships, as stated by both male and female participants, could lead to feelings of unworthiness and reduce awareness and capacity to manage HIV. Sarah explained the situation when a relationship is over:

*Sometimes you know it's over when you don't get things, or people tell you ... and you feel bad.*

Participants stated that communication was most effective when it had purpose and touched on heartfelt matters. However, the topic of safe sex and the purpose of managing HIV did not appear a priority. One male participant, Tony, found communicating with a sexual partner futile as, in his opinion, the only thing women wanted was money. Participants, both male and female, felt there was an urgency for communication between partners, though not one suggested how this may happen. Participant discourse in interview, and notably among females, suggested that mutual respect in intimate relationships was the cornerstone of managing the risk of HIV, and respect hinged on trust. However, participants, both men and women, did not equate respect and trust to authentic and effective communication.

#### **4.2.2.2 *Sex, Morality and Condoms***

Condoms had an ambiguous status for participants: thought of as an important part of healthy sexuality by most, yet for some, as promoting promiscuity and offending ethical norms. Moral guardians, as the findings show, exerted influence over

participants, including condom use; although to what extent remained conjecture.

Chrystal said:

*In church you might hear from people that condoms are bad, but no one really talks about it.*

There was a 'give and take' attitude among male and female participants expressed in interviews and photovoice regarding messages of sex and morality, such as the rights to have multiple concurrent partnerships. This research found that what passed as moral virtue took many forms and was shaped by the exigencies of day-to-day survival. Participants explained how 'being moral' sanctioned what measures needed to be taken in the context of day-to-day survival, including carrying condoms to a sexual encounter, and how far one would go in negotiating their use. For these participants, a certain 'home-grown' morality was necessary suited to local context and could underpin behaviour, including the right to find personal gratification. Participants did not believe that sexual behaviour necessarily needed explaining, nor justifying, but if their actions were 'ethically acceptable', such as selling sex to support dependents, then all the better. Tony explained, in the context of transactional sex:

*People have to do things to get money, it's hard to find a job, and jobs don't pay...*

Participants felt that condoms were used in private and away from judgemental and moral eyes. Therefore, a certain flexibility was possible in deciding on the merits of their use. Both male and female participants felt that it was correct to reach consensus on the practice of safe sex and how much risk was 'morally acceptable'. For instance, self-identified sex workers mentioned how hard it was to practice safe sex with a regular client, as to do so might be interpreted as insulting and falling outside moral codes of decency. Participants would state that if they did raise the matter of using a condom with their partner and if the discussion took an awkward turn, the matter would be dropped; it was not worth pursuing. Self-respect did not allow further embarrassment as he/she was out of kilter with moral sexual codes of young people. Further, if the main concern for women was not to conceive, then there were less intrusive options than condoms. Trevor in his photovoice (see Figure 4.11) was eager to stress the importance of condom use but less clear about whether they were always used.



*Figure 4.11. Condom Use:* Trevor highlighted the dilemma of knowing the importance of condoms and the challenges involved in their consistent use.

The findings demonstrate the difficulty of continuous use of condoms in long-standing relationships, even when HIV statuses had not been determined. To stop using condoms in long-lasting liaisons, according to female participants, signified a leap to a new level of intimacy and could be construed as worth the risk; the gains justified the risks. But the question remains of the catastrophic effect of an unknown HIV status on a relationship. Sarah spoke of how she became pregnant by her partner and upon a medical check-up discovered he had given her HIV. The intimacy, in this case, was shattered; feeling humiliated and in her mid-teens, this participant turned to sex work to support herself and her newborn. As she said:

*I do sex work and stripping so I can support my children.*

#### **4.2.2.3 Gender and Social Organisation**

This study established the importance of gender in identifying perceptions of risk. As became apparent in the interviews, relationships between young people were governed by traditional values of male dominance, which, as reported, could be violent. Gender-based violence was physical, verbal and/or emotional and involved the withdrawal of material support or, just as likely, in a demand for material support. To self-protect, participants reported a closing down of self and not, so the discourse showed, open communication between partners to deal with instances of abuse. As stated by Klara, whose younger sister had been repeatedly raped and now feared the world at large:

*Young men here steal, rape; they do very many bad things.*

In a climate of fear, findings from the interviews demonstrated that starting conversations such as condom use or inquiring into suspected infidelity by a partner becomes very hard. Although participants felt that the specifics of a relationship, such

as age disparity and purpose, were key considerations, the overriding nature of male coercion whether blatant or subtle defined the parameters of unequal power dynamics between partners. Female participants expressed an awareness of the many moral overtones depicting female submissiveness in relationships and any deviance from the norm demanded self-capacity. Personal empowerment, as female participants explained, was rarely achieved in the confines of a relationship. Nancy, in her photovoice (see Figure 4.12) expressed a constant fear of sexual violence, particularly among young and unprotected women.



*Figure 4.12.* Sexual Violence: The young woman had been sexually abused on several occasions and now preferred to stay within the safety of her home but, as Nancy explained, still wanted to be photographed and had not ‘given up’.

Adding to cultural myths surrounding male sexual impulsivity are perceptions reported by female participants of male sexual passion that could be expressed violently, claiming it as no more than uncontrollable love and, therefore, desirable. Yet just as often female participants would speak of wanting a loving relationship free of harassment. This sentiment was expressed as if through a distant dream and not based on personal experience. In one photovoice narrative, the female participant expressed her idea of a dignified relationship by photographing a magazine cover showing two young people entwined in each other’s arms, happy and content; this for her echoed the perfect life because dignity, so she explained, was expressed through kindness and compassion.

Reports of male sexual violence were often followed with an account of how such acts drove females away from a relationship, though this decision did appear to be influenced by socioeconomic circumstance. Chrystal stated that:

*If there is violence (in a relationship) you must go even if he is giving you things.*

Female participants would speak highly of women who resisted violence and took affirmative action, which may involve meting out the same level of violence against the offending male. Asserting one's right to personal safety was described as morally defensible. Young women knew they were morally justified in speaking out against violence and male participants were equally aware that justifying the use of violence was never an easy task. However, the men and women agreed that intimate partner abuse carried out in private and away from public scrutiny and moral sanction was a very different matter. One self-identified female sex worker, Klara, explained measures taken to minimise risk of sexual violence from clients included paying part of their earnings for protection from a local hotel guard. According to Klara, 'her friends' shared values and wanted to stay safe, described as a form of social insurance.

Female participants easily identified with the triple role of women in society<sup>17</sup> and spoke of the enormous burden placed on them. They also spoke in interviews, and demonstrated through domestic scenes in photovoice, of their 'die-hard spirit' based on an innovative resourcefulness that drew on collective female strength. This is further demonstrated in Figure 4.13.



*Figure 4.13. A Woman's Day: Sharon detailed the burden of work placed on women: 'here, women do everything'. This woman was preparing food while looking after her own and a neighbour's children; the food was to be sold at the market for household income, part of which would likely go towards a church fundraiser.*

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<sup>17</sup> Gupta, Kemelgor, Fuchs and Etzkowitz (2005) describe the triple roles as reproductive (domestic, child caring and rearing, adult care, nursing of dependents, providing sustenance); productive (subsistence work including income generation); and community engagement (community-level work involving provision of items for collective consumption).

This interpersonal connection among women was considered critical in fulfilling the triple roles as going it alone would be impossible—there was just too much to do, with too few resources. To succeed demanded collective action to achieve a common goal. Young women were all too aware that not only their own lives, but also those of their household, their dependents and their community counted on it, as probably did the entirety of social and political organisation of the slum.

Female participants would often mention controlling vital resources as a result of absentee fathers, husbands, uncles, brothers and so on, who not unexpectedly appeared, so this research learned, when in need or on hearing that a new resource had arrived in the household. Young women expressed a wish to be as self-sufficient as possible by generating vital resources, especially cash. To generate resources, the young sex worker risked life and injury, but to have that freedom made possible with disposable income, in their eyes, made it worthwhile. Female participants thought that sex work in the slum, as elsewhere, was primarily the preserve of young women and a viable option for only a limited period of their life. The findings suggest that participant perceptions of moral judgement shifted according to age from labelling sex work as ‘misguided’ to ‘unacceptable’. Perceptions of the morality of sex work and the risks involved by sex workers were ambiguous and demonstrated a practical and fitting moral evaluation. As Nancy, a self-identified sex worker explained:

*You are forced to use these drugs (marijuana and alcohol) because you can't go stripping when you're sober.*

And in the words of Sharon, describing how it was to be a sex worker:

*Sometimes you get humiliated, at times you are in the community and some people know the kind of job you do and how you dress ... someone will tell you that you're a prostitute and call you names.*

All female participants explained in interviews that sex had direct moral connotations. The same-sex peer group stood out as the primary mechanism for generating meaning on sexuality, including discerning that which is morally correct and acceptable. Peer pressure did not manifest itself in the same way for everyone as there was still the matter of interpretation and agency. Social organisation, according to all participants, was invariably based on gender lines. Discussions of collective resilience, managing vulnerability and reducing risks, the findings show, were characterised by same-sex groups; for example, small business enterprises, self-help groups, credit schemes, community watch and support for dependents. Participants explained that men



organising around a common purpose was rare and when it did happen—for example, a savings scheme—the initiative invariably crumbled after a relatively short time.

A key unit for support and based on a common identity was family. The family, however constituted, held the potential to provide the basis for building personal capacity and resilience. Definitions of family included immediate and extended family members and even long-standing neighbours and dependents. The family bond, as explained by Sarah, was critical:

*If you are in a big family, you can be sharing your problems with each other and there is joy in the house.*

The discourse in interviews and photovoice shows that families were principally made up of female figures, with older women playing the role of moral guardians. As Nancy put it:

*You know, the family keeps you together. The moment you get away from the family, and say you don't want a family near, that's how we end up getting into these unwanted behaviours (sex work).*

And in highlighting the importance of the mother figure in family life, Trevor said:

*My mother died just a day before the beginning of my exams, and I didn't pass as expected. And so, as a young man, like other young men, I joined a gang.*

In discussions of family, female participants would speak of mothers, sisters and daughters; rarely mentioning male figures. Males, according to the discourse, were often fleeting figures posing as much threat as support. Male participants, in talking of family, also would speak of mothers, sisters and daughters and rarely mention a male figure. It was not uncommon for men to have a series of families, moving from one to the next; and any support that might have existed soon ended. As Suzan stated:

*Then our father decided to marry the second wife. He did not want to stay with us. So, I was living with an elder sister who was hustling (sex work) at the time. She decided to stay with us, we were six children.*

Liz stated:

*life turned against me or something ... just realised all my fathers, those I called my fathers, had all left me.*

#### **4.2.2.4 The Social Organisation of HIV Care and Support**

Social expectations shared by participants reflected the immediacy of the physical and organisational environment of the slum. Health services offering HIV

testing and screening were offered by participants as a case in point. With the noted limitation of health care, male and female participants reported using an extensive network of informal sources to obtain wellness-related commodities, though accessing HIV tests was never mentioned. These commodities included ‘morning after pills’, condoms, hormonal contraceptives and items used in the treatment of bodily injuries. As stated by John, the slum was no different in following the rules of supply and demand; if formal health facilities did not exist or failed to meet demand, then alternative sources appeared to fill the gap.

Participants would speak of the plethora of private health care institutions stocked with various health-related commodities. The quality of services and commodities at these private institutions was often wanting and were less preferred to those available at formal facilities. However, the only option very often, as explained in interviews, was to use informal, unregulated and poorly managed establishments. As Trevor stated:

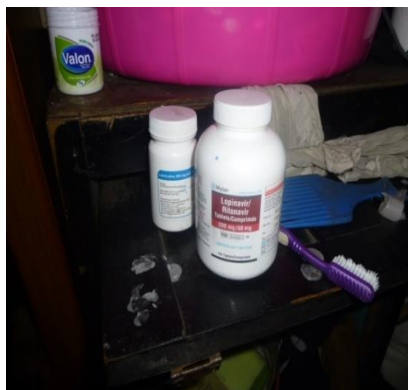
*Sometimes you don't find what you want (medicines) and you just get told 'it's malaria'.*

There was some inference, however, that staff in these alternative facilities were likely to be more approachable, being driven by the rules of needing to make the sale.

Social knowledge of the environment was described as crucial for ranking private institutions and such information was passed among residents by word of mouth and, as reported, mainly within same-sex peer groups. Friends shared knowledge on where and how to access health care and even how to approach service providers to acquire commodities of a ‘sensitive’ nature. The physical assets of the environment were evaluated and given meaning through formal and informal interaction among young residents.

There was a vibrant network among peers in sharing health- and HIV-related commodities. Very often the first course of action was to see what could be loaned, borrowed, or obtained freely. Among participants—and this did not follow gender lines—so much was traded that there was always a debt to recall or some line of credit that needed repaying in cash or kind. Friendship networks often proved the only alternative for accessing health-related items. Even ART, as Figure 4.14 shows, could be shared among peers, if necessary, with medication accessed from formal health facilities being most preferred given the perception that it is more likely to be genuine if it came from a known institution. For participants living with HIV, they mentioned

choosing the right time to visit health facilities to obtain ART and avoiding suspicion from on-lookers, as well as when to ask a friend for medication if their supply had been exhausted, or requesting a third party to go to the facility on their behalf. It appeared that all options had been utilised at different times by HIV positive participants.



*Figure 4.14. ART:* In her photovoice, Liz described the plethora of medicines available as well as their frequent unreliability. ART, because it was from the clinic, was said to be more reliable.

With the crumbling infrastructure of the slum and across the board, substandard social service provision ranging from education to transport to health, feelings of ‘being let down’ and ‘being denied’ by these same services carried a dehumanising message of ‘less than’ for some participants. Participants affixed a social value that was commonly shared concerning their place of residence and services available compared with more affluent, non-slum residential areas. In talking about health care in Majengo compared with elsewhere, Chrystal stated:

*It's bad here; no one cares; not like Westlands (suburb of Nairobi).*

#### **4.2.2.5 Sharing and Connecting, the Nexus of HIV Risk**

The photovoice illustrates how, for these participants, life was lived on the streets and alternatives to street life were few. As explained by all participants, travelling to places with a different lifestyle involved cash, the one commodity always in short supply. Street life had its advantages for mixing and socialising, for building social alliances, and an efficient way for keeping abreast of developments; participants would explain the importance of gossip and gossip lived on the streets. Gossip, as female participants explained in interview discourse, was a critical part of building social processes, affixing moral and social value shaped and given meaning on the street. Figure 4.15 shows one such example of open spaces.



*Figure 4.15.* Public Events: At social events, so Liz explained in photovoice, such as queuing for water, stories were shared, and people kept abreast of developments in the vicinity likely to affect their lives.

Participants repeatedly emphasised the interconnectedness of their lives, with the gossip of street life paramount. Chrystal stated:

*We are always outside (streets) doing things, you don't want to stay inside because you don't know what's going on.*

Associated with street life, according to participants, was the presence of illicit drugs and alcohol. Participants mentioned an array of concoctions bringing about mood change and lowering sexual inhibition. These substances were taken in social settings among peers, and social connections directed users to locations where they could be consumed. As part of the interview discourse on use of substances, an active trade in home brewing of alcohol was reported, all of which was illegal and beyond any notion of control. 'Good money', it was said, was to be made from 'drinking dens' and provided livelihood for many, notably women; making and selling alcoholic beverages was, according to the evidence, a female line of work. Places of consumption were roundly perceived as very dangerous and often the site of sexual violence. As with sex work, the risks of working in a drinking den were known, yet the lure of remuneration, as reported by female participants, made it an attractive option, possibly the only option. If something resulted in a form of payment, as stated by both male and female participants, and preferably if it took the form of cash, it was invariably considered worthwhile. As Nancy explained, this was survival and survival justified choices made, even if de-humanising.

The use of drugs and alcohol was reported in interviews and shown in photovoice as a means of escaping the drudgery of daily life. Participants described the lack of recreational space and virtual non-existence of public spaces, as open land

represented somewhere to live and trade. No one reported wishing to be by themselves as a way of coping with stress and, in the absence of recreational options, this often meant socialising on streets or within the confines of residences. Participants, at different times in the interviews, would allude to the fact that sex was a means of alleviating boredom and finding connection.

There appeared a gender dimension in seeking gratification. Young women never reported having free time; their day was relentlessly busy from start to finish. All participants were clear in their assertion that ‘lazy women’ were ‘bad’ and ‘immoral’. Much of the photovoice depicts busy scenes of women working, communicating, fixing. The converse was true for young males: ‘idleness’ among men, as stated by Tony, was justified as there was nothing else to do. The underlying assumption, therefore, was the low value of female labour vis-à-vis leisure time and the values attached to male non-activity, which, by and large, seemed to be tolerated. Women’s work, as shown in Figure 4.16, was often open and made them vulnerable.



*Figure 4.16.* Making Money: In the photovoice of Sarah, she explained how women, to earn cash, could often be absent from home for long periods of time, which meant that dependents often had to be entrusted to a young neighbour.

The findings from interview but not through photovoice suggest that in addition to sex, notably for young men, forms of social deviance provided a means of gratification. One male participant, Damien, spoke of the joy of owning a gun and how it made him friends and gave him safety. As he stated:

*If you have a gun in Korogocho you will live a peaceful life.*

Sex and social deviance, the findings suggest, both depended on interpersonal connection and were framed within moral social worlds principally made up of same-sex peer groups.

As with private health establishments, there were innumerable places of worship and each participant spoke of a faith actively practised and personally owned. Places of worship, the findings suggest, offered a means of dependable support. Participants explained how their spirituality helped them define morality and evaluate sexual desire. Religious interpretation of morality and sex were beyond question, according to participants, yet data from interviews suggests a different picture, one far more fluid. Participants insisted on the importance of maintaining a moral climate through faith-based groups organised in formal or informal spaces as critical in managing HIV. The dictates of religion, so participants explained, were manifested in their behaviour and shaped their attitudes towards risk and HIV. This is further illustrated in Figure 4.17.



*Figure 4.17.* Religion: John explained in photovoice how church was where one learned about good and bad, right and wrong, and that keeping a bible close by helped keep him righteous, including on matters of sexuality.

### **4.2.3 Structural: The Social and Political Organisation of HIV**

#### **4.2.3.1 *Sex and Power; the Gender Fault Lines***

Participant descriptions of gender power dynamics relating to a high-HIV-prevalence setting reflected a particular social and political organisation. Although female participants never appeared subservient in their interpretation of what had to be done to get ahead—avoid unwanted pregnancies, remain HIV free and build a life for themselves and their dependents—relationship scripts rarely mentioned attempts to effect change in sexual power dynamics. As part of the process of securing protection for themselves and dependents, female participants described through interviewing, and

further clarified by photovoice, opportunities to be found in the informal economy for generating cash. According to their accounts, income generation often included highly visible roadside trade in the vicinity; people knew who was making money and who could likely offer lines of credit. Petty trading carried risk and female participants were aware that they needed to stay vigilant; street life was dangerous, but the lure of cash, so it was explained, in securing sustenance and a more favoured lifestyle outweighed risks associated with living a life for all to see. For young women, economic ventures included food preparation and sale of food, clothes washing, house and office cleaning, clothes repair and sex work. Aside from sex work, which demanded a certain dress code, income generation for young women, it was reported, demanded little prior investment. In contrast, young men would talk of securing positions of social and economic prestige, such as being a taxi driver or politician, professions requiring substantial start-up funds. Figure 4.18 captures a typical scene of work available for women.



*Figure 4.18.* Roadside Work: Klara in her photovoice depicted a friend preparing food for consumption in a roadside kiosk, stating ‘this way we have money and are not dependent on men and family’.

Female participants, while aware of the gender division of labour characterised by low status of female employment, were also cognisant of the fact that it provided, at the least, a means to access vital resources. As demonstrated in photovoice, assets of young woman were shared with neighbours and dependents, yet unwillingly, according to interview dialogue, with male adults. Young women’s work gave them the edge vis-à-vis male counterparts to earn an income and a degree of autonomy. The gender division of labour put men at considerable disadvantage and, as reported by female participants, could lead to young women being attacked as they now had the means of

sustenance. No male participant reported office work; the closest was volunteering at a local NGO, which allowed access to office space and use of a computer. Volunteering, while socially approved, did not carry with it the weight of paid employment; status, as reported by male participants, came with affluence and recognition. According to Damien:

*you know with our area, it's your pockets that speak and people will not respect me without it and there are no jobs (in Korogocho).*

Time and again, participants reported that cash was the key resource in the slum and accessing it never assured. Cash, as Figure 4.19 suggests, was first on each participant's mind, it was the stuff of life in the slum.



*Figure 4.19.* Cash: In depicting pride and self-respect, Klara photographed a pile of cash now at her disposal; as she said, ‘with it you live, without it you die’.

Participants explained the moral imperative of finding cash or, as Chrystal stated in an interview, it was a ‘duty’ as lives depended on it. The social value of attaining at least a modicum of wealth, conspicuous and demonstrable through dispensing cash in public places, was similarly explained as important for personal wellbeing and standing in the community.

The photovoice demonstrated that female participants perceived opportunities to express identity, personally and collectively, and assert a distinct individualism. Female participants stated that taking risks could build an innate and personally defined resilience robust enough to withstand recurrent shocks as well as dignified in the craft of survival. In a highly proscribed social setting in which gender roles were clearly set and largely went unquestioned, the findings show that innovation and initiative, as shown by women of this study, appeared as the key variables in structuring many aspects of slum life. Both male and female participants spoke of very successful



women, in business, as property owners, as politicians—all of whom exercised considerable influence and held respect from swathes of the population. As Sarah stated, if they could do it, so could she. This sentiment is illustrated in Figure 4.20.



*Figure 4.20.* Sharing Work: Washing clothes was described in the photovoice of Nancy as woman’s work and regularly shared among women. Mutual help in earning cash, so Nancy stated, minimised risk and women who helped others were respected in the community.

#### 4.2.3.2 *Agency and Morality: the Structural Drivers of Wellbeing*

Principally through interviewing, female participants would talk of the need for procreation drawing on the values of traditional custom and, at the same time, uphold the value of sexual liberty falling outside of conventional expectation. Female participants would talk of ‘rights’ in choosing a course of action. However, the same participants would also state there was little recourse to rights, as demanding rights demanded money, which was forever in short supply. With the exception of only one male participant, Tony, participants expressed little confidence in the rule of law or the role of law enforcement agencies in enhancing or protecting their rights. As one female participant, Keji, said, the practice was for young women to find their rights, notably regarding sexuality, through circumspection and avoidance behaviour as this was the means to personal safety and affirming self-identity. Chrystal explained:

*You have to rely a lot on yourself to stay away from danger; who is going to help you if you’re by yourself?*

For these participants, morality and self-protection were deeply entwined; in the discourse both constructs would be construed as one. It was a moral good to self-respect through enhancing personal wellness. However, there was disagreement between male and female participants on how wellness was to be defined. In taking care of oneself,

and for female participants this also included dependents, it was explained that one must take risks, including risking contracting HIV. Nancy said that risking was an essential coping strategy of the slum and there was little choice. In the interviews, participants demonstrated a clear sense of right and wrong, what had to be done, and life was spoken of in simple black-and-white terms, polar opposites of good and bad, with no middle ground. Both male and female participants described the morality of obtaining cash, a case of the end justifying the means. Photovoice demonstrates happiness in obtaining resources and the means of its generation. Conversely, those, especially young women, so the findings suggest, who did not find a path to obtain at least a minimum amount of cash were considered frivolous and subject to abuse. As said by Sharon:

*Here in Korogocho when some people see you are not earning, they disrespect you.*

Having cash, as explained by all participants, provided a measure of freedom from risky circumstance and brought respect. In interview discourses of morality, religious and political concepts of ‘moral’ and ‘ethical’, ‘lax’ or ‘conservative’, were explained through a pure dialect (right or wrong) and never by considerations of a multi-polar reality. One had money or did not. One had the capacity to make money or did not. This was explained by John as the ‘practical ethics’ of the slum. Figure 4.21 captures an aspect of the ethics of engendered lines of work.



*Figure 4.21.* Gender and Work: In her photovoice, Klara explained that some jobs, like car washing, were mostly for men but women, when they had to, could also do them especially when there were few other options available. It was accepted that women could cross the line into men’s work easier than could men into women’s work.

In explaining the moral consequences of sexuality, participants were emphatic on the ‘rights’ and ‘wrongs’ of sexual health. There were commonalities running through interview discourses: sex was natural; sex should/could not be avoided; it was

normal for young people to want sex; and both men and women were sexually active, but men probably more so than women, and therefore needed more sex. The perception that men needed more sex also had social value among peers and, as male participants explained, could lead to multiple partnerships. As John stated:

*Having more than one girlfriend makes you appear good in your friends' eyes ... this is almost everywhere, and it makes you feel great.*

#### **4.2.3.3 Social and Demographic Mobility—Demonstrations of Capacity**

Around half of the participants were born in rural areas and moved to the city at different stages of adolescence. Given the barrage of demands, such as the agricultural cycle, a backwards and forwards with rural homes was reported until a final break with home of origin and urban identity established. Migrating adolescents, it was explained, played a vital role in rural homes, especially young women, and knew the burden of responsibility from an early age. Finding a new life required dexterity and a sense of resolve, which was described by Sharon as the essence of resilience. Female participants would describe how, as a new arrival to the slum, they would need to find personal capacity that drew on previous rural experience to meet the structural demands of an urban environment.

Reasons for coming to the city were mostly owing to a lack of domestic resources coupled with loss of primary caregivers. Keji explained that when she was living at the family rural home, her mother died first and then her grandmother, and although she was taken in by a relative, her school fees and medical costs were not paid and the only option was to come to another relative in Nairobi. As Keji said:

*The people who should have cared for me all died and now no one was interested in me ... I was told to come and live here (Korogocho) and given bus fare.*

Participants explained how they would arrive in a strange environment and, if lucky, were assisted by extended family members to whom they had to prove their worth; they were another mouth to feed. This was especially so for adolescent girls. There was no participant who spoke of wealthier and happier times and a comfortable upbringing. The slum was a variation on a theme—a life lived in poverty.

Participants spoke of the bonus associated with city life. Unlike rural homes, urban residence offered hope—the urban dividend—that things could change for the better. Sarah spoke of her dream to go to Nairobi, even though her abode was in the heart of Nairobi. Coming to Nairobi meant so much more, it was symbolic of a

comfortable and secure life. If the promise of Nairobi did not materialise there was always the option of returning to rural homes but to do so would be an admittance of failure; a public disgrace in front of family and friends; a statement that city life had proved too much. This, as reported by participants, was not acceptable; they had to keep going on and trust that the triggers of poverty did not lead to a life-long spiral of deprivation. The situation demanded that risks were taken and taken again and again if necessary.

If one left a slum neighbourhood, it was invariably to another neighbourhood or to a neighbouring slum. Reasons given for moving included having to flee violence, zealous and demanding relatives or pending bills. Notably, having one's HIV-positive status discovered was never given as a reason to move. Moving was never explained on the grounds of happening upon good fortune. Mobility, as the findings show, was more a coping mechanism and it was not unusual to hear a participant relate how they had moved home several times over the course of the past year in the search for opportunity. John stated:

*People often move, sometimes we go and sleep and keep our things in different places, sometimes, we don't have a place to call home.*

In the interview discourse, there did not appear to be a notable distinction between long-stay residents and new arrivals regarding patterns of risky sexual behaviour. A new arrival, as explained by participants, had to follow established cultural norms concerning partners and sex. Tony stated:

*When I came here (Majengo) I needed to make friends and look like everyone else, if not it would be dangerous.*

The rules already existed and had to be learned. All participants agreed that assimilating into peer groups, while connected to family, was an important element of 'fitting in'. Notably, male participants also mentioned that as part of the process of assimilation, one might be pressurised in engaging in sexual encounters, which, if this resulted in solidifying relationships, was worth it.

#### **4.2.3.4 *Dignity, Poverty and Wellbeing***

Participants gave, through both interview and photovoice, an account of the structural determinants in managing HIV and how to sustain physical, mental and emotional health. A very practical understanding of the continuum of treatment and care was demonstrated by participants, particularly the need for a holistic approach in which

food and non-food items were as important as medication. This is echoed in the words of Liz who explained why it was hard to maintain HIV treatment:

*A person may be having HIV and thoroughly counselled, but they lack food.*

And Sharon, although very much aware of the pitfalls of treatment breaks perceived the need for immediate feelings of wellness as equally as important in keeping to her medication, reasoned when asked if she kept to the treatment programme:

*No, because such drugs require you to eat well and they also cause dizziness.*

One male participant, Damien, described finding sustenance as a hunt in which the result is never assured, in the same vein as contracting HIV. No participant reported living their life in a state of privation as accounts of occasional ‘windfalls’ were reported. However, all participants recalled days, even periods of their lives, when cash was so scarce that a full meal was a luxury but always believed that things would get better, by and by...

Participants demonstrated an awareness of the link between poverty and HIV. Oftentimes in interviewing, both male and female participants spoke of the impact of HIV in the context of poverty. Participants felt vulnerable to both poverty and HIV and felt they lacked opportunities for self-care and protection. Figure 4.22 depicts the uncertainty of everyday life in Korogocho.



*Figure 4.22.* Scavenging: Tony explained in his photovoice that many of the residents of Korogocho depended on the nearby city dump for scavenging, which, most participants, it appeared, had engaged in as a means of survival. Scavenging, especially after dark, was said to be risky and often violent.

Female participants, in times of privation, described how they may turn to negative coping mechanisms, such as risky sex, as a survival mechanism. Successfully managing processes of HIV risk, so the findings suggest, appeared most effective,

though never assured, when there was at least a degree of economic security. As illustrated in Figure 4.23, participants at both Korogocho and Majengo would speak of the unsanitary conditions to be found in their neighbourhoods.

There was a stark difference, however, with the cleanliness found inside participants' homes, which were without exception immaculately kept, as photographed by Liz (see Figure 4.24) and stated by Klara:

*It is disrespectful not to have a clean home, people will think bad of you if your home is dirty and not respect you. Korogocho is dirty but I am not.*



*Figure 4.23.* The Dirt of the Street: Damien, through photovoice, captured a pathway strewn with litter covering an open drain that ran outside two participants' homes. Suboptimal housing was stated by Damien and others as a major cause of ill health.



*Figure 4.24.* The Cleanliness of Homes: As Liz showed in her photovoice, one's home was a place to honour and feel safe.

The life-threatening pitfalls of abject poverty were a constant fear factor for participants and challenged processes for managing HIV. The photovoice illustrated how that fear remained a mainstay of daily discourse and could lead to risky behaviour

as a way of dealing with the threat of destitution. To live in abject poverty is a deeply humiliating experience and, as described by all participants, in the slum where the daily fight to self-protect against having nothing was the constant variable, abject was is something to be avoided, at all costs. The ramifications for social health were devastating and as Klara poignantly stated:

*Here, the least respected are those who are poor.*

It appears from the data that having no cash and material possessions to speak of was a benchmark against which a person's success or failure was roundly gauged. The precarious nature of building a home and providing sustenance for oneself and one's dependents, as the findings show, could result in a situation whereby ensuring a continuum of care was neither a priority nor a realistic option. Generally, young people in this research felt they lived on the margins of society and had to deal with poverty, risk and exclusion as daily reality. Notions of wellness were always seen through the lens of first meeting daily needs, which often did not include aspects of preventative health care.

Absence of material items was never perceived as having nothing. Finding a dignified life, participants explained, was more than tangible goods. Personal identity was defined in interviews as having a sense of self and respected social presence. Across the board, participants exhorted that no matter what, there was always an identity to protect and affirm which was, by and large, based along cultural, religious, family and/or ethnic lines. Participants showed a very keen sense of knowing who they were and never questioned the essence or purpose of this identity. Self-identity was not reliant on the perceptions of others; however, to seek respect from that identity, as it was explained, required affirmation in social spheres. This, in the words of Chrystal was 'total identity':

*I am more than my pockets.*

The findings suggest that privation was a major factor behind the commodification of sex and shaped the social process of establishing and protecting self-identity within sex work. Female participants would talk of falling on hard times and getting by through forms of transactional sex and, in so doing, seeking an image of personal strength among peers while simultaneously risking condemnation from moral guardians. It was difficult to gauge how many young women, or men, were involved in forms of commercial or survival sex. Trevor spoke of a relationship with an older woman that involved receiving substantial gifts but, for him, this was not related to any

form of sex work. Keji was adamant in her refusal to engage in sex work but also recounted having sexual relations with her landlord to pay rent, which, for her, was not sex work.

#### 4.2.3.5 *Manifestations of Stigma, Discrimination and Prejudice*

Impacted by myth and misconception, the high incidence of HIV at the project sites had not lessened the stigma attached to an HIV positive status. The structural expression of stigma associated with HIV was omnipresent. HIV-positive participants reported experiencing forms of discrimination, perceived or actual, at health facilities and places of worship as well as from family, friends and neighbours. HIV-positive participants, both male and female, were also aware that stigma associated with the illness was a violation of one's rights but something they had little control over. As this research found, discrimination from an HIV-positive status was structurally endemic and woven into the very structure of slum life. Participants stated how the fear of AIDS and those who carried the virus came across as a rallying point in the community and as a platform for asserting moral and communal indignation. As Suzan stated on being asked about integrating into community life:

*there are those insulting you, there those who don't want you, you feel rejected.*

Self-protection against discrimination was often manifested as denial or an HIV-positive status simply kept secret. Participants mentioned positive discrimination and the language of 'rights' as expounded in slum-based micro-credit schemes aimed at supporting people living with HIV. The findings suggest a connection between economic advantage and claiming human rights.

In the discourse, young slum residents expressed feelings of being at disadvantage and discriminated against owing to slum habitation. HIV was not the only cause of stigma and shame that could increase likelihood of risky behaviour, as prejudice, writ large, was structurally formed and, as this research discovered, influenced self-perception and behaviour. As Trevor stated:

*When people know that you are from Korogocho, they perceive you as a thief; if you are a girl, they take you as a prostitute; it is the name that makes people think Korogocho is a bad place.*

Stephen explained through photovoice that it was often the type of jobs people did in Korogocho that gave it a bad name; as illustrated in Figure 2.25, this included collecting plastic for recycling.





*Figure 4.25.* Stigma of Slum Work: For Stephen, much of the work in Korogocho was dirty and no one wanted to work in ‘filthy places’.

#### 4.2.3.6 *Sexuality, Gratification and Social Capital*

Sex was spoken of by both male and female participants as a form of social currency. Except for Stephen, born with HIV and perceiving sex as roundly ‘bad’, the association between sex, pleasure and security was seemingly taken as a given; it was the criterion on which relationships were judged to be of high or low significance. Defined along socioeconomic lines, participants affixed degrees of value to a sexual event.

The evidence suggests that young men and women had different socially driven agendas affecting how sex was perceived and given value. Participants gave degrees of value, a currency, to personal experiences that included places, people and institutions, and measured if it resulted in some form of remuneration or personal security. Happiness, time and again, was expressed in terms of accessing money and support. Participants assigned a currency to people and things that made them happy or unhappy, dignified or humiliated. If a social transaction involved sex, it was described by participants in the terminology of currency; it was good or bad; it was easy or involved risk ... and whether the act was worth it. Young women reported feeling humiliated when their physical or psychological resources were demanded and not appreciated or—as currency—were undervalued. The slum social ecology involved placing value on relationships and the value of that relationship, as stated by participants, was based, so often, on financial criteria and whether self-identity was protected or threatened. As Sarah stated:

*Money, not sex, makes you feel proud because you feel you’re on top.*

### 4.3 Chapter Summary

The storyline built on the findings of this study highlighted individual agency, which was reflected in structural and environmental determinants that shaped processes of managing HIV. This perspective gave substance and form to the social theory: HIV and the Integrity of Risk—Dignifying Resilience in Disadvantage.

The findings established a social theory made up of three interlinking domains—individual, environmental and structural—that provide an explanation on processes for managing risk of HIV by young people. Based on the perceptions of participants, the chapter is an account of each of these domains and details the cross-cutting themes of awareness, capacity and opportunity that help define the contextual nature of HIV and the Integrity of Risk.

The evidence shows there is nothing permanent in managing risk as social processes belong to a particular time and place. Slum life, as described by participants, is experiential and driven by the exigencies of dearth and opportunity. The chapter showed how, for participants, processes of managing HIV involved no small measure of risk taking. Moreover, through interview and photovoice, it became clear that social processes do not exist in isolation but change in relation to prevailing and shifting conditions in the wider social sphere. Perceptions of self-efficacy and resilience against AIDS were informed by an awareness of self, others and the environment.

Managing HIV risk, as explained by participants, involves minimising that risk. Participant risk thresholds differed: for some, risk was low and for others, often owing to circumstances beyond their control, consistently high. Personal, emotional and social intelligence played a role in how effective a young person proved to be at managing risk, and perceived and interpreted episodes of humiliation, which, as the chapter shows, impact notions of self-capacity and self-worth.

The constructivist perspective of this study looked to the social realm in understanding the symbolic content of personal risk thresholds and the lengths to which young people will go to protect themselves. Structural factors, depicted in photovoice, held sway over subjective evaluation of managing risk and reflected the physical and social environment.

The critical component in the process of managing risk involves the social normalisation of gender roles. Seeking to stay HIV free or not risk reinfection very often depended on the nature of intimacy as culturally defined and how gender power

dynamics were shaped within social, sexual and confidential unions; as well as notions of how to dignify feelings of romantic love between two confidants. Young women displayed an adaptive response to the challenges posed by the patriarchy of the slum. The multifarious process of managing HIV among female participants was found within their triple roles and a proactive resilience that never appeared subservient or subdued. Socioeconomic empowerment against the risk of HIV hinged on connection and building common identity; a veritable social capital.

The chapter demonstrated through perceptions of agency and opportunity that there was little evidence to suggest a ‘scarcity mentality’ among participants. Life, as captured in photovoice and interview, was busy and always open to change for the better. It was a case of perception and interpretation. Figure 4.26 points to this understanding of daily life in the slum.



*Figure 4.26.* Perceptions of Plenty: Sarah photographed the family cat as it brought joy to the house. While the cat lived in a dirty place, she focussed on the positive; for Sarah you saw what you wanted to see in Korogocho.

## **Chapter 5: Discussion—Managing HIV and Risk**

### **5.1 Introduction to Chapter**

This study created a social theory for young people depicted in the model of HIV and the Integrity of Risk - Dignifying Resilience in Disadvantage. The theory demonstrates that processes of managing risk of HIV are fashioned by individual traits, the immediate environment and structural setting. Only through a discussion of the ‘slum universe’ can the factors that inhibit or promote HIV prevention be discerned.

The paradox of infection, as this chapter shows, is that young people, while possessing knowledge of the modes of HIV transmission, and perceiving their vulnerability towards contracting the virus, still engage in high-risk behaviour. This is conceptualised in the chapter as the ‘constraints of HIV prevention’.

In the close-knit community of the slum, participants explained the importance of social integration and achieving some form of public acclaim based on demonstrable strength. Moreover, integration and recognition are critical for finding opportunity and sustaining resilience. Social affirmation facilitates vital connections with significant others and helps to overcome fears of exclusion. This chapter deals with these concerns and shows how very often for young people, especially young men seeking honour among peers, long-term consequences are sacrificed for short-term gain.

As shown in this chapter, trust is the essential element for managing risk: trusting in one’s perception, trusting in others and trusting in prevailing moral codes. Trusting requires active intent by both partners. Trusting is risky, but without it there is little hope of dignifying a relationship and establishing a liaison of integrity able to manage HIV.

Gender is a critical unit of analysis for this social theory. Although young men and women share a common goal—to live a life fulfilled—pathways differ owing to gender power dynamics. Learning of one’s HIV-positive status may be experienced as something different between young men and women, but the outcome is still the same—an invariable denigration of self, at least in the short term, and perceived attack on personal resilience. The criticality of gender is discussed in this chapter, along with how young men and women negotiate relationships and social standing within a patriarchal society.

The chapter concludes with a discussion of building theories of health and how the model, HIV and the Integrity of Risk – Dignifying Resilience in Disadvantage, aligns with other such models, notably, the Health Belief Model.

## **5.2 Knowing, Perceiving, Acting**

There is high-risk behaviour among many young slum dwellers. HIV rates for some cohorts of young people in Nairobi remains consistently high (Madise, Ziraba, Inungu, Khamadi, Ezeh, Zulu, Kebaso, Okoth and Mwau, 2012). There is a crisis in HIV prevention (UNAIDS, 2014c). There are equally high levels of knowledge on HIV and AIDS as well as the effectiveness of condoms to prevent infection (Mberu et al., 2014). Young people perceive the dangers of unprotected sex and are keenly aware of the trauma of an HIV-positive status. The discordance between knowing, perceiving and acting, the findings suggest, is that young people are constrained in utilising prevention technologies. Reasons for this constraint, or disconnect, are widely debated in the literature (Adedimeji, Omololu and Odutolu, 2007). The model, HIV and the Integrity of Risk, addresses this dilemma by pointing to the tensions and inconsistencies in processes for managing HIV that lie within the social construction of reality. The multiple realities of young people and the fluidity of young people's perception, and truth, leads to an array of social processes—entwined, in conflict and in harmony for managing HIV.

Findings from this research agrees with other studies referencing the social dimensions of self-protecting sex, such as that of Rice and Dolgin (2005), and the need, as Smith (2003) states, to examine agency within the social construction of risk. The social construction of reality is premised on an individual's perception, which in turn is shaped through the collective generation of meaning.

The findings, which support the work of Adedimeji et al. (2007), included the fatalistic attitude of many young slum residents regarding infection and the notion that there is only so much one can do to affect behavioural outcomes. This is a philosophy of convenience, perhaps, but stems from them being largely disempowered from mainstream society and shut out from political processes that could bring real change to their lives. A resignation that things are beyond control exists among many young slum dwellers. Religious belief, arguably, helps sustain a fatalism in that one's life has already been planned and this can lead to a stated reluctance in attempting to reshape the natural order (Smith, 2003).

Another reason for the tension between perception and action lies within the structural domain that Kabiru, Beguy, Crichton and Zulu (2011) indicate involves the physical infrastructure of the slum. HIV-related services are limited and those that do exist primarily focus on testing and awareness raising. There is little point-of-site testing and treatment options with ART are only offered in referral hospitals and antenatal clinics outside the vicinity. Moreover, as Lee, Yehia, Gaur, Rustein, Gebo, Keruly, Moore, Nijhawan and Agwu (2016) state, many of these establishments are not suited to meeting the needs of young people. While testing and treatment may be free, transport to and from the health facility and supplementary medication are not.

Questions of managing HIV, the findings suggest, could also be conceptualised as reducing risk, learning to live with risk or taking risks and not worrying about the outcome. The presence of HIV, it appears, is accepted as an unfortunate fact of life, but one that can be controlled through treatment regimens. The findings have resonance with the work of Mwale and Muula (2017) in that four generations into the epidemic, young people born into a world of HIV have learned to live within that reality. HIV is not the main concern for most young people; there are bigger and more pressing priorities in sustaining life.

The findings were at odds with the work of Grunbaum, Kann, Kinchen, Ross, Hawkins, Lowry, Harris, Chyen, McManus and Collins (2004) which purports that the more vulnerable one feels to infection, the greater the effort taken to avoid situations of risk. This research demonstrated that being aware of risk did not necessarily lead to measures to mitigate that risk, certainly over the long term. There are other factors at play. Many participants, the evidence suggest, approached avoidance behaviour as more an aspirational goal than a practical solution. As stated by Dellar, Dlamini and Karim (2015), calculated risk is the bedrock of success and, arguably, the greater the reward the less time spent pondering the risk. However, this still raises questions about the effectiveness of self-perceived vulnerability and self-perceived risk of HIV and perceptions of reward.

New HIV technologies such as PrEP and PEP have affected perceptions of HIV risk among many young people. Perceptions of how to manage HIV risk are quite different now from what they were 20 years ago at the height of the AIDS pandemic. Perceptions of how to manage HIV evolve as do prevention technologies. Change in one domain of influence leads to change in another; this is the totality of HIV prevention.

### 5.3 Intention and Perception

For constructivist grounded theory, the role of ‘intention’ is crucial. In agreement with the work of Carrington, Neville and Whitwell (2014), intent provides insight into interpreting the level and nature of risk and uncertainty. Understanding intent is key in unravelling the complexity of social processes and the intersection of gender and power. Volition, by its very nature, is affected by the dynamics of social interaction that may help or hinder effectiveness in preventing HIV infection.

Having the intent to self-protect and protect the health of others is the cornerstone of HIV and the Integrity of Risk. Taking measures to avoid HIV transmission involves the decision to trust one’s own perception of risk. From the findings of this study, respecting a partner’s decision to trust is the foundation of a relationship of integrity and takes no small amount of courage. As Moery, Preusse and Meek (2014) in their study on deception state, risking demands trust, a variable over which one often has little sway, for example, in believing that one’s partner will respect the sanctity of a relationship. The constant is the ‘intent to dignify’. Intent is not the same as ‘blind faith’ as dignifying a relationship implies a presence and according to Lindner (2009), an active awareness and an inquisitiveness to unravel the facts of what it means to stay safe in an intimate relationship. This research did not attempt to discover a quantitative correlation between intent and behaviour, but an association was noted.

All participants expressed the intent to practise faith in a higher power. Without exception the young people of this research claimed to be ‘religious’ as well as ‘sexual’, stating they wanted religion to have an important part in their lives, and by inference, their sexuality. Having the intent to be sexual while belonging to organised religion appeared to cause little consternation.<sup>18</sup> The evidence suggests that, for young people, it is possible to balance the intent to enjoy religion and engage in sexual activity in and out of stable relationships. As Shaw and El-Bassel (2014) reason, faith and sex are considered ‘natural’ and not to be questioned but embraced.

As Smith (2003) states, risk is very often interpreted in ethical terms and involves a moral assessment of self and others that draws on the teachings of organised religion and traditional belief. The intent to disclose an HIV status may be linked to

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<sup>18</sup> I did not choose to probe issues of ‘morality’ and doctrines of abstinence from sex before marriage as to do so may lead to shaming participants on the part of the researcher.

perceptions of morality derived from formal belief systems. Intention draws on perceptive interpretation and what makes sense in the here and now. Ajide and Balogun (2018) state that intentions are multifarious constructs with a multitude of meanings. Most male participants, while keeping to the line that concurrent relationships are ‘bad’, would mention having numerous intimate partners ‘kept’ in different locations, reflective, as Sultana (2012) states of male patriarchy and political prestige.

Discordance between saying and doing, so this research discerns, is, as Onoya, Zuma, Zungu, Shisana and Mehlomakhulu (2014) consider, strongly influenced in the social realm by levels of peer pressure and the need to be accepted and valued. As part of the construct of intent and as chiefly echoed by young men is the desire for immediate gratification and a belief that things will take care of themselves, naturally. Having the intent to reduce self-perceived vulnerability and effectively manage the risk of HIV—and in so doing build personal resilience—is real, at least in its intent.

#### **5.4 Capacity and Connection**

Wild, Flisher, Bhana and Lombard (2004) demonstrate a connection between perceptions of self-worth and sexual behaviour. Although personally felt, as Diener and Diener (2009) state, it is within the social realm that an individual with low self-esteem will likely turn for affirmation of their place in the world. Perceptions of low sexual worth, harbouring feelings of unattractiveness and an inability to sustain a relationship may be addressed through seeking multiple sexual encounters (Diener & Diener, 2009). Demonstrating visible sexual prowess for most male participants is also flight from the fear of humiliation where masculinity is defined by building sexual experience-cum-conquests. For men engaging in multiple sexual partnerships, the findings agree with Bowleg, Lucas and Tschann (2004) and Sultana (2012) in that sex becomes one of the few channels by which male prestige is preserved.

Socialised into gender roles, young people always have the option to turn to socially and morally ascribed rules of sexual behaviour as a means of proving self-worth. Rosenthal, Moore and Flynn (1991) proposed that swayed by the attitude of others in deciding what is considered worthwhile, young people (particularly those with low self-esteem) in anticipating rejection might engage in self-defeating behaviours. Avoiding being shamed in the public eye, having a non-risky lifestyle is not the priority. Reputation and self-identity outweigh the personal intent to stay safe. The converse is



true whereby engendering feelings of self-reliance and self-confidence feed resilience in which incurring the displeasure of others is subordinate to self-affirmation.

The findings from this research found resonance in the work of Perkel, Strelbel and Joubert (1991) regarding the relationship between self-esteem and HIV. An individual with low self-worth is less likely to take preventative measures against acquiring HIV for fear of upsetting a sexual partner. Further, such an individual is more likely to ridicule abstinence from sex, finding little to be gained in abstinence as sexual visibility is the main concern (Perkel et al., 1991).

This study did not test for levels of self-esteem or self-worth, but a link was inferred between self-affirming and self-negating behaviour and perceptions of risk. In line with the work of Meyer-Weitz (2005), this research found that participants tending towards negative beliefs regarding their self-efficacy in effecting substantial change also demonstrated a fatalistic attitude in the context of HIV prevention. Intrapersonal conflict stemming from unresolved humiliating events—for example, early adolescent abuse—can, as shown by Brownmiller (2013), lead to emotional stress and a desire to act out inner turmoil during times of intimacy. Lindner (2009) shows the link between self-shaming and humiliation as a forerunner to poor life choices sustained personally and within a continuing complexity of moral social worlds.

## **5.5 Interpreting Processes of Prevention and Risk**

The social processes for limiting risk of infection are learned and re-learned, and perceptions of risk change accordingly. The social reality for managing HIV is never certain as new meanings are generated, for example, on PEP and unprotected sex, which, in turn, shapes processes of HIV prevention. Given the unsettled nature of many of the social processes for managing HIV, knowing what to do in minimising risk of infection for many is not well understood.

The model HIV and the Integrity of Risk – Dignifying Resilience in Disadvantage depicts the totality of a social process through classifying three domains of influence. Conceptualising themes and their practical application as presented in the model, such as gender and resource mobilisation, will differ according to the person, the situation and the setting. The social model does not suggest that each dimension within the domains is of equal measure, to do so would be to construct a predictive model of behaviour with replicable value. This is not the intent of this grounded theory. Factors that might be in synch one day—for example, achieving a degree of gender parity in a

relationship combined with economic autonomy—may change owing to events in the environment. Young people’s agency in processes for managing HIV may appear counterintuitive, such as selling sex to obtain resources for a routine check-up at the local hospital.

Of relevance is the question to what extent young people are willing to go to avoid known situations of enhanced susceptibility and over which they know they have little control. It is about intent. Young people are aware of the pitfalls of unsafe sex with wellbeing very much on their minds (UNAIDS, 2014c). However, the personal desire to remain HIV free, as Kirby, Laris and Roller (2007) state, must be seen in the light of social interaction within a high-risk context and social world that, as Tomé, de Matos, Simões, Camacho, and AlvesDiniz (2012), consider, may promote a measure of risk taking concomitant with youthful desire. There is a temporal dimension to risk taking and being able to sustain a path away from undue risk, past the present and over the long term. Even if condoms are used in the short term, as Smith (2003) proposes, there is little chance of them being continually used as the relationship evolves. Even in long-standing relationships, as Montgomery, Lees, Stadler, Morar, Ssali, Mwanza, Ntambo, Phillip, Watts and Pool (2008) state, it is not uncommon for the HIV status of one partner not to be known by the other, though this does not appear to affect the decision regarding whether to continue using condoms.

Social processes for managing HIV are complex, echoing the reality of slum life. Young people, although aware of the ever-present threat of HIV, still talk of the need for continual sexual union with another. Shearer, Hosterman, Gillen and Lefkowitz (2005) reason that attitudes to sex and relationships are never constant, but part of a process shaped by perceptions of the person and their partner’s emotional wellbeing.

The journey of identifying social processes is never fully complete and with qualitative grounded theory it rests, in part, on the assumptions of the researcher. The process of constructing meanings to do with HIV and risk is not fixed but shifts with the fluid nature of reality (Galdas, 2017). It is within this universe of interpretation and meanings that constructs of risk and resilience are discovered and rediscovered; there is never an exactness or a permanence in these constructions. Moreover, as Toews, Glenton, Lewin, Berg, Noyes, Booth, Marusic, Malacki, Munthe-Kaas and Meerpohl (2016) state, interpretation of an action, a judgement or pattern of logic will likely be different to the researcher as to the participant.

The volatility of slum life necessitates constant reappraisal of options based on information available and seeing the best course of action, possibly the only viable course, as events will often take on different meanings (Balogun & Odeyemi, 2010). However, the authenticity of that information, as Morrow and Samir (2009) state, is never to be assumed. According to Holtz, Sowell and Velasquez (2012), ‘feeling resilient’ is never a constant. The findings suggest that for young HIV-positive people, staying buoyant and perceptive of one’s circumstance, and unfailingly choosing the right course of action is simply not possible. Although the pain of hunger has a more absolute form, and is an experience suffered at some time in most slum dwellers’ lives, its meaning does not; hunger might be interpreted as an evil curse or a need to increase household earnings. As such, the process of managing risk and creating pathways of resilience is always grounded in a myriad of judgement calls. Nothing is forever—only the knowledge that each day will create its own set of demands and with it, new opportunities.

## **5.6 The Intersection of Gender**

In agreement with the work of Palermo, Bleck and Peterman (2013), this body of evidence found that how men and women perceive morality, responsibility, desire and aspiration is key in understanding HIV risk. Kebede (2012) points out that it is within social worlds that young people, especially young women, forge networks of support and build alliances of trust to minimise risk. Among young people, successfully managing risk is perceived as a moral good and reflects personal effectiveness and a clever resilience. The findings show that young women, more than young men, as Kebede (2012) shows, draw on networks of support in which they are expected to play an active role. In the discourse, young women would talk of coping strategies that counter male attitude and behaviour, which is roundly seen as the major challenge in staying HIV free. It is a case of ‘us’ against ‘them’.

Similar to Amirkhanian (2014), the findings suggest that while young male bravado may acclaim sexual prowess via boasting multiple relationships, the social expectation, as Carr and Gramling (2004) state, is that young women are responsible for HIV transmission. Therefore, young women unwittingly become the custodians of the process for managing HIV. It follows, then, that women, not men, will likely be held culpable if a sexual liaison results in HIV transmission.

According to Matovu, Wanyenze, Wabwire-Mangen, Nakubulwa, Sekamwa, Masika, Todd and Serwadda (2014), testing rarely involves both sexual partners and women are often the first to learn of an HIV status. The idea of ‘couples testing’ is, it appears, not widely practised. As Matovu et al. (2014) states, men may well use their partner’s HIV status as proxy for determining their own. Global evidence suggests that risks associated with multiple concurrent relationships can be minimised with regular HIV testing, more so if it involves all parties to the sexual liaison, yet this is not reported in the findings. The apparent tolerance of male infidelity does not accommodate male personal responsibility.

Solomon, Mehta, Latimore, Srikrishnan and Celentano (2010) argue that even when a positive status is known by one sexual partner, it may not be disclosed to the other. In agreement with the findings of Ssali, Atuyambe, Tumwine, Sequija, Nekesa, Nannungi, Ryan and Wagner (2010) reasons for not disclosing an HIV-positive status largely follow gender lines. The decision for non-disclosure, especially for young women, can be based on fear of intimate partner violence, domestic abuse and abandonment. The social context, as shown in the model of HIV and the Integrity of Risk – Dignifying Resilience in Disadvantage, is a major determinant in choosing whether to disclose an HIV-positive status and, as Ssali et al. (2010) explain, this will involve expectations of the response from the ‘disclosure target’. Findings point to the fact that critical to questions of disclosure is the level and extent of HIV stigma in the home and in the community. Social networks and de facto matriarchy of the household provides a level of empathy in the event of disclosure for young women and possible access to valuable resources. This support, so the findings suggests, is largely not available to young men.

As King, Katuntu, Lifshay, Packel, Batamwita, Nakayiwa, Abang, Babirye, Lindkvist, Johansson, Merin and Bunnell (2008) state, disclosure of an HIV status can be life threatening and as dangerous to emotional health and wellbeing as the disease itself. It is very often a risk not worth taking; it is a case of protecting the integrity of self. Disclosure may lead to loss of standing in the community, and in an environment where social acceptance and recognition of personal strength are held in high esteem, the result can be devastating. Being able to trust is critical regarding the matter of disclosure, which, according to this research, is so often broken. Bhatia, Harrison, Kubeka, Milford, Kaida, Bajunirwe, Wilson, Psaros, Safren, Bangsberg, Smit and Matthews (2017) show that distrust, or more particularly, young women’s distrust of

male hegemony, is grounded in repeated negative encounters that can leave young women bereft and feeling humiliated.

## **5.7 Morality and the Stigma of HIV**

Stigma of HIV remains a major factor driving the epidemic (Plummer & McClean, 2010). Stangl, Lloyd, Brady, Holland and Baral (2013) demonstrate that a cyclical relationship informs stigma and HIV; people experiencing stigma are likely to become increasingly marginalised and vulnerable to HIV, while people living with HIV stay vulnerable owing to stigma and discrimination. Associated with behaviour shunned in the wider community, HIV infection evokes notions of promiscuity and a lax morality.

Young people, particularly late adolescents, according to Kar, Choudhury and Singh (2015) have a keen sense of right and wrong pertaining to sexual norms. Becoming infected with HIV may be construed as violating cherished values passed down from one generation to the next regarding sexual conduct and therefore open to moral condemnation; a social code, a trust, has been broken. Rao, Kekwaletswe, Hosek, Martinez and Rodriguez (2007) show that young people, as much as any other age group, can go to inordinate lengths to hide an HIV-positive status. Exceptions do exist, but whether someone is born with HIV or acquires the virus through sexual behaviour the effect is the same—ostracisation. Premised on a relational perspective of humiliation, Hartling (2007) emphasises the importance of social connection. Disclosure of an HIV-positive status can sever life-affirming connections, leading to ‘social pain’ from rejection and exclusion and is therefore to be avoided (Hartling, 2007).

Putting distance between a potentially humiliating event, such as being discovered to have acquired HIV is, arguably, an act of self-preservation and allows a moral high ground to be maintained against charges of immorality. It is an exercise in shifting personal moral judgement away from oneself to imaginary ‘immoral’ others (Smith, 2003). This gives way to moralistic interpretations regarding infection: ‘a good (moral) person’ is protected, for instance, through the grace of a ‘higher power’. The findings show that the lexicon easily joins the terms ‘HIV positive’ with ‘immorality’ and ‘fallen, misguided, lost’.

Despite the existence of efficacious treatment for HIV, fears of AIDS-related morbidity and mortality persist; scientific breakthroughs have made little dent in

changing mindsets, owing to what these findings term ‘the immorality of infection’. Singh and Banerjee (2004) argue that perceptions of HIV prevention, treatment and care, whether correct or not, are shaped by moral social worlds that stigmatise AIDS and pronounce moral judgements on people living with HIV. Perceptions of stigma and HIV, however, have not led to significant behaviour change; they are just another factor in a condition that needs to be kept in check, as and when the need arises.

Social worlds and social arenas shape codes of morality and give meaning to notions of ‘ethical behaviour’. In agreement with Fassin (2014), knowing how to navigate and find advantage in this evolving universe often depends on discerning ethically sanctioned behaviour that suits one’s action and can justify one’s behaviour.

Moral approbation has a limited and temporal dimension. Barnett and Parkhurst (2005) demonstrate that morality, while often self-serving, can also be used to good effect in sustaining positive behaviour change. This is explained through, in the words of participants, becoming ‘reformed’. To be reformed is a moral term used for describing a young deviant’s return to normal life. According to Moyo and Müller (2011), a reformed person is socially rehabilitated into community life. Reform is a way of offering young deviants, as defined by the community, a way back in and to regain a lost sense of pride. As Vellem (2013) writes, it is a public demonstration of moral virtue that is valued and life affirming.

Self-identified sex workers in this study claimed that selling sex was a way to dignify their world as it provided for themselves and dependents. It was, in this sense, ‘decent money’. Selling sex, as it was explained, involves a contractual agreement with a client that must be honoured, and if not, it is tantamount to stealing, and the label of ‘sex worker’ is preferred to that of ‘thief’. Therefore, the young female sex worker could side-step moral denigration as she was dignifying a contract of trust. This ‘moral escape route’ is not available to the young offending male: he could not explain violence through mutual consent; it was his own volition. As Kim (2016) states, to say he was pressurised into this behaviour carries negative overtones of weakness and lack of self, connotations to be avoided in male gang culture. His only option for safety from a risky lifestyle is to embrace the process of becoming a ‘reformed character’ and ensure that significant others in the community can see and pass judgement in his favour.

## 5.8 The Social Organisation of Sex and Relationships

Sex is a private matter, according to participants of this study, yet sexual experiences are shared, so the findings demonstrate, and shape expectations of sexual liaisons. As Tomé et al. (2012) state, same-sex peer groups provide the means for sharing such experiences. There is some evidence in the findings that young women will share stories of pleasure, risk and consequences of sex, while young men will more likely focus on pleasure gained from a sexual experience.

Gender roles and gender relations are discerned through patterns of social organisation unique to the slum and define cultural norms that give meaning to sexual behaviour among young people. Slum neighbourhoods are closely tied and reflect patterns of social organisation, including sexual activity of young people. As Anugwom and Anugwom (2016) discover, patterns of risky behaviour and the sociocultural vulnerabilities of young women go beyond personal boundaries. The social organisation of male sexuality can define risk taking among young men as a means of asserting masculinity that does not flag in the face of HIV (Plummer, 2011). To yield to the threat of HIV is to show weakening when confronted with imminent danger. Jones (2016) makes the point that it is a personal resilience bound to fail; a social process that pits peer values against personal safety.

In the patriarchal society of the slum, young men may see coercion as justified on the grounds that it follows the 'natural order' and is an expression of the innate rights of men to determine rules of sexuality. The findings of this research agree with the work of Gibbs, Sikweyiya and Jewkes (2014) that highlights culturally embedded values of masculinity and its impact on decision-making processes between young men and women. Male dominance has been explained as a rite of passage for the young man, and impregnating a young woman, as Volpp (2000) states, is a sure way to demonstrate manhood. Pregnancy and child rearing are the responsibility of women, the findings suggest, and interference on the part of men would upset the natural order replete with moral overtones of stepping outside of accepted behaviour.

Krishnan, Dunbar, Minnis, Medlin, Gerdtz and Padian (2008) show that structural factors are held to influence the unequal nature of gender power dynamics in which young women who have spent a lifetime steeped in poverty are very likely to be more accepting of male dominance and sexual coercion. Jewkes and Morrell (2010) and Parker, Barbosa and Aggleton (2000) show how unequal gender power dynamics are a

key factor in driving the HIV epidemic. The evidence from this research supports the notion that being unable to meaningfully affect sexual outcomes greatly minimises options for young women to manage HIV. Airhihenbuwa (1995) establishes that traditional patriarchy in Africa and its manifestation in sexual relationships is a major risk factor for a continuing epidemic. Sexual coercion, as stated by Ekstrand, Bharat, Ramakrishna and Heylen (2012) is more than a simple show of force used to obtain something desired; as this research discovered, it is also symbolic of social mores emblematic of male dominance.

The findings point to collective ingenuity of social organisation from disempowered young women, which forms an effective social resilience and becomes part of the process of managing HIV risk. The findings suggest that subservience to patriarchy does not equal a dimming of the senses, rather the opposite; it leads to a resilience born out of necessity that continually reinvents itself.

### **5.9 Social Processes of HIV Prevention**

The findings show that self-identified sex workers and HIV-positive women are more likely to suggest use of a condom owing to the fear of infection or reinfection. For many other young people, condoms are not prioritised in the same way. Madiba and Ngwenya (2017) claim that suggesting use of a condom can be interpreted as a statement of distrust from one partner to the other—an attack on one’s integrity—and, as Willig (2014) states, implies the presence of AIDS and, by inference, promiscuity.

In the close-knit community of the slum, identity and self-image are fundamental components of social life and communicating messages of distrust that might signify a personal weakness constitutes a risk. Managing risk of infection is constrained, particularly among young women, by moral worlds that shape values and gender-socialisation practices that promote a docile image of young women and the necessity of young men’s dominance in the course of sexual liaisons. The effect, as Adedimeji et al. (2007) explain, is that sexual norms of young people can create situations of risk in defining what it means to be a ‘good woman’ and a ‘good man’.

Research carried out by Tschann, Adler, Millstein, Gurvey and Ellen (2002) shows that the use of condoms and other forms of prevention requires interpersonal skills involving intrapersonal qualities of self-efficacy, self-esteem and knowledge of risky and non-risky sex. However, even if the young person feels confident in the process of managing HIV risk using condoms, they may lack the essential know-how to



put it into practice; the social process, for them, is likely now to be more concerned with minimising risk through damage limitation.

For a young woman to propose condom use is affected by a combination of personal, environmental and structural factors that, according to these findings, often result in one not being used. According to Madiba and Ngwenya (2017), gender inequality along with the social and structural organisation pertaining to the slum prevents young men and women from successfully negotiating the terms of sexual relationships and managing the risk of HIV despite possessing knowledge of that risk.

The HIV and the Integrity of Risk – Dignifying Resilience in Disadvantage model demonstrates strong links among each of the three domains; individual, environmental and structural. Intrapersonal competencies that make up a ‘skill set for negotiation’ are informed by processes of social interaction fitting to the local environment. In considerations of uptake of HIV-prevention technologies, understanding one domain of influence, as Eaton et al. (2003) state, only makes sense through a study of the other. Yet much of the advocacy for prevention, and particularly condom use, focusses on the individual domain, the intrapersonal dimension of HIV prevention. It is the totality of managing HIV risk, which this research discovered, and acknowledgement of the interconnectedness of processes that can provide the basis for effectively preventing infection.

According to MacPhail and Campbell (2001), condoms are more likely to be used by an unfaithful partner seeking sexual liaisons outside of a committed relationship. However, the findings suggest that this is not the case for young slum-dwelling people as condom use is not widely practised in all forms of relationship—monogamous and/or polygamous and short and/or long term.

Blanc (2001) shows that effective communication on HIV prevention is long established as a sure way to limit risk of infection. Moreover, as Wanyenze, Tumwesigye, Kindyomunda, Beyeza-Kashesya, Atuyambe, Kansiime, Neema, Ssali, Akol and Mirembe (2011) state, discussing risks involved between partners prior to sexual intercourse will likely correlate with a higher uptake of condom use. In the absence of a cure for the virus, social processes in managing HIV need to see value in condom use—but then this is what young people already know. According to Parsons, Halkitis, Bimbi and Borkowski (2000), use of condoms between two consenting individuals promotes respect and transparency, and builds self-confidence as feelings of anxiety and suspicion diminish. These traits further build personal and collective skills

in managing HIV (Dilorio, Dudley, Kelly, Soet, Mbwarra and Potter, 2001). However, young people, according to the findings, would put much store in having the 'right partner' as the surest way of preventing HIV risk. Seeking, finding and maintaining relationships of trust becomes the means for managing HIV.

HIV has become an accepted part of all forms of relationship, including those based on romantic love and intimacy (Cusick & Rhodes, 2000). Finding and losing a relationship in which HIV is transmitted from one partner to the other can lead to feelings of humiliation, anger, resentment and a sense of having been manipulated. Yet sexual desire and the social imperative of finding intimacy does not, in and of itself, end with a traumatic experience. A young person not having found intimacy runs the risk of being regarded as a child and their opinions seen as unworldly and of little import (Vaillancourt & Hymel, 2006). The implicit assumption is a desire to be respected by peers through having an intimate partner as it shows capacity and an ability to attract and, as Tome et al. (2012) explain, falls squarely within moral codes of decency. Relationships are fraught with risk and choosing to continue seeking intimacy and connection is, if nothing else, a demonstration of the integrity of that risk.

### **5.10 Social Arenas of Violence and Poverty**

According to Smith (2003), there is a critical need for understanding poverty and inequality, gender and generation in the transmission of HIV. Zulu, Doodoo and Chika-Ezeh (2002) demonstrate the link between socioeconomic conditions and non-protective sex. Grinding poverty as experienced by many young slum dwellers places an inordinate burden on young people to negotiate or adopt protective behaviour (Smith, 2003). The findings show the problem compounds in cases of age-disparate relationships in which a younger female attempts to persuade the older male to practise safe sex, which may result in loss of tangible resources. The fact that transactional and/or survival sex is so widely practised in slum communities is testament to the importance of identifying the link between poverty and HIV. As Pellowski, Kalichman, Matthews and Adler (2013) state, persistent inequality and abject poverty are core structural determinants that drive the social distribution of risk within relationships. It is these structural inequities that form perceptions of need and want and what needs to be done to dignify life in an uncertain universe with or without the presence of HIV. Young people use the means available to them for building a life of repute; however, in

the slum, choices are limited and invariably involve levels of risk not found in non-slum locations.

Young slum dwellers express feelings of intimacy and desire within a physical environment characterised by violence and structural poverty. In discussing how to dignify life and livelihood, young people very often couch their response within a discourse of personal safety, connection, wealth and power. Within this world, HIV becomes part cause and part effect of impoverishment, and remains just another factor of risk. There is no enrichment from an HIV-positive status; there is only, as Drimie (2002) explains, deepening poverty as household assets and personal strength decline. Yet, as the findings show, young people are aware of the efficacious nature of HIV treatment, which allows participation in socioeconomic endeavours. The issue, as Kim, Gerver, Fidler and Ward (2014) state, is the consistent adherence to treatment regimens involving safe keeping of prescribed medication away from judgemental eyes. However, slums are overcrowded spaces with little, if any, room for privacy and seclusion. HIV medication cannot be taken without food and a balanced diet is crucial for building the body's immune system. Ready supply of food and nutrition for many young slum residents is a challenge, and keeping to a treatment regimen, therefore, is seriously put in doubt.

The work of Becchetti, Conzo and Romeo (2013) shows that street life, and especially homelessness, is characterised by the constant threat of violence and is a daily reality for many young slum residents. Findings from the photovoice depict the dignity of walls; a house made of iron sheets in discussions of personal and collective resilience. Social processes of managing HIV involve minimising threats of insecurity, which given the lack of material resources will often demand no small measure of personal innovation to succeed. Relational, social and personal connections such as those with criminal entities are, paradoxically, perceived as a means of reducing risk of violence and death.

Social arenas influence personal choice, sexual behaviour and HIV risk. Systemic poverty and traditional notions of male sexual privilege remain critical challenges in the process of managing HIV. As this grounded theory demonstrates, the genesis of sexual risk and nature of the social process for young slum residents is the persistence of urban social, economic and political disadvantage. However, it is also within these confined urban spaces of disadvantage and the omnipresence of violence that life flourishes and young people feel content with their place and their connections.

## 5.11 Knowledge Assemblage and Communicating Information

The findings agree with the work of Holschneider and Alexander (2003) that perception of HIV needs to be understood as existing within interdependent normative value systems that give shape to identity and status. It is local knowledge, however construed, that informs interaction among peers and shapes the processes for managing HIV. The findings are in agreement with Naur (2001), who shows how local knowledge of HIV constitutes a form of indigenous knowledge and premises the interpretation of facility-based health messages. Indigenous knowledge that establishes ‘local truths’, as the results of this study show, informs the social distribution of knowledge relevant to young slum dwellers’ sexual behaviour and, as Burr (2006) states, helps clarify the value of those sexual relationships. The complexity of social processes that demonstrate the integrity of risk are shaped by inter-relationships and the intersection of these knowledge assemblages.

Young people’s indigenous knowledge may lead to perceptions at odds with formal messages on HIV, for example, the efficacy of female condoms. Basu and Dutta (2009) explain that while having the potential to reach large audiences, HIV messaging may lose aspects of meaning or change irreversibly. How an AIDS message twists and turns was illustrated by PEP, its importance now established yet with lingering doubts, for example, on whether medication needs to be taken for the number of days prescribed by health professionals. Official messages on HIV are filtered by local reality, shaped by local necessity and influenced by slum-based social organisation and the structural environment.

Social media plays a significant role in generating meaning on HIV. Taggart, Grewe, Conserve, Gliwa and Isler (2015) demonstrate that regular access to media is a positive factor in disseminating accurate information on HIV. In Korogocho, FM radio stations are popular among young people and address the need for interactive, youth-friendly ‘phone-ins’ that ‘speak their language’. The internet is similarly a major source of information but is used for a variety of reasons and can prove a source of mixed, if not confusing, messages: for example, sites with HIV messages on safe sex alongside sites providing pornography with ample scenes glorifying ‘free sex’. One female participant, a self-identified sex worker, as part of her photovoice took photographs of pornography from the internet, explaining that it dignified her world in the here and now. The internet sends out a barrage of images relating to safe and unsafe sex, often

depicting worlds very far removed from the reality of the slum yet still making perfect sense to the young people in this study.

In agreement with the finding of Veinot (2009), the social process of managing HIV influences how new information is received and evaluated and, critically, whether it is roundly substantiated or only in part. The findings from this research include that nothing is a given; there is no immediacy about an HIV message; there is a social process for fixing HIV truth grounded in the life of a subcultural value system.

Spaulding, Brickley, Kennedy, Almers, Packel, Mirjahangir, Kennedy, Collins, Osborne and Mbizvo (2009) show that through mother–child clinics, many women discover their HIV-positive status. A relationship of trust established between a health care professional and a young user of the service, as Speizer, Magnani and Colvin (2003) contend, appears to have the greatest impact on driving the right message home and preventing opportunity for misinformation. However, these relationships are not always established given the reluctance of either party to engage in affirmative dialogue. A common feature of health care in the slum is substandard testing facilities, run-down infrastructure and overworked, underpaid and largely demotivated health staff, an uncertain variable of many faces. If an important component of self-care is in dignifying one’s environment, trust becomes a core element of the paradigm. Given the precarious nature of health care in the slum, trusting in its integrity becomes anomalous and stands to challenge the very process of wellbeing.

## **5.12 Modelling HIV Risk**

As Cho and Lee (2015) state, conceptualising agency remains problematic in building models of health and risk. The model of HIV and the Integrity of Risk – Dignifying Resilience in Disadvantage draws on elements of social-cognitive theories of health and behaviour and positions agency within the individual domain while recognising the influence of environmental and structural factors. According to Montano and Kasprzyk (2015), within the Theory of Planned Behaviour and Theory of Reasoned Action, the role of agency and intention becomes a core determining factor that drives health-related behaviour. The social theory of this research is aligned to other models of HIV risk and resilience that emphasise the need for inclusivity and the role of perception and agency. There exists a plethora of models on the continuum of HIV prevention, treatment, care and support as well as the universe of urban-dwelling young people. In contrast, there is a dearth of studies linking moral and social worlds

that inform perceptions of dignity and humiliation linked to risk of exposure to HIV. Rarely is each respective component integrated into the same model.

HIV is a communicable disease and its route is transmission specific. Modelling HIV has predominately focussed on modes of transmission, social networks and sexual behaviour. The various models have their antecedents in social theory, which may be implicitly or explicitly stated. As McLachlan and Garcia (2015) write, philosophical positions along the positivist–constructivist spectrum continue to inform models of health and wellbeing. The findings from this research indicate that although there is a general move towards a constructivist perspective of risk and behaviour, the body politic of HIV research and practice still leans heavily on the strictures of positivism. Modelling HIV risk, such as that derived from MoT studies for key populations, reflects an anti-dualistic position encompassing theoretical principles along the positivist–constructivist continuum. The conceptualisation of HIV and the Integrity of Risk–Dignifying Resilience in Disadvantage, while based on constructivist theory, contains elements of relevance to the anti-dualist tradition.

Studies primarily from the behavioural sciences and social psychology focussing on social-cognitive theory and value-expectancy models, principally derived from the work of Godin and Kok (1996), hold resonance with findings from this research. These models help give clarity to the myriad of influences affecting individual, environmental and structural aspects of health and wellbeing.

Although variations of the Health Belief Model have emerged since its inception in the 1950s, as LaMorte (2016) states, the philosophical perspective that prioritises perceptions of susceptibility, severity, reward, challenges, agency and self-capacity. The model of HIV and the Integrity of Risk encompasses elements of this conceptualisation; in particular, notions of volition. However, the model produced by this research appreciates more fully the role of agency with environmental and structural confines than does the classic Health Belief Model. The social theory of this research equally emphasises an individual's values, attitudes and interpretation of behaviour; habitual behaviour affecting the decision-making process; affirming non-health-related behaviour; environmental and structural factors affecting health-seeking behaviour; the social distribution of knowledge on HIV; and the fact that physical health is not always the first concern in an individual's decision-making processes. Further, the social theory of this research attempts an explanation for, not just a description of, risky behaviour. Construction of the model HIV and the Integrity of Risk – Dignifying Resilience in

Disadvantage was informed by the assertion of Eaton et al. (2003) that the principal concern in modelling is to discern patterns of behaviour linked to personal, proximal and distal domains and how they relate to each other.

A common thread for modelling health is depicting perceptions of vulnerability thresholds and an individual's evaluation of the severity of risk on one's health. However, according to these findings, focussing solely on the individual fails to comprehend the total universe of the urban slum and entwined social processes in attempting to stay HIV free. As Bradley et al. (2011) and Plummer (2011) state, the validity of 'correct assessment' of risk by young people is never certain and can lead to discordance between knowledge, perception and behaviour. Drawing on the work of Mberu (2012) and Krieger (2001), the HIV and the Integrity of Risk – Dignifying Resilience in Disadvantage model is expansive and not limited in its conceptualisation of human behaviour.

King (1999) and Mberu et al. (2014) note that social learning theory highlights structural–environmental elements in accounting for young people's behaviour. The social theory of this study, while aware that HIV transmission is caused by identifiable action, also questions the extent to which individuals can control perceived levels of personal and social vulnerability and proceed to make judgement calls informed by social arrangements. Contracting HIV is socially determined, as is the ability to manage and live with HIV and prevent regression to AIDS. In agreement with Krieger (2001), the model HIV and the Integrity of Risk – Dignifying Resilience in Disadvantage draws on social epidemiology and highlights social distribution as a key determinant of managing risk of HIV.

Schimmack, Schupp and Wagner (2008) emphasise the role of subjective experience coupled with the influence of the immediate environment in moulding perceptions of risk and severity of behavioural outcomes. As shown by Cialdini and Goldstein (2004), cultural factors and their interpretation in the social realm are key in shaping perceptions of whether behaviour is conceived as high or low risk. However, social organisation within young people's collectives—notably, same-sex peer groups—must consider, as Eaton et al. (2003) state, the socioeconomic and political arrangements forming within the physical and structural environment.

Interpretive theory provided the bedrock for the social theory of this research. The model of HIV and risk produced demonstrates the need to understand the meaning people give to what they and others do; that interpretation of experience is, as Porter

and Robinson (2011) have it, premised on social interaction leading to patterns of behaviour. While acknowledging the pervasiveness of social influence, this model also allows for notions of free will and sees human behaviour as the outcome of subjective interpretation of the environment. The HIV and the Integrity of Risk model was informed by the tenets of symbolic interactionism: ‘meaning, action and interaction, self and perspectives’ (Chamberlain-Salaun et al., 2013, p. 1) in its study of the social world. In drawing conclusions from the findings, and in agreement with Finn and Mikheyenkova (2011), the inductive sociology of this research emphasised a heuristic analysis of how individuals experience the world and give it layers of idiosyncratic meaning to elicit the reality that matters most to them. In so doing, and as McLachlan and Garcia (2015) point out, this approach to building social theory accounts for the drivers behind apparent ‘irrational’ choices and paradoxes of social behaviour.

Modelling health inclusive of physical, mental and social factors established that individuals living in an environment with a lower life expectancy—such as the urban slum—may, as Sterk, Klein and Elifson (2005) state, have lower levels of self-esteem and broadly dismiss health-seeking behaviour, leading to an increase in risk taking including exposure to HIV. As Chamberlain-Salaun et al. (2013) write, social theory must discern the link between emotion, action and inaction in creating a constructivist grounded theory. Dignity and humiliation studies demonstrate the social construction and interpersonal nature of vulnerability, risk and resilience and associated behaviour patterns (Hartling, Lindner, Spalthoff & Britton, 2013). Experiences of being humiliated and shamed, resulting from episode(s) of neglect and deprivation, as shown by Lindner (2010), may lead to poor life choices affecting health, wellbeing and protection that increase levels of vulnerability. The findings show that in seeking honour, slum-dwelling youth may opt for behaviour that brings respect (strength) in the short term and puts at risk health in the long term (weakness). Referencing a (sub-) value system intelligible to slum-dwelling youth, the greater goal of immediate security and connection and avoiding the chance of humiliation is prioritised over staying HIV free. In this context, sex is a social currency and critical to subjective perceptions of acceptance and wellbeing. Sex has a tangible value that can be counted and costed. As one female participant stated:

*Money is sex and sex is money.*



### 5.13 Study Limitations

There are several limitations to this research. The original sample size included an equal balance between males and females, and short- and long-stay residents. Although it was always envisioned that this was a soft quota, there was a bias towards long-stay young women. With the rich data provided by the small number of young, male short- and long-stay residents, it was still possible to construct social theory inclusive of young men; however, the imbalance between sexes is noteworthy.

The age group for study participants was 18–24 years; that is, late adolescence. Many of the perceptions towards HIV and risk had been formed during early and middle adolescence and had a substantial impact on participant worldviews. Research into the formation of perception prior to late adolescence would be instructive for understanding processes of managing HIV risk throughout all stages of adolescence. Moreover, as sexual debut in the Nairobi slum for many begins from early adolescence, more needs to be known for all adolescent cohorts on behaviour patterns, particularly as they relate to sexual activity.

This study is concerned with the primary root of transmission: non-protective sex between heterogeneous couples. However, HIV is also transmitted within same-sex liaisons, notably, Men who have Sex with Men (MSM) and Intravenous Drug Users (IDU). A more substantial account of risk and resilience would need to include patterns of risk and non-risk behaviour among these groups. Some of the female participants self-identified as sex workers, but this was not a study of sex work. Given the high levels of HIV prevalence among sex workers, further research is required on how information concerning coping strategies is interpreted and disseminated among sex workers and their clients.

Field research took place in a relatively short timeframe and captured the perceptions of young slum residents for a given moment in time. It can be argued that if data generation had gone on longer then new information may have come to light, possibly from new arrivals at the project sites. Coping mechanisms can change over time, as too processes of managing HIV; given time limitations, this is not covered in the research.

This research is about HIV and risk. However, inclusion of HIV-related co-morbidities, especially tuberculosis (TB) may have led to a more thorough account of participant health and vulnerability. Co-morbidities as with HIV compromise the

immune system leading to opportunistic infection. Even if a strict HIV treatment regimen is followed, this does not cover other communicable and non-communicable diseases that equally demand a personal and social cost.

In the social context of managing HIV, integration into collectives, notably same-sex peer groups, are of critical importance. More must be known of those aspects of assimilation theory regarding sexual networking that can shed light on the changing nature of risk perception and personal protection.

As new HIV-prevention technologies are developed, the evidence needs strengthening on their impact on young people's coping strategies, in particular the use of PrEP and PEP among key populations. Compensation theory needs to explore further if perceptions of managing HIV risk are changing with the advent of PrEP and PEP in regard to risky behaviour, and notably among key populations. The underlying principle for PrEP is prior awareness of the presence of HIV risk which can be effectively minimised and reduce the chance of infection. The utility of PEP is that it counters likelihood of HIV infection following a risk event, which has immediate relevance for populations continuing to engage in high-risk behaviour.

Dignity and humiliation are encompassing terms used broadly in this research to denote the presence or absence of wellbeing. There is much debate in the literature over the precise nature and import of these constructs. Although this research did not examine, notably from a social psychology perspective, the specificities of meaning, further research would unpack these compound constructions and help clarify conceptual difference between dignity, honour and pride, as well as humiliation, shame, disgrace and embarrassment.

The embeddedness of researcher values is a constant risk in qualitative studies and may limit the validity of findings and conclusions. The researcher has substantial agency in data generation, analysis and building theory, which if not executed correctly, can limit the authenticity of a study.

## **5.14 Chapter Summary**

The findings led to a grounded theory, HIV and the Integrity of Risk – Dignifying Resilience in Disadvantage, which knit a mosaic of subjective perceptions into one coherent whole. The social theory of this research agrees with Clarke (2005) that the field is messy and defies attempts to find a social process. Data generated in this research were oftentimes inconsistent, counterintuitive and contradictory but this is

what makes the findings wholly plausible. This is the nature of young peoples' slum-based reality. Definite accounts of the intersections of HIV vulnerability do not do justice to the complexity of the lives of young people. This social theory depicts young people as perceptive agents navigating diverse social worlds that often necessitated a response that was, very often, spontaneous and unpredictable.

Taking risks is a necessity for living in a risk environment. A high-risk environment requires a level of risk taking to find personal safety and fulfilment. Many young people possess a fatalistic attitude towards risky behaviour, and harbour notions of 'what will be will be'. Relationships for young slum dwellers are built, as elsewhere, on both trust and risk that may or may not be apparent or well understood, especially regarding the presence of HIV. As the chapter showed, relationships among young slum dwellers can be affected by the presence, or assumed presence, of HIV.

Moral social worlds give meaning and form to multiple realities that create multiple social processes for managing HIV. This research setting is quintessentially diverse in its processes, in its symbolism and in its resilience. The slum is a crowded space, and symbols representing that which is acceptable and that which is not, need to be constantly learned; reality has a fluid quality, nothing very much appears of permanence. Formal religion, for many, can fill the void of uncertainty, but even then, there is little permanence in moral conviction because morality, its interpretation and influence, evolves, like everything else, according to the situation.

This is a patriarchal society, and men make the rules, including that pertaining to sexuality; however, a very practical power arguably is in the hands of women, who form collectives, run households, earn income and in a myriad of ways set the tone and pace of social life.

The slum is violent. Violence is endemic and omnipresent, on the streets and in homes. The findings clearly show how the ever-present threat of violence is foremost in young minds. It is the processes born through violence with protection and safety as key concerns into which HIV fits; managing HIV is not a separate process but forms part of the routine of daily life.

According to the findings, young slum dwellers are industrious and proactive. If risk is involved, including in the context of sexual relationships, then that was life, and life is to be lived. For the participants of this study, finding resilience in disadvantage is the pith of slum existence. This is the integrity of risk, the essence of slum-based advantage.

Avoiding shaming events and seeking recognition, as interpreted by moral norms, may lead to high-risk behaviour that weakens theirs' and others' health and wellbeing. This is the antithesis of dignity. The findings suggest, ultimately, young slum dwellers will more than likely want to dignify their lives and those who matter most to them. The findings point to an inherent resilience among young people, even a *joi de vivre*; environmental and structural decline has sharpened perception and self-awareness.

## Chapter 6: What Next? —A Fitting Future for HIV and Young Slum Dwellers

### 6.1 Introduction to Chapter

As this chapter shows, the global AIDS response is based on accepted practices of health care, termed the ‘normal professionalism’. The AIDS response has seen ground breaking research, notably in prevention technology and the discovery of effective HIV treatment. Yet despite advances made globally in lowering HIV prevalence, within the Nairobi slum concentrated epidemics persist, particularly among young people. As the evidence strengthens, four decades into the epidemic, new thinking emerges on how to control HIV. However, given an uncertain political environment, the social organisation of the slum and structural inequality, new perspectives in HIV care are not necessarily translated into practice.

Developments in the AIDS response, described as the ‘new normal’, is essentially a rethinking of the HIV paradigm from a less facility-based approach to one that is multi-sectoral and inclusive. Quintessentially, it is a step towards ‘dignifying HIV’, and conceives the young person, centre of their universe, as an active and innovative agent of change.

The chapter describes how an emerging professionalism aligned to the *The Fast Track to End AIDS* (UNAIDS, 2014b) needs to come of age and within the reach of a more fitting paradigm of social action. A new way of conceiving the processes of managing HIV for slum-based young people highlights the role of agency informed by biomedical, social and structural factors that drive the epidemic. To end AIDS, what is required is a new genre of innovative people-centred research that challenges accepted norms of slum-based HIV treatment, prevention and care. Such research, as the chapter describes, investigates symbolic meanings within causal pathways that mould perceptions of resilience and agency as well as dignity, self and wellbeing. Conclusions presented in the chapter agree with Auerbach, Parkhurst and Cáceres (2011) that no single causal pathway can be established from a social driver to perception or behaviour. A fitting response begins with feelings, desires, wants and needs of young people discerned through cultural values systems that impact the direction and effect of causal pathways.

As Bankole, Ahmed, Neema, Ouedraogo and Konyani (2007) state, sexual risk taking within cohorts of youth has not been comprehensively addressed owing,

oftentimes, to the tools of investigation that do not fully capture spheres of influence between cultural practice, physical environment and belief. A new people-centred research paradigm interrogates how risk is interpreted and interwoven in processes of managing HIV and in which sexual relations are dignified, including ‘unsafe sexual liaisons’, in meeting a hierarchy of personal need and social reward.

A results-driven research explores the nexus of subjective perception and symbolic content generated within interlinked social arenas impacting physical, mental and emotional health. Such a response, as this chapter discusses, examines, for example, the practicality of effective point-of-site testing and uptake of prevention technologies within the structural confines of urban slum life.

The chapter examines the conceptualisation of slum-based inhabitants as subjects of humanitarian concern and the increasing phenomenon of mobile populations within slum residencies. As Miller-Thayer (2010) state, the exponential rise in humanitarian population mobility within these settings compounds challenges in the provision of health care.

## **6.2 The Normal Professionalism**

A normal professionalism underpins approaches to HIV. However, as Navarro (2007) states, given that current health care practice at the local level is based on the principles of neoliberalism and globalisation, and does not deal with root causes of inequality, it is bound to fail. The practice of ‘delivering’ wellness does not, as Chambers (1995) states, fit the reality of resource-poor settings, nor account for agency of its inhabitants. As Omran (2005) writes, the normal professionalism cannot account for the diversity of needs and interests characteristic of resource-poor settings.

As this research found, HIV prevention and treatment targets for young slum dwellers often fail to deliver at the level expected. The findings point to the need to more fully appreciate the dynamic universe of young slum dwellers and hard to measure, hard to crystallise, notions of youthful desire. Yet, it is those often-neglected areas of research and practice that hold the key to managing HIV. The conventional approaches to dealing with HIV are essentially premised on empirical (positivist) epidemiology, so—the body of evidence suggests—must be re-imagined and reconceptualised; and the centre point shifted to young slum residents. Young slum dwellers need to be seen as creative agents of change and not public health concerns.

The work of Solar and Irwin (2010) helps conceptualise social determinants of health highlighting factors of care and support, but the depth of privation for so many young slum residents is often missed. The threshold of risk for many young slum dwellers is rooted in homelessness, poor diet, violence and the crippling effects of HIV stigma and discrimination. This is the politic real that informs the model HIV and the Integrity of Risk – Dignifying Resilience in Disadvantage. In the slum, as this research discerned, a young person’s resilience, and surety for managing processes of HIV, is based very often on a short timeframe challenging any notion of long-term planning.

### **6.3 Conceptualising Health Care**

In agreement with Nöstlinger and Loos (2018), qualitative research methods in the study of HIV are underutilised and largely devalued in epidemiological inquiry. Community-based participatory approaches to discovering the complexity of HIV do not enjoy the same status as broad-based survey. But it does not have to be one or the other. Complementing longitudinal epidemiological data with longitudinal qualitative data can work well and, as Moss (2017) states, provide valuable insight into culturally constructed meanings of risk and gratification. In strengthening the normal professionalism, this research holds, a carefully nuanced mixed research approach can go far in helping to profile and establish risk thresholds for young slum dwellers regarding HIV.

Kenya is among the five countries globally with the highest HIV prevalence, and young residents of Nairobi’s slums have among the highest rates of incidence anywhere (Madise et al., 2012). In responding to the enormity of the challenge to end AIDS, the global AIDS response has pushed for ‘big data’ conceived by normal professionalism as vital in going to scale and meeting the need. Qualitative study focussed on the social ecology of key populations is not generally perceived as fitting to the task. Yet, as Kingori and Sariola (2015) state, relying on quantitative research alone to conceptualise behaviour risk fails to appreciate the level of depth required to explain, as this study shows, the constant interaction among young people (as actors) and institutions (as actants). The normal professionalism’s leaning towards a priori truth, upon which replicable models of processes for managing HIV risk are built, misconceives the multiplicity of social reality and presence of multiple moral social worlds. Simply put, people are people and do not necessarily fit the mould. Predictive behaviour is offset by notions of agency and challenges finding the general rule that

premises models of health. Compulsive behaviour in the context of young sexuality rarely follows predictive pathways.

### **6.3.1 Dignifying the Nexus of HIV Risk and Resilience**

From the body of evidence, there needs to be further realignment of health and social priorities appropriate for young slum dwellers. In line with Ngulube and Ngulube (2017), this research found much value in the indigenous knowledge of young people towards managing HIV. Knowledge for the young slum resident is real in its consequences and to be appreciated, not undermined. The situation, a social universe, gives meanings to symbols of personal growth and honour, which may appear inconsistent or irrational elsewhere and with other age cohorts. Risky sex can be understood as making sense in the eyes of young slum dwellers; it does not have to be justified, nor does youthful desire and ambition need to be defended. It is what it is. Within slum environments young residents take pride in where and how far they have come and in what the future might hold; a testament to their own sense of agency. A new paradigm of HIV must grapple with the notion that to survive is to succeed, not by avoiding risk but by embracing and dealing with persistent risk.

### **6.4 Rights, an Urban Perspective**

Sustainable health care is a major focus of the urban development agenda. The right to health is a right to dignify one's world. Its absence is undignifying and experienced by participants as humiliating. Affected by exponential and mostly ungoverned growth, the urban slum, and in line with the work of David, Mercado, Becker, Edmundo and Mugisha (2007), this research noted the challenges of sustainable health care in an unsustainable environment. To effectively control infectious disease characteristic of the slums, such as HIV, a new paradigm is required suited to the agency of young slum dwellers. It is an instance of seeking to dignify health care through personal innovation and initiative. People-centred research that underpins a new professionalism must bring to light these challenges facing the goal of sustainable and dignifying health care for populations excluded from the urban dividend. As David et al. (2007) has it, the heavy reliance on facility-based care, the normal professionalism, will unlikely deliver on the mantra of 'rights' for all until the bigger picture of inequity, bias and access constraint is addressed.

Aligned to the findings of Jorgenson and Rice (2012), this grounded theory notes the tenuous link between ill health and wellness; to move from the former to the



latter is, as it always has been, contentious. Marmot, Friel, Bell, Houweling and Taylor (2008) note that this is the underlying assumption in comprehending and responding to persistent poor health among vulnerable populations. A new professionalism founded on a strengths-based approach to research and action seeks to identify the context of structural challenges obstructing the path from sickness to wellness in urban slum settings. Such an approach, as Lindner (2012) states, deals with the question of power relationships in the distribution of key assets and upholds the goal of finding a life of dignity for all. In seeking to overcome the challenges confronting universal coverage of ART a socioeconomic analysis of the distribution of gains made from technological breakthroughs in HIV is urgently required.

### **6.5 Reconceptualising Morality, Sexuality and HIV Risk**

Turok (2013) shows that cities in Africa are increasingly made up of young people. HIV is now primarily an urban phenomenon affecting mostly young people. This research identified a link between the often-chaotic expansion of slum settlement and the myriad of approaches, often incoherent, that young people deploy in managing HIV; it is, arguably, a mirror reflection. It is here, within the ecology of slum survival, that research must now turn to conceptualise wellness among a most at-risk population. Urban spaces are risk environments and shape evolving perceptions of risk by their inhabitants. This is the social ecology of survival: risks are taken in risky situations; risk demands risk. People-centred research must understand the energy and drive encapsulated in taking risk and the intent to achieve the best of whatever is available. A fitting response to ending AIDS recognises that risk is embedded in every aspect of slum life and that moving forwards, stepping outside the mould, demands for many young people even greater levels of risk taking.

The evidence suggests increasing sexual activity among young slum dwellers in Nairobi (Kabiru, Beguy, Undie, Zulu and Ezeh, 2010). Although notoriously difficult to determine with certainty, heightened sexual activity does fit with a broad sway of interpretation explaining risk behaviour among young people and the rise in HIV infection (Erulkar & Matheka, 2007). The picture, however, remains inconclusive. The social advantages of successful sexual networking, as Glen-Spyron (2009) explains, is long established. However, people-centred research must explore further the link between establishing personal advantage and building self-capacity within the context of managing HIV.

Research into sexuality and behaviour draws on notions of morality and ethical behaviour (Fassin, 2014). The evidence suggests that moral assumptions are often not made explicit, especially regarding behaviour considered ‘right’ or ‘wrong’. This, it is argued, has biased the approach to understanding processes of managing HIV and the value of young people’s perceptions towards behaviour risk. Morality is a complex construct and, arguably, little understood within the body politic. Research and policy that has shaped the normal professionalism is informed by conceptions of a priori moral truth. The priority for research, as the findings suggest, is to discern processes that generate ‘truths’ among young people and the genesis of positive gender norms that enhance life—the social good—and provide the basis of sustained resilience against HIV.

## **6.6 Perceiving Resilience—The Dynamics of Age and Gender**

This research holds that staying HIV free is not necessarily a priority among slum youth. An innovative young person-centred approach will shed light on the persistent disconnect between knowledge and action; action that might be impulsive but just as likely to follow a code of ethics aligned to prevailing value systems. A new normal professionalism must seek to know more about subjective interpretations of need and desire and the integrity of risk as felt and prioritised by young slum-dwelling people. It is a case of rethinking how to demonstrate the exceptionalism of AIDS (UNAIDS, 2014b).

The evidence needs strengthening on the temporal dimension of older adolescents’ self-perceptions, especially regarding risk, status and ideas of personal security. Given the lowering age of sexual debut for many slum inhabitants, much more needs to be known how this affects self-perceptions of older adolescents, as many are already sexually active and have made it this far in life, with or without knowing their HIV status. It might be an instance of a false sense of security or an effective agency concerning sexual liaisons; in each case, the ramifications of risk taking are immediate. Research must address gaps in the body of knowledge concerning older adolescents most at risk of HIV infection and as they transit to adulthood.

As Machado, Galano, de Menezes Succi, Vieira and Turato (2016) point out, for the first time, there are now older adolescents born with HIV and sexually active. How these young people dignify and create meaningful relationships of trust in locations such as the slum, as Bakeera-Kitaka, Nabukeera-Barungi, Nöstlinger, Addy and

Colebunders (2008) state, requires immediate attention. Given that such groups put themselves and others at potential risk of infection or reinfection from HIV, more needs to be known of their perceptions of agency. For example, how does an adolescent female sex worker born with HIV perceive a dignified life lived on the margins, and establish a personal resilience that side-steps public rebuke?

There must be more focus on young male engagement, which is often precluded in explaining the hyper-vulnerability of young women. Many young male residents, as this research found, appear to search for and assert a lost identity in a patriarchal world over which they seemingly have little control (Arowojolu, Ilesanmi, Roberts & Okunola, 2002; Slap, Lot, Huang, Daniyam, Zink & Succop et al., 2003). The evidence would suggest that the instruments of population-based survey do not provide the level and depth of detail necessary to deal with the matter of male perceptions of identity amid risk, disempowerment and HIV. As Varga (2003) states, the mainstream approach has been to determine how public health messaging is incorporated into young male behaviour. Principally, it is about behaviour change. Male engagement in reducing HIV risk leans invariably to treatment access by heterosexual men and women, and in so doing creates a blind spot concerning the diversity of adolescent age cohorts, social groups and sexual networks.

A new research paradigm must address the fact that men are routinely overlooked in studies of young women's susceptibility to infection. The result, as Brusamento, Ghanotakis, Tudor Car, van-Velthoven, Majeed and Car (2012) find, is a lack of empirical evidence on the sexual power dynamics of young people's relationships. This anomaly is striking, given, as Isiugo-Abanihe (2003) states, the patriarchy of sexual and social relationships, and expected subservience of young women.

More needs to be known of the humiliating effects of sexual stereotypes. This research found in some male participants, notably one born with HIV and another with TB (whose HIV status was not established), a deep compassion towards others, which sat at odds with cultural definitions of manhood: non-feeling and dispassionate. Gender, as found in this research, is the key element in discerning HIV risk and resilience. Nuanced research must examine the construction of gender stereotypes, agency of young men and women and evolution of power and influence within sexual and non-sexual relationships in the resource-constrained environment of the slum. There is no

one easy definition of gender and a new professionalism does not attempt to make one given its recognition of the fluidity of social worlds.

## **6.7 Mobility, Space and Boundaries**

The relational value of mobility and assimilation to gain social acclaim requires further exploration. Examining how young people affix value to social standing while geographically mobile in slum locations is critical as there is no status to be gained from residing in the poorest part of the slum. Qualitative research is well suited for examining perceptions of mobility and status within the slum and their impact on managing HIV risk. More specifically, and as Arnold, Theede and Gagnon (2014) outline, the questions of how change of location drives changes in behaviour and if forms of risky behaviour are more clearly identified with a certain slum area need addressing. Essentially based in qualitative research, a new genre of investigation needs to shed light on perceptions of intra-urban movement and associated processes of managing HIV involving reinterpretation of forms of social organisation.

Of relevance to building a future for the AIDS response is the question of social space and its interpretation. The work of Lefebvre, as captured by Elden (2007), in conceptualising the ‘spatial triad’ highlights many of the issues regarding place and HIV risk; service delivery and interaction between providers and users of services. Space, as explained by Brenner and Elden (2009) is generated by the dynamic inter-relationships of representational space (ideals and vision); representations of space (plans and designs); and practice (everyday routines and urban reality). This perspective illustrates in a neo-capitalist system, such as Nairobi, the close relationship between daily reality and networks linking places of income generation, residence, community and leisure (Brenner & Elden, 2009; Elden, 2007). While these spaces may show signs of cohesiveness, this does not automatically translate to being logically coherent. The ‘history of space’ helps build the paradigm that explains the processes relevant in developing an urban meshwork of mental and social activity contained within shifting networks shaped by dominant political frameworks and the physical environment.

## **6.8 The Ecology of the Slum—Intersections of Vulnerability**

As shown by this study, a new research paradigm needs to investigate theories of social capital in the context of HIV and, as explained by Chorley, Whitaker and Allen (2015), perceptions of risk as currency; for example, the rewards of sexual violence or demonstrations of ‘hedonistic adaptation’ as perceived by male peer groups

(Sheldon & Lucas, 2014). To fully comprehend the nature of currency and the value of risk generated by social groups found within the congested slum is to take an ethnographic approach that seeks the interconnection between elements existing in situ and the relative value young people give to institutions within their immediate habitat (Pink, 2013). This is the substance of the new paradigm, a new professionalism, that seeks to more fully comprehend processes of evaluating risk and reward.

Points of social intersection are often places of heightened vulnerability reflecting the spatial dimension of risk. Social networks of young people found at points of intersection in slum environments need to be better understood, as do the social mechanisms involved in generating shared perceptions of humiliation associated with these locations. Powers (2017) states that concepts of pathways, intersections and hotspots provide insight into the social and spatial experience of young people and processes of managing HIV in slums. Place matters. More needs to be done in forming a unified conceptual framework that reflects the intent and purpose of social groups within locations of physical and social convergence, and the means of reducing risk and building personal protection.

## **6.9 Urban Humanitarian Settings**

Mahabir, Crooks, Croitoru and Agouris (2016) describe how there is a gradual mind shift in seeing many slum inhabitants as ‘populations of humanitarian concern’ conceptualised by levels of deprivation, lack of effective coping mechanisms and inability to access daily sustenance. Entrenched poverty that denies the right to sustenance is a humanitarian emergency. Persistent poverty and threat of HIV challenges attempts at sustaining health and livelihood and constitutes a human catastrophe. Since its proclamation in 1999, Kenya continues to officially declare HIV an emergency, and the burden of the emergency now resides in its slums.

As described by Hilhorst and Jansen (2010), in typical humanitarian settings, a commonality is assumed among inhabitants; however, how well this conceptualisation works for slum settings is yet to be established. In agreement with Zulu, Beguy, Ezeh, Bocquier, Madise, Cleland and Falkingham (2011) understanding processes of vulnerability and the desire to build resilient dignity needs further substantiating in the complex world of the urban humanitarian environment.

Min-Harris (2010) holds that increasing numbers of young people are involved in rural-to-urban and intra-urban migration, arriving in places of inherent instability.

With increasing frequency of humanitarian crises in Kenya, combined with the cyclical arrival of new populations into slum settings seeking solace from extended family networks, as Humphries (2013) states, more needs to be known of the impact of this on aspects of resilience and humanitarian coping strategies. Vearey (2010) shows that with more mouths to feed and greater numbers of people to shelter, an intolerable strain is placed on family units with resources already stretched to the limit. The process of adopting coping mechanisms relevant to a new residence and gradual assimilation of new arrivals into neighbourhood networks needs to be further explored and explained by a new professionalism. While there is evidence concerning adaptation and assimilation, there is far less on the crucial matter of humanitarian populations' self-perception of forced migration, including intra-slum mobility, and notably regarding one's sense of dignity and/or humiliation and side-stepping risk of HIV infection. A people-centred approach to the nature of inter-relational social organisation will provide information on aspects of dignity and humiliation among young mobile humanitarian populations and help explain the impact of episodes of trauma. Challenges faced by mobile and possibly traumatised youth are likely to show a very different pattern to that of multigenerational residents even if other variables, such as wealth, remain constant. A core component of the new professionalism is in disaggregating all aspects of data concerning managing HIV risk among young slum dwellers.

### **6.10 The Dignity of Mobility; Social and Structural Decline**

There is much to be said for the young person uprooted from a known universe and transplanted into a city slum, and now seeking personal as well as familial advantage in an unknown environment. This is the pith of resilience. This equally applies in moving from the familiarity of one slum, for example from Korogocho to Majengo. How far the experience of displacement holds sway on rational decision making relating to managing HIV requires further inquiry.

Explanations regarding structural constraints as well as forms of social advantage and disadvantage within slums all too often define poverty on strictly economic terms and fail to see the innovative mindset of young inhabitants active in the informal economy. Empathetic research must explore how social and private wealth is perceived among young slum dwellers. There is a need to identify interpretations of capacity and opportunity among slum-dwelling populations, notably as populations of humanitarian concern.

In addition to economic analysis on per capita Gross Domestic Product and services, conceptualising dignity and humiliation as social capital shaped by interpersonal phenomena rarely becomes part of considerations for human development. In humanitarian settings, suffering is assumed to have one face and requires a standard response. However, in failing to see the nuances of vulnerability within a heterogeneous population, there is a chance of running roughshod over specific needs and aspirations of marginalised groups, considered agency in dignifying life and livelihood.

A link between mobility and HIV risk (individual factors) and vulnerability (structural factors) has been demonstrated (Nöstlinger & Loos, 2018). Kimuna and Djamba (2012) believe that inter- and intra-slum mobility can greatly increase chances of HIV exposure by dismantling social worlds and demanding realignment of sexual networks. Suphanchaimat, Sommanustweechai, Khitdee, Thaichinda, Kantamaturapoj, Leelahavarong, Jumriangrit, Topothai, Wisaijohn and Putthasri (2014) argue that many mobile and transitory groups residing in the slum are excluded from effective HIV combination prevention strategies. As migration in all forms increases, gaps in the evidence become apparent. Urban research must learn more concerning timing of HIV acquisition as part of the mobility trajectory; its impact on HIV prevention and acquisition; and the causal pathways of HIV for mobile populations arriving or shifting residence within slum locations. The evidence is inconclusive and needs strengthening regarding social dynamics of sexual networking and the role of peer group influence among mobile populations in the Nairobi slums.

The temporal dimension of assimilation into social networks vis-à-vis levels of risk taking needs to be understood more fully. In agreement with Nöstlinger and Loos (2018), it is likely that the efficacy of HIV services after the first two years of arrival in a new slum changes and as such requires further examination. More must be known on HIV acquisition and treatment access as part of the mobility-related dynamic occurring as part of broader social processes involved in managing HIV. Building a rights-based body of knowledge will ensure an evidence-based ecology relevant to tackling, for example, xenophobic discourses regarding young people residing or transiting through slum locations.

Hartling's (2007) work adds to the body of knowledge concerning upheaval and social dislocation, related effects on patterns of humiliation, and determining risk thresholds. This research notes the absence of empirical inquiry in Nairobi slum settings in regard to displacement, change of abode and inculcated feelings of humiliation.

According to Horwood and Reitano (2016), Nairobi is well suited for empirical inquiry into the nexus of risk and humiliation as it provides the perfect storm of vulnerability and uncertainty.

According to Lee, Helke and Laczko (2015), questions of urban mobility and impact on city health systems have become a priority area of research. Partly in response to rising HIV prevalence, the sexual health and wellbeing of cohorts of adolescents is similarly seen as a major area for study leading, as Schiffman, Darmstadt, Agarwal and Baqui (2010) state, to new perspectives of health care among the very poor. Much of the fact finding still turns to quantitative studies for data collation and analysis including on matters of sexual behaviour (Luke, Xu, Mberu & Goldberg, 2012). In agreement with Kidd and Kral (2005), qualitative research will prove a useful tool in understanding perceptions of community empowerment as part of the compendium of health care. Through ethnographic inquiry, more will be known on questions relating to ART access and multi-month HIV scripting based on the integrity of health care.

### **6.11 Framing a ‘New Normal’**

It is envisioned that a new professionalism will create a genre of evidence based on individual, environmental and structural domains of HIV risk and resilience. A paradigm shift will lead to greater appreciation of the multifaceted constructs at the centre of managing HIV. Controlling the epidemic in Nairobi slums depends on innovative research that creates an evidence base reflecting the plurality of slum life. This is the backbone of the new professionalism that informs policy and public health. At the heart of this work is understanding the often-troublesome relationship between HIV and wellbeing within social worlds and the myriad of approaches taken by young people to establish identity morally acclaimed and as defined by local perception.

Dignifying the response is to address HIV-related stigma and discrimination. Fear of being known to have HIV and perceiving the reaction by significant others on learning of one’s HIV-positive status is a continuing barrier in accessing prevention and treatment services (Brashers, Basinger, Rintamaki, Caughlin & Para, 2017). Fitting to the new professionalism is an approach that emphasises creating ‘safe space’ for young HIV-positive residents drawing on the language of inclusion and compassion. It is a rights-based approach. Nuanced research needs to investigate the claim that money speaks in the slum and clouds issues of an HIV-positive status. In Nairobi, it is



purported by Van der Elst, Gichuru, Muraguri, Musyoki, Micheni, Kombo, Smith, Graham, Sanders and Operario (2015) that gains have been made in addressing stigma by sensitising community health care workers as part of the process of providing non-judgemental and stigma-free HIV care. The approach recognises the criticality of social interaction between provider and user of HIV services. A new professionalism seeks to explain through qualitative and people-centred research the many shades of stigma within moral worlds by first understanding the symbolic content of social interaction that appreciates the power dynamics of the situation: the giver and the receiver of care.

A new professionalism is manifested in community-level attempts shaped by community members themselves to eradicate the stigma of HIV. A key component of a new approach sees the purpose and effect of sustained agency and a people-centred and people-driven agenda in ending stigma. In reducing consistently high levels of stigma at the project sites, establishing adolescent-dignifying points of care in a protected and non-judgemental space needs to become routine practice. The emphasis shifts in this paradigm of care to the world of the young slum dweller and acknowledges the reality of risk that is not easily side-stepped as it is real and omnipresent. A non-threatening environment is shown by Kabiru et al. (2011) as key in discovering the facts behind the uptake of services by young people and building a sustainable treatment response. The new professionalism calls for a continuing paradigm shift in which power is further decentralised away from the centre; that is, medical professionals, to first line responders and users of HIV services. Crowley and Mayers (2015) demonstrate the need for task shifting in which service delivery is carried out by trained members of the community, including young people respected and accepted within the immediate environment.

Babigumira, Sethi, Smyth and Singer (2009) show that HIV testing using mobile clinics is effective in providing services to hard-to-reach young populations. Mobile clinics take the HIV testing to the user of the service and do not wait for 'drop-ins' at formal health establishments. In the slums with health care limited in the extreme, mobile clinics facilitate HIV testing for young people. Liang, Erbeding, Jacob, Wicker, Christmyer, Brunson, Richardson and Ellen (2005) state that mobile clinics can greatly reduce waiting time in crowded and often poorly run health facilities in which confidentiality may not be assumed; as such, they represent an instance of dignifying wellness and wellbeing. Empathetic research must explore further how an approach

such as this can become progressively effective and the norm for prevention strategies within slum settings, and slowly change perceptions of HIV service delivery.

The new normal must be innovative as well as proactive in managing HIV risk, and reflective of processes used by young people. Alternatives to current practices, which so often fail in their objective of enhancing public health, are necessary. Within the new normal, wellness cannot be delivered; wellness as locally perceived is a state of mind that, as and where necessary, seeks support from external services. The new normal advocates for immediate and confidential support provided through a 'point-of-site' approach, which is in keeping with the fast-moving and often-changing fortunes of young people. Further, a more nuanced approach to HIV re-emphasises the need for use of digital mobile database technology that is more secure in protecting user confidentiality. However, this can only become reality or sustained in the long run through appreciating the dignity of young people's choice to use HIV services, and by respecting their right to access health care freely and without fear or prejudice. This is no easy matter as social worlds evolve and circumstances change. The tables are turning towards a new professionalism and, as this research asserts, the locus must continue to become the young user of HIV services.

In agreement with Krakowiak (2016), home-based testing for HIV is another aspect of dignifying the continuum of preventing and treating HIV. This approach allows the young person to enjoy confidentiality and choose the time and place for testing; and recognises the capacity of young people in taking responsibility for their own wellbeing. HIV self-testing similarly helps overcome barriers found in conventional testing services and makes testing more accessible and acceptable by allowing the young person to perform and interpret their own HIV test result in a private space. The knowledge base needs to expand concerning how home-based testing in one location may not necessarily work in another.

Innovative approaches to HIV empower and recognise the dignity of HIV testing among young people. Innovation stems from looking at things differently, in drawing on research that perceives health and wellbeing from a new perspective. Research needs to explore further innovative approaches seeking to promote knowledge of acute HIV infection among young people by empowering young champions; for example, to recognise symptoms through online applications that assist with risk assessment capable of referring, if the need arises, to HIV point-of-care testing and treatment (Larson, Schnippel, Ndibongo, Xulu, Brennan, Long, Fox and Rosen, 2012).

All available scientific and medical technologies need to be deployed towards ending the AIDS epidemic by 2030. However, given structural challenges in the slum, the question becomes how to sustain innovative approaches in curbing the epidemic cognisant of the tendency for health professionals to fall back on established practice. With innovation comes the need for advocacy on the part of the research community to show what is and is not working with HIV service delivery. Small-scale empirical study does not equate to limited impact or diminished knowledge and must continue to inform innovative approaches and be shared widely as part of the goal of ending AIDS.

The goal of innovation and associated strategies to end AIDS in the slums is to reach young people with a suite of contextualised tools to prevent new infections that includes PrEP and treatment-as-prevention; and promote overall health and wellbeing. Access to PrEP for high-risk populations, especially young people, has been shown to work well (Van der Elst, Mbogua, Operario, Mutua, Kuo, Mugo, Kanungi, Singh, Haberer, Priddy and Sanders, 2013). The provision of PrEP, male and female condoms and lubricants to young people at high risk, alongside HIV and STI testing are critical components of successful treatment programmes (Okwunde, Uthman & Okoromah, 2012). This approach challenges conventional morality in regard to the supply of commodities directly relating to sex among young people. Qualitative research that can demonstrate the efficacy of this approach through falling rates of infection needs to support bold new initiatives that prioritise the sanctity of preserving young lives and does so by recognising the paramountcy of moral worlds shaping sexuality and behaviour.

Ending AIDS, notably among young people, involves addressing behavioural, biomedical and structural factors and goes beyond the conventional remit of clinical health. A sustained response encompasses social support mechanisms necessary to the health and wellbeing of people infected by HIV and maintaining treatment regimens tailored to meet the demands of a young population. For example, the Nairobi City Council can provide its slum residents with HIV prevention and health care services including safe housing, food and nutrition. With enduring poverty facing so many slum inhabitants, it is imperative that anyone living with HIV should not have to choose between HIV medication and house rent, or HIV medication and sustenance. The question becomes again—the how. Wealth creation schemes couched in terms of poverty eradication policy likely hold the key, but the obstacles are great as are the resources required to make it reality. A new direction, a new urban agenda, must be

kept informed and deal with the real time; the social process of health and wellbeing for young slum dwellers.

A new normal put ‘the last first’ (Chambers, 1995); the marginalised and disempowered become the power brokers for ending AIDS, which ensures that no one is left behind (Scorgie, Vearey, Oliff, Stadler, Venalbes, Chersich and Delany-Moretlwe, 2017). This involves a research agenda that empowers young people in ways fitting to their social and structural environment. Empathetic research demands that the conception and rollout of nuanced studies dignifies the social worlds of young people and, if necessary, take on prevailing attitudes and practice. A new professionalism must be wholly cognisant of the need for social transformation as part of the process of health care capable of tackling structural and social drivers of HIV in the slums.

The new normal must contend with gender inequality regarding access to HIV services and all forms of gender-based violence that compound risk of contracting HIV. As this research found, young female sex workers in the slums are at particular risk. Dedicated clinics within the slum environment to provide care for survivors of sexual violence and provision of PEP has been shown to be effective (Izulla, McKinnon, Munyao, Karanja, Koima, Parmeres, Kamuti, Kioko, Nagelkerke, Gakii, Wachichi, Muraguri, Musyoki, Gelmon, Kaul and Kimani, 2013). These clinics essentially work through young peer educators in providing protection and information on managing HIV. This approach to managing HIV among a young population at risk works with and through their social worlds in a non-judgemental manner.

HIV can leverage social transformation and become the mainstay for positive change in urban slums, leading to significant reduction in rates of infection as well as providing benefit for public health concerns. It follows that positive social transformation at the heart of ending AIDS is as much concerned with sustainable wealth creation in resource-poor environments, promoting gender equality and dealing with discriminatory social norms. Through building the body of knowledge on contextual factors associated with HIV risk, young people are now centre stage in dealing with the more intractable social problems such as HIV stigma.

## **6.12 Reconceptualising HIV: The Politics of Ending AIDS**

Auerbach et al. (2011) state that there is an ongoing reconceptualisation away from an emergency to a long-term response to AIDS and a shift of focus away from individual and broad-based HIV-prevention initiatives to comprehensive strategy

emphasising a structural perspective. This is at the heart of a new professionalism seeking to address, as a priority, socio-structural conditions impacting HIV infection. However, it is one thing conceptualising a new approach to ending AIDS; it is another reaching consensus among AIDS powerbrokers. Success of a new professionalism hinges on sustained political advocacy that finds its evidence from hotspots of infection—the slums—and takes it to the highest echelons of the AIDS response.

Leading on from the work of Van Donk (2006), the new normal for HIV must continue to work towards a broader conception of prevention and treatment. Notably, regarding the context of urban development planning, HIV is still seen as a behavioural and health issue with minimum focus on impacts of the epidemic (Van Donk, 2006). This conception oversimplifies the complex reality of slum life and social determinants of health. In tackling risky behaviour, conventional approaches to risk mitigation have often had the opposite effect to that intended in that they can disempower and stigmatise young people unable to respond to the message as directed, such as abstinence from sex. As Van Donk (2006) states, what is called for is a new professionalism that seeks a broader conceptualisation that recognises HIV as a complex and dynamic development issue. Structural and social determinants associated with slum settings that compound young people's vulnerability to HIV have direct consequence for urban development and health outcomes in deprived areas. Aligned to Van Donk (2006), this research holds that equitable development offers the best protection for individuals and urban slum neighbourhoods against the likelihood and consequences of HIV infection.

The evidence shows that health inequities are profoundly affected by overlapping social worlds entwined with micro- and macro-economic systems. Integral to social structures and economic systems, as Marmot et al. (2008) states, is the totality of social and physical environment, health systems and structural and societal factors. Encapsulated in the conceptualisation of the universe of health is the inequitable distribution of money, power and resources. Equitable development that tackles the determinants of health vulnerabilities is the purpose and outcome of a new professionalism to end AIDS.

In agreement with Fineman (2010), as fresh evidence is generated, new perspectives on how to control the epidemic must continue to broaden a comprehensive conceptualisation of vulnerability, highlighting the responsibility of government and municipal authorities in taking measures towards a fairer and more egalitarian urban environment. Vulnerability is a complex construct and perceived on multiple levels by a

multitude of interested parties. As this research found, it is best seen as a universal and constant variable and essentially part of the human condition. It is argued that the conventional approach to reducing vulnerability is premised on an 'equal protection analysis' and now, through a revised paradigm of action, must focus more on 'post-identity' that widens the scope from accounts of discrimination against specific social groups to include, according to Fineman (2010), discourse on privilege and favour enjoyed by certain segments of the population. For example, in studying the ramifications for personal health of overcrowding, 'slum landlords' charging high rents with little investment on their part to address living conditions needs to be an integral part of slum-based HIV action and research. In this way, a new analytic paradigm highlights social structures and socio-political arrangements to shed light on the formation of collective vulnerability.

A new professionalism takes the discussion past the limited confines of prevailing discrimination-based models towards a more substantive vision of social equality. Theorising the concept of vulnerability thus provides for a more robust account of the subject of HIV risk and speaks to issues framing urban policy and social protection measures involving the haves and have-nots. It is a political agenda; AIDS remains a political matter and HIV-prevention strategy must make the link between rights, equity and justice. This research upholds that it is not necessarily science or technology that continues to deter populations most vulnerable to HIV from accessing life-saving services but misplaced policy reflecting misinformed ideology and prejudice.

A broader perspective concerning HIV prevention and care redefines and expands ideas of state involvement in the provision of health care for all, about municipal responsibility towards slum-dwelling people and their wellbeing. A 'vulnerable subject' perspective takes the discourse beyond an autonomous and independent subject analysis typical of the neo-liberal tradition and becomes the centre of theoretical study (Fineman, 2010). The vulnerable subject approach does not dismiss individual-level interventions but simply holds they are not enough. Social and structural barriers including local and nationwide institutions must be addressed by academia to help build a comprehensive HIV prevention relevant to most affected communities, which calls for state intervention to up the resources available to address the challenges of AIDS care.

### **6.12.1 Gender; the Intersection of Vulnerability and Resilience**

As Krishnan et al. (2008) state, at the root of the hyper-vulnerability of young women are socioeconomic gender inequities that directly affect processes for managing HIV. The conventional professionalism pays too little attention to social determinants of health and gender power dynamics in the context of entrenched poverty. Accordingly, a more nuanced approach to HIV and wellbeing prioritises the specific, the micro study, that delves into processes whereby gender inequality and associated patterns of sexual risk taking are brought into clear focus. A new professionalism must identify the relational value between gender and poverty, and pathways of HIV risk and infection.

### **6.12.2 Grounding Research Priorities**

Engendered qualitative approaches that delve with compassion and empathy into the root of health outcomes form part of the new normal that complements well-crafted quantitative analysis. The role of health professionals and agents of change within the community needs to be redefined and should address the question of where the root of knowledge exists for ending AIDS. An inclusive theoretical framework based on empirical rigour is required that can accommodate ecological and multilevel relationships of young people in the urban slum and demonstrate their active participation in managing HIV and risk.

A new genre of research must prioritise the ‘here and now’ approach to slum life. Within this universe, inhabitants adopt an experiential approach to life as a way of realising wellbeing and purpose. An approach such as this would highlight the plurality of reality and complexity of deprivation itself. The piloting of a new approach involves a degree of risk—only so much can be prepared for and assumed in advance—but if this is not done, the AIDS response in Kenya as elsewhere will fail to make that critical turn in its demise. The *Fast Track to End AIDS*, is exactly that—a call to think outside the square—a new way of seeing, hearing and responding to HIV and making an impact where it is needed the most.

## **6.13 Chapter Summary**

The means exist to end AIDS now (UNAIDS, 2015). However, as Campbell and Nair (2014) claim, there is a point in the discourse where rhetoric meets reality. Theorising about a public good without real-time action becomes redundant. As the chapter shows, to end AIDS the focus must be investing in community participation that addresses the structural drivers of HIV risk. A new normal prioritises operational and

implementation science able to provide strategic information on new areas for people-centred research focussing on vulnerable-prone communities. As Granich, Williams, Montaner and Zuniga (2017) state, it is not possible to end AIDS through treatment. The answer rests on the intuition, steadfastness and resilience of young people. This chapter detailed conventional approaches to HIV and AIDS and, while acknowledging substantial gains made, highlighted points of continuing concern. AIDS is, as the chapter shows, a political affair involving dimensions of power, resources and privilege.

There are gaps in the evidence. The chapter points to lines of inquiry failing to inform the body politic on the AIDS response. Through presenting the gaps, the chapter considered the role of the 'new normal' in the global HIV response. In many instances it is a further development of current practice but relying far more on qualitative people-centred inquiry that constructs social theory on their perceptions, their actions and their behaviour. Based on the evidence, described as nuanced research, a people-centred approach addresses many of these gaps through drawing on emerging technologies that protect the space of young people wanting to test and receive treatment for HIV in a way that is respectful of their situation.

The thesis does not provide a quick fix on how to end AIDS. It presents the case for a more resilient and sustainable approach to HIV care and support. However, only in consideration of the totality of their situation and an appreciation of the multiplicity of moral social worlds can daring to risk to seek advantage be understood. Slum life is harsh and demands questions are asked of powerbrokers in the AIDS response. The new normal is political as it is informed, and as the chapter concludes, critical in dealing with enduring social and structural drivers that negate attempts to end AIDS. But there is hope: the energising resilience of youth; a light that will not be dimmed. In the words of Klara, a long-stay resident of Korogocho:

*I am proud of what I am and everything that I am ... I love my life.*



## References

- Adedimeji, A. A., Omololu, F. O., & Odutolu, O. (2007). HIV risk perception and constraints to protective behaviour among young slum dwellers in Ibadan, Nigeria. *Journal of Health, Population, & Nutrition*, 25(2), 146-157.
- African Population and Health Research Center—see APHRC
- Ahearn, L. M. (2016). *Living language: An introduction to linguistic anthropology* (2nd ed.). Chichester, England: Wiley Blackwell.
- Airhihenbuwa, C. O. (1995). *Health and culture: Beyond the Western paradigm*. Thousand Oaks, CA: Sage.
- Ajide, K. B., & Balogun., F. M. (2018). Knowledge of HIV and intention to engage in risky sexual behaviour and practices among senior school adolescents in Ibadan, Nigeria. *Archives of Basic & Applied Medicine*, 6(1), 3-8.
- Allan, K. (2013). Introductions. In K. Allen (Ed.), *Organizing ordinary life*. In *Contemporary social and sociological theory: Visualizing social worlds* (3<sup>rd</sup> ed., pp 1-19). Thousand Oaks, CA: Pine Forge Press.
- Amirkhanian, Y. A. (2014). Social networks, sexual networks and HIV risk in men who have sex with men. *Current HIV/AIDS Reports*, 11(1), 81-92.  
doi:10.1007/s11904-013-0194-4
- Anderson, K. G., Beutel, A. M., & Maughan-Brown, B. (2007). HIV risk perceptions and first sexual intercourse among youth in Cape Town, South Africa. *International perspectives on sexual and reproductive health*, 33(3), 98-105.
- Anugwom, E., & Anugwom, K. (2016). Socio-cultural factors in the access of women to HIV/AIDS prevention and treatment services in south-southern Nigeria. *Iranian Journal of Public Health*, 45(6), 754-760.
- APHRC. (2002). *Population and health dynamics in Nairobi's informal settlements: Report of the Nairobi cross-sectional slums survey (NCSS) 2000*. Nairobi, Kenya: Author.
- APHRC. (2014). *Population and health dynamics in Nairobi's informal settlements: Report of the Nairobi cross-sectional slums survey (NCSS) 2012*. Nairobi, Kenya: APHRC.
- Arnold, C., Theede, J., & Gagnon, A. (2014). A qualitative exploration of access to urban migrant healthcare in Nairobi, Kenya. *Social Science & Medicine*, 110, 1-9.

- Arowojolu, A., Ilesanmi, A., Roberts, O., & Okunola, M. (2002). Sexuality, contraceptive choice and AIDS awareness among Nigerian undergraduates. *African Journal of Reproductive Health*, 6(2), 60-70.
- Auerbach, J. D., Parkhurst, J. O., & Cáceres, C. F. (2011). Addressing social drivers of HIV/AIDS for the long-term response: Conceptual and methodological considerations. *Global Public Health*, 6(Suppl 3), S293-S309.
- AVERT (2018). *AVERT 1986–2017*. Retrieved from <https://www.avert.org/stay-date/AIDS2018>
- Babigumira, J. B., Sethi, A. K., Smyth, K. A., & Singer, M. E. (2009). Cost effectiveness of facility-based care, home-based care and mobile clinics for provision of antiretroviral therapy in Uganda. *Pharmacoeconomics*, 27(11), 963-973.
- Bajos, N. (1997). Social factors and the process of risk construction in HIV sexual transmission. *AIDS Care*, 9(2), 227-238.
- Bakeera-Kitaka, S., Nabukeera-Barungi, N., Nöstlinger, C., Addy, K., & Colebunders, R. (2008). Sexual risk reduction needs of adolescents living with HIV in a clinical care setting. *AIDS Care*, 20(4), 426-433.
- Ball, G. F., & Balthazart, J. (2008). How useful is the appetitive and consummatory distinction for our understanding of the neuroendocrine control of sexual behavior? *Hormones & Behavior*, 53(2), 307.
- Balogun, M., & Odeyemi, K. (2010). Knowledge and practice of prevention of mother-to-child transmission of HIV among traditional birth attendants in Lagos State, Nigeria. *Pan African Medical Journal*, 5(7), 1-12.  
doi:10.11604/pamj.2010.5.7.209
- Bankole, A., Ahmed, F. H., Neema, S., Ouedraogo, C., & Konyani, S. (2007). Knowledge of correct condom use and consistency of use among adolescents in four countries in Sub-Saharan Africa. *African Journal of Reproductive Health*, 11(3), 197-220.
- Barnett, T., & Parkhurst, J. (2005). HIV/AIDS: Sex, abstinence, and behaviour change. *The Lancet Infectious Diseases*, 5(9), 590-593.  
doi:[https://doi.org/10.1016/S1473-3099\(05\)70219-X](https://doi.org/10.1016/S1473-3099(05)70219-X)
- Barrington, C., Arandi, C., Aguilar-Martinez, J., & Miller, W. M. (2018). Introduction. In D. Kerrigan, & C. Barrington (Eds), *Structural dynamics of HIV* (pp. 3-18) London, England: Springer International.

- Basu, A., & Dutta, M. J. (2009). Sex workers and HIV/AIDS: Analyzing participatory culture-centered health communication strategies. *Human Communication Research, 35*(1), 86-114.
- Becchetti, L., Conzo, P., & Romeo, A. (2013). Violence, trust, and trustworthiness: Evidence from a Nairobi slum. *Oxford Economic Papers, 66*(1), 283-305.
- Berger, P. L., & Luckmann, T. (1966). *The social construction of reality*. New York, NY: Doubleday.
- Bernard, H. R. (2002). *Research methods in anthropology: Qualitative and quantitative methods* (3rd ed.). Walnut Creek, CA: AltaMira Press.
- Bhatia, D. S., Harrison, A. D., Kubeka, M., Milford, C., Kaida, A., Bajunirwe, F., ..., Matthews, L. T. (2017). The role of relationship dynamics and gender inequalities as barriers to HIV-serostatus disclosure: Qualitative study among women and men living with HIV in Durban, South Africa. *Frontiers in Public Health, 5*(188). doi:10.3389/fpubh.2017.00188
- Binswager, H. (Ed.) (1986). *The Ayn Rand lexicon: Objectivism from A to Z*. New York, NY: Meridian.
- Birks, M., & Mills, J. (2015). *Grounded theory: A practical guide* (2nd ed.). Los Angeles, CA: Sage.
- Birks, M., Mills, J., Francis, K., & Chapman, Y. (2009). A thousand words paint a picture: The use of storyline in grounded theory research. *Journal of Research in Nursing, 14*(5), 405-417.
- Bjørnholt, M., & Farstad, G. R. (2014). 'Am I rambling?' on the advantages of interviewing couples together. *Qualitative Research, 14*(1), 3-19.
- Blanc, A. K. (2001). The effect of power in sexual relationships on sexual and reproductive health: An examination of the evidence. *Studies in Family Planning, 32*(3), 189-213.
- Blumer, H. (1973). A note on symbolic interactionism. *American Sociological Review, 38*(6), 797-798.
- Böhm, A. (2004). Theoretical coding: Text analysis in grounded theory. In U. Flick, E. von Kardoff, & I. Steinke (Eds.), *A companion to qualitative research* (pp. 270-275). London, England: Sage.
- Bowleg, L., Lucas, K. J., & Tschann, J. M. (2004). 'The ball was always in his court': An exploratory analysis of relationship scripts, sexual scripts, and condom use

- among African American women. *Psychology of Women Quarterly*, 28(1), 70-82.
- Boyer, C. B., Greenberg, L., Chutuape, K., Walker, B., Monte, D., Kirk, J., & Ellen, J. M. (2017). Exchange of sex for drugs or money in adolescents and young adults: An examination of sociodemographic factors, HIV-related risk, and community context. *Journal of Community Health*, 42(1), 90-100.
- Bradley, H., Tsui, A., Hindin, M., Kidanu, A., & Gillespie, D. (2011). Developing scales to measure perceived HIV risk and vulnerability among Ethiopian women testing for HIV. *AIDS Care*, 23(8), 1043-1052.
- Brashers, D. E., Basinger, E. D., Rintamaki, L. S., Caughlin, J. P., & Para, M. (2017). Taking control: The efficacy and durability of a peer-led uncertainty management intervention for people recently diagnosed with HIV. *Health Communications*, 32 (1), 11-21
- Breckenridge, J., Jones, D., Elliott, I., & Nicol, M. (2012). Choosing a methodological path: Reflections on the constructivist turn. *Grounded Theory Review*, 11(1), 64-71.
- Brenner, N., & Elden, S. (2009). Henri Lefebvre on state, space, territory. *International Political Sociology*, 3(4), 353-377.
- Brewer, J. D. (2000). *Ethnography*. Philadelphia, PA: Open University Press.
- Brown, B. (2006). Shame resilience theory: A grounded theory study on women and shame. *Families in Society*, 87(1), 43-52.
- Brownmiller, S. (2013). *Against our will: Men, women and rape*. New York, NY: Open Road Media.
- Brusamento, S., Ghanotakis, E., Tudor Car, L., van-Velthoven, M. H., Majeed, A., & Car, J. (2012). Male involvement for increasing the effectiveness of prevention of mother-to-child HIV transmission (PMTCT) programmes. *Cochrane Database of Systematic Reviews*, 10. doi:10.1002/14651858.CD009468.pub2
- Bryant, A., & Charmaz, K. (2007). *The Sage handbook of grounded theory*. Thousand Oaks, CA: Sage.
- Burr, V. (2006). *An introduction to social constructionism*. London, England: Routledge.
- Campbell, C., & Nair, Y. (2014). From rhetoric to reality? Putting HIV and AIDS rights talk into practice in a South African rural community. *Culture, Health & Sexuality*, 16(10), 1216-1230.

- Carr, R. L., & Gramling, L. F. (2004). Stigma: A health barrier for women with HIV/AIDS. *Journal of the Association of Nurses in AIDS Care*, 15(5), 30-39.
- Carrington, M. J., Neville, B. A., & Whitwell, G. J. (2014). Lost in translation: Exploring the ethical consumer intention–behavior gap. *Journal of Business Research*, 67(1), 2759-2767.
- Carroll, N., Richardson, I., & Whelan, E. (2012). Service science: An actor–network theory approach. *International Journal of Actor–Network Theory and Technological Innovation (IJANTTI)*, 4(3), 51-69.
- Carson, D., Gilmore, A., Perry, C., & Gronhaug, K. (2001). *Qualitative marketing research*. London, England: Sage.
- Chamberlain-Salaun, J., Mills, J., & Usher, K. (2013). Linking symbolic interactionism and grounded theory methods in a research design: From Corbin and Strauss' assumptions to action. *Sage Open*, 3(3), 1-10.
- Chambers, R. (1983). *Rural development: Putting the last first*. Harlow, England: Longman Scientific & Technical.
- Chambers, R. (1995). Poverty and livelihoods: Whose reality counts? *Environment & Urbanization*, 7(1), 173-204.
- Charmaz, K. (2000). Grounded theory: Objectivist and constructivist methods. In N. K. Denzin, & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 509-535). Thousand Oaks, CA: Sage.
- Charmaz, K. (2002). Stories and silences: Disclosures and self in chronic illness. *Qualitative Inquiry*, 8(3), 302-328.
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative research*. London, England: Sage.
- Cho, H., & Lee, J. S. (2015). The influence of self-efficacy, subjective norms, and risk perception on behavioral intentions related to the H1N1 flu pandemic: A comparison between Korea and the US. *Asian Journal of Social Psychology*, 18(4), 311-324.
- Chorley, M. J., Whitaker, R. M., & Allen, S. M. (2015). Personality and location-based social networks. *Computers in Human Behavior*, 46, 45-56.
- Cialdini, R. B., & Goldstein, N. J. (2004). Social influence: Compliance and conformity. *Annual Review of Psychology*, 55, 591-621.
- Clarke, A. (2005). *Situational analysis: Grounded theory after the postmodern turn*. Thousand Oaks, CA: Sage.

- Clarke, A. E., Friese, C., & Washburn, R. (2015). *Situational analysis in practice: Mapping research with grounded theory*. Walnut Creek, CA: Left Coast Press.
- Clough, P., & Nutbrown, C. (2012). *A student's guide to methodology*. London, England: Sage.
- Cluver, L. D., Orkin, F. M., Boyes, M. E., & Sherr, L. (2014). Cash plus care: Social protection cumulatively mitigates HIV-risk behaviour among adolescents in South Africa. *AIDS*, 28(Suppl 3), S389-S397.
- Cohen, J. H. (2004). *The culture of migration in southern Mexico*. Austin, TX: University of Texas Press.
- Cole, N. L. (2018, October 22). Studying race and gender with symbolic interaction theory. Retrieved from <https://www.thoughtco.com/symbolic-interaction-theory-application-to-race-and-gender-3026636>
- Coleman, C. H., Menikoff, J. A., Goldner, J. A., & Dubler, N. N. (2005). *The ethics and regulation of research with human subjects: Teacher's manual*. Newark, NJ: Lexis.
- Corbin, J., & Strauss, A. (1990). Grounded theory research: Procedures, canons and evaluative criteria. *Qualitative Sociology*, 13(1), 3-21.
- Corbin, J., & Strauss, A. (2008). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (3rd ed.). Thousand Oaks, CA: Sage.
- Creswell, J. W., & Plano Clark, V. L. (2017). *Designing and conducting mixed methods research* (3rd ed.). Los Angeles, CA: Sage.
- Crossman, A. (2017). An overview of qualitative research methods. *ThoughtCo*. Retrieved from <https://www.thoughtco.com/qualitative-research-methods-3026555>.
- Crowley, C., Harré, R., & Tagg, C. (2002). Qualitative research and computing: Methodological issues and practices in using QSR NVivo and NUD\* IST. *International Journal of Social Research Methodology*, 5(3), 193-197.
- Crowley, T., & Mayers, P. (2015). Trends in task shifting in HIV treatment in Africa: Effectiveness, challenges and acceptability to the health professions. *African Journal of Primary Health Care & Family Medicine*, 7(1), 1-9.
- Cunliffe, A. L. (2004). On becoming a critically reflexive practitioner. *Journal of Management Education*, 28(4), 407-426.

- Cusick, L., & Rhodes, T. (2000). Sustaining sexual safety in relationships: HIV positive people and their sexual partners. *Culture, Health & Sexuality*, 2(4), 473-487.
- David, A. M., Mercado, S. P., Becker, D., Edmundo, K., & Mugisha, F. (2007). The prevention and control of HIV/AIDS, TB and vector-borne diseases in informal settlements: Challenges, opportunities and insights. *Journal of Urban Health*, 84(1), 65-74.
- Degenova, M. K., Patton, D. M., Jurich, J. A., & MacDermid, S. M. (1994). Ways of coping among HIV-infected individuals. *Journal of Social Psychology*, 134(5), 655-663.
- DeLamater, J. D., & Hyde, J. S. (1998). Essentialism vs. social constructionism in the study of human sexuality. *Journal of Sex Research*, 35(1), 10-18.
- Dellar, R. C., Dlamini, S., & Karim, Q. A. (2015). Adolescent girls and young women: Key populations for HIV epidemic control. *Journal of the International AIDS Society*, 18(2S1), 64-70.
- Dey, I. (2007). Grounding categories. In A. Bryant, & K. Charmaz (Eds), *The Sage handbook of grounded theory* (pp 167-191). London, England: Sage.
- Diener, E., & Diener, M. (2009). Cross-cultural correlates of life satisfaction and self-esteem. In E. Diener (Ed.), *Culture and well-being* (pp. 71-91). Dordrecht, The Netherlands: Springer.
- Dilorio, C., Dudley, W. N., Kelly, M., Soet, J. E., Mbwara, J., & Potter, J. S. (2001). Social cognitive correlates of sexual experience and condom use among 13-through 15-year-old adolescents. *Journal of Adolescent Health*, 29(3), 208-216.
- Drimie, S. (2002). *The impact of HIV/AIDS on rural households and land issues in Southern and Eastern Africa*. A background paper prepared for the Food and Agricultural Organization, Sub-Regional Office for Southern and Eastern Africa. Retrieved from <http://www.fao.org/3/a-ad696e.pdf>
- Drimie, S. & Casale, M. (2009). Multiple stressors in Southern Africa: The link between HIV/AIDS, food insecurity, poverty and children's vulnerability now and in the future. *AIDS Care*, 21(sup1), 28-33, DOI: 10.1080/09540120902942931
- Duffy, K., Ferguson, C., & Watson, H. (2004). Data collecting in grounded theory—some practical issues. *Nurse Researcher*, 11(4), 67.
- Eaton, L., Flisher, A. J., & Aarø, L. E. (2003). Unsafe sexual behaviour in South African youth. *Social Science & Medicine*, 56(1), 149-165.

- Edirisingha, P. (2012). Interpretivism and positivism (ontological and epistemological perspectives). *Research Paradigms & Approaches*. Retrieved from <https://prabash78.wordpress.com/2012/03/14/interpretivism-and-positivism-ontological-and-epistemological-perspectives/>
- Ekstrand, M. L., Bharat, S., Ramakrishna, J., & Heylen, E. (2012). Blame, symbolic stigma and HIV misconceptions are associated with support for coercive measures in urban India. *AIDS & Behavior, 16*(3), 700-710.
- Elden, S. (2007). There is a politics of space because space is political: Henri Lefebvre and the production of space. *Radical Philosophy Review, 10*(2), 101-116.
- Ember, C. R. (Ed.). (2006). *Discovering anthropology: Researchers at work-cultural anthropology*. Upper Saddle River, NJ: Pearson Prentice Hall.
- Eriksson, M., & Emmelin, M. (2013). What constitutes a health-enabling neighborhood? A grounded theory situational analysis addressing the significance of social capital and gender. *Social Science & Medicine, 97*, 112-123.
- Erulkar, A., & Matheka, J. K. (2007). *Adolescence in the Kibera slums of Nairobi, Kenya*. Nairobi, Kenya: Population Council.
- Fassin, D. (2014). The ethical turn in anthropology: Promises and uncertainties. *HAU: Journal of Ethnographic Theory, 4*(1), 429-435.
- Fineman, M. A. (2010). The vulnerable subject: Anchoring equality in the human condition. In M. A. Fineman (Ed.), *Transcending the boundaries of law: Generations of feminism and legal theory* (pp. 177-191). London, England: Routledge-Cavendish.
- Finn, V. K., & Mikheyenkova, M. A. (2011). Plausible reasoning for the problems of cognitive sociology. *Logic & Logical Philosophy, 20*(1-2), 111-137.
- Fitzpatrick, K., & LaGory, M. (2002). *Unhealthy places: The ecology of risk in the urban landscape*. New York, NY: Routledge.
- Floersch, J., Longhofer, J. L., Kranke, D., & Townsend, L. (2010). Integrating thematic, grounded theory and narrative analysis: A case study of adolescent psychotropic treatment. *Qualitative Social Work, 9*(3), 407-425.
- Fossey, E., Harvey, C., McDermott, F., & Davidson, L. (2002). Understanding and evaluating qualitative research. *Australian & New Zealand Journal of Psychiatry, 36*(6), 717-732.



- Freshwater, D. (2009). A thousand words paint a picture: The use of storyline in grounded theory research. *Journal of Research in Nursing, 14*(5), 419-420.
- Galdas, P. (2017). *Revisiting bias in qualitative research: Reflections on its relationship with funding and impact*. Los Angeles, CA: Sage.
- Gibbs, A., Sikweyiya, Y., & Jewkes, R. (2014). ‘Men value their dignity’: Securing respect and identity construction in urban informal settlements in South Africa. *Global Health Action, 7*(1), 23676.
- Glanz, K., & Bishop, D. B. (2010). The role of behavioral science theory in development and implementation of public health interventions. *Annual Review of Public Health, 31*, 399-418.
- Glaser, B. G. (1978). *Advances in the methodology of grounded theory: Theoretical sensitivity*. Mill Valley, CA: Sociology Press.
- Glaser, B. G. (1992). *Basics of grounded theory analysis: Emergence vs forcing*. Mill Valley, CA: Sociology Press.
- Glaser, B. G. (2005). *The grounded theory perspective III: Theoretical coding*. Mill Valley, CA: Sociology Press.
- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago, IL: Aldine.
- Glen-Spyron, C. (2009). *Risky sexual behaviour in adolescence*. Washington, DC: Prime Press.
- Godin, G., & Kok, G. (1996). The theory of planned behavior: A review of its applications to health-related behaviors. *American Journal of Health Promotion, 11*(2), 87-98.
- Granich, R., Williams, B., Montaner, J., & Zuniga, J. M. (2017). 90-90-90 and ending AIDS: Necessary and feasible. *The Lancet, 390*(10092), 341-343.
- Grunbaum, J. A., Kann, L., Kinchen, S., Ross, J., Hawkins, J., Lowry, R., ..., Collins, J. (2004). Youth risk behavior surveillance—United States, 2003. *Morbidity & Mortality Weekly Report, 53*(2), 1-96.
- Guetterman, T. C. (2015). Descriptions of sampling practices within five approaches to qualitative research in education and the health sciences. *Forum: Qualitative Social Research, 16*(2), Art 25.
- Gupta, N., Kemelgor, C., Fuchs, S., & Etzkowitz, H. (2005). Triple burden on women in science: A cross-cultural analysis. *Current Science, 89*(8), 1382-1386.

- Haque, N., & Eng, B. (2011). Tackling inequity through a photovoice project on the social determinants of health: Translating photovoice evidence to community action. *Global Health Promotion, 18*(1), 16-19.
- Hartling, L. (2007). Humiliation: Real pain, a pathway to violence. *Revista Brasileira de Sociologia da Emocao, 6*(17), 276-290.
- Hartling, L. M., Lindner, E., Spalthoff, U., & Britton, M. (2013). Humiliation: A nuclear bomb of emotions? *Psicologia Politica, 46*, 55-76.
- Henwood, K., & Pidgeon, N. (2006). Grounded theory. In G. M. Breakwell, S. Hammond, C. Fife-Schaw, & J. A. Smith (Eds.), *Research methods in psychology* (3rd ed., pp. 342-365). Thousand Oaks, CA: Sage.
- Higgins, J. A., Hoffman, S., & Dworkin, S. L. (2010). Rethinking gender, heterosexual men, and women's vulnerability to HIV/AIDS. *American Journal of Public Health, 100*(3), 435-445.
- Hilhorst, D., & Jansen, B. J. (2010). Humanitarian space as arena: A perspective on the everyday politics of aid. *Development & Change, 41*(6), 1117-1139.
- Hogan, T. P., & Palmer, C. L. (2005). Information preferences and practices among people living with HIV/AIDS: Results from a nationwide survey. *Journal of the Medical Library Association, 93*(4), 431.
- Holloway, I., & Freshwater, D. (2007). Vulnerable story telling: Narrative research in nursing. *Journal of Research in Nursing, 12*(6), 703-711.
- Holschneider, S. O., & Alexander, C. S. (2003). Social and psychological influences on HIV preventive behaviors of youth in Haiti. *Journal of Adolescent Health, 33*(1), 31-40.
- Holton, J. A. (2007). The coding process and its challenges. In A. Bryant, & K. Charmaz (Eds.), *The Sage handbook of grounded theory* (pp. 265-289). Thousand Oaks, CA: Sage.
- Holtz, C. S., Sowell, R., & Velasquez, G. (2012). Oaxacan women with HIV/AIDS: Resiliency in the face of poverty, stigma, and social isolation. *Women & Health, 52*(6), 517-535. doi:10.1080/03630242.2012.690839
- Horsburgh, D. (2003). Evaluation of qualitative research. *Journal of Clinical Nursing, 12*(2), 307-312.
- Horwood, C., & Reitano, T. (2016). A Perfect Storm? Forces shaping modern migration and displacement. In *RMMS Discussion Paper no. 3*. Nairobi, Kenya: Regional Mixed Migration Secretariat (RMMS).

- House, E. R. (1991). Realism in research. *Educational Researcher*, 20(6), 2-9.
- Hudson, L. A., & Ozanne, J. L. (1988). Alternative ways of seeking knowledge in consumer research. *Journal of Consumer Research*, 14(4), 508-521.
- Humphries, V. (2013, April 30). Improving humanitarian coordination: Common challenges and lessons learned from the cluster approach. *Journal of Humanitarian Assistance*. Retrieved from <http://sites.tufts.edu/jha/archives/1976>
- Hurd, T. L. (1998). Process, content, and feminist reflexivity: One researcher's exploration. *Journal of Adult Development*, 5(3), 195-203.
- International Organization for Migration—see IOM.
- IOM (2013). *A study on health vulnerabilities of urban migrants in greater Nairobi*. Nairobi, Kenya: Author.
- Isiugo-Abanihe, U. C. (2003). *Male role and responsibility in fertility and reproductive health in Nigeria*. Orogun, Nigeria: Centre for Population Activities and Education for Development.
- Izulla, P., McKinnon, L. R., Munyao, J., Karanja, S., Koima, W., Parmeres, J., ..., Kimani, J. (2013). HIV postexposure prophylaxis in an urban population of female sex workers in Nairobi, Kenya. *Journal of Acquired Immune Deficiency Syndromes*, 62(2), 220-225.
- Jenkins, R. (2000). Categorization: Identity, social process and epistemology. *Current Sociology*, 48(3), 7-25.
- Jewkes, R., & Morrell, R. (2010). Gender and sexuality: Emerging perspectives from the heterosexual epidemic in South Africa and implications for HIV risk and prevention. *Journal of the International AIDS Society*, 13(1), 6.
- Joint United Nations Programme on HIV/AIDS—see UNAIDS.
- Jones, G. (2016). *HIV and young people: Risk and resilience in the urban slum*. Dordrecht, The Netherlands: Springer.
- Jorgenson, A. K., & Rice, J. (2012). Urban slums and children's health in less-developed countries. *Journal of World-Systems Research*, 18(1), 103-115.
- Kabiru, C. W., Beguy, D., Crichton, J., & Zulu, E. M. (2011). HIV/AIDS among youth in urban informal (slum) settlements in Kenya: What are the correlates of and motivations for HIV testing? *BMC Public Health*, 11(1), 685.
- Kabiru, C. W., Beguy, D., Undie, C.-C., Zulu, E. M., & Ezech, A. C. (2010). Transition into first sex among adolescents in slum and non-slum communities in Nairobi, Kenya. *Journal of Youth Studies*, 13(4), 453-471.

- Kahneman, D., & Krueger, A. B. (2006). Developments in the measurement of subjective well-being. *Journal of Economic Perspectives*, 20(1), 3-24.
- Kar, S. K., Choudhury, A., & Singh, A. P. (2015). Understanding normal development of adolescent sexuality: A bumpy ride. *Journal of Human Reproductive Sciences*, 8(2), 70-74. doi:10.4103/0974-1208.158594
- Kebede, W. (2012). Women, social networks, and HIV. *Journal of Community Practice*, 20(1-2), 52-68. doi:10.1080/10705422.2012.648077
- Kenya National Bureau of Statistics. (2009). *Population and housing census*. Retrieved from [http://www.knbs.or.ke/index.php?option=com\\_phocadownload&view=category&id=109:population-and-housing-census-2009&itemid=599](http://www.knbs.or.ke/index.php?option=com_phocadownload&view=category&id=109:population-and-housing-census-2009&itemid=599)
- Kenya National Data Archive (KeNADA). (2015). *Kenya AIDS indicator survey*. Retrieved from <http://statistics.knbs.or.ke/nada/index.php>
- Kidd, S. A., & Kral, M. J. (2005). Practicing participatory action research. *Journal of Counseling Psychology*, 52(2), 187.
- Kim, J. (2016). The effect of peers on HIV infection expectations among Malawian adolescents: Using an instrumental variables/school fixed effect approach. *Social Science & Medicine*, 152, 61-69. doi:10.1016/j.socscimed.2016.01.036
- Kim, S.-H., Gerver, S. M., Fidler, S., & Ward, H. (2014). Adherence to antiretroviral therapy in adolescents living with HIV: Systematic review and meta-analysis. *AIDS*, 28(13), 1945-1956. doi:10.1097/QAD.0000000000000316
- Kimuna, S. R., & Djamba, Y. K. (2012). Migration, sexual behavior and perceptions of risk: Is the place of origin a factor in HIV infection? *Advances in Applied Sociology*, 2(3), 67-178.
- King, R. (1999). *Sexual behavioural change for HIV: Where have theories taken us?* Geneva, Switzerland: UNAIDS.
- King, R., Katuntu, D., Lifshay, J., Packel, L., Batamwita, R., Nakayiwa, S., ..., Bunnell, R. (2008). Processes and outcomes of HIV serostatus disclosure to sexual partners among people living with HIV in Uganda. *AIDS & Behavior*, 12(2), 232-243. doi:10.1007/s10461-007-9307-7
- Kingori, P., & Sariola, S. (2015). Museum of failed HIV research. *Anthropology & Medicine*, 22(3), 213-216. doi:10.1080/13648470.2015.1079302
- Kirby, D. B., Laris, B. A., & Rolleri, L. A. (2007). Sex and HIV education programs: Their impact on sexual behaviors of young people throughout the world. *Journal*

- of Adolescent Health*, 40(3), 206-217.  
doi:<https://doi.org/10.1016/j.jadohealth.2006.11.143>
- Kompa, J. S. (2013). *An introduction to grounded theory and phenomenology*. Retrieved from <https://joanakompa.com/2013/08/01/an-introduction-to-grounded-theory-and-phenomenology/>
- Krakowiak, D. (2016). *Effectiveness of home-based HIV testing and education among partners of pregnant women in Kenya: A mixed methods approach* (PhD thesis, University of Washington). Retrieved from <https://digital.lib.washington.edu/researchworks/handle/1773/35201>
- Krause, D. D., & May, W. L. (2016). Is it a trust issue? Factors that influence trust for persons living with HIV/AIDS. *Health Promotion Practice*, 17(5), 711-721.
- Krieger, N. (2001). Theories for social epidemiology in the 21st century: An ecosocial perspective. *International Journal of Epidemiology*, 30(4), 668-677.
- Krishnan, S., Dunbar, M. S., Minnis, A. M., Medlin, C. A., Gerds, C. E., & Padian, N. S. (2008). Poverty, gender inequities, and women's risk of human immunodeficiency virus/AIDS. *Annals of the New York Academy of Sciences*, 1136(1), 101-110.
- Kyobutungi, C., Ziraba, A. K., Ezeh, A., & Yé, Y. (2008). The burden of disease profile of residents of Nairobi's slums: Results from a Demographic Surveillance System. *Population Health Metrics*, 6(1), 1.
- LaMorte, W. (2016). *The health belief model: Behavioral change models*. Boston University School of Public Health. Retrieved from <http://sphweb.bumc.bu.edu/otlt/MPH-Modules/SB/BehavioralChangeTheories/index.html>
- Larson, B., Schnippel, K., Ndibongo, B., Xulu, T., Brennan, A., Long, L., ..., Rosen, S. (2012). Rapid point-of-care CD4 testing at mobile HIV testing sites to increase linkage to care: An evaluation of a pilot program in South Africa. *Journal of Acquired Immune Deficiency Syndromes*, 61(2), e13.
- Law, J., & Hassard, J. (1999). *Actor network theory and after*. Oxford, England: Blackwell.
- Lee, J. J. H., Helke, J., & Laczko, F. (2015). *World migration report 2015*. Retrieved from <https://www.iom.int/world-migration-report-2015>
- Lee, L., Yehia, B. R., Gaur, A. H., Rutstein, R., Gebo, K., Keruly, J. C., ..., Agwu, A. L. (2016). The impact of youth-friendly structures of care on retention among

- HIV-infected youth. *AIDS Patient Care & STDs*, 30(4), 170-177.  
doi:10.1089/apc.2015.0263
- Leeds-Hurwitz, W. (2009). *Social construction of reality* (Vol. 2). Thousand Oaks, CA: Sage.
- Leedy, P., & Ormrod, J. (2013). The nature and tools of research. *Practical Research: Planning & Design*, 1, 1-26.
- Letherby, G. (2002). Claims and disclaimers: Knowledge, reflexivity and representation in feminist research. *Sociological Research Online*, 6(4), 1-13.
- Lever, S. (2010, May 30). *Personal resilience*. Retrieved from <http://www.refreshers.com/personal-resilience/>
- Liang, T. S., Erbelding, E., Jacob, C. A., Wicker, H., Christmyer, C., Brunson, S., . . . Ellen, J. M. (2005). Rapid HIV testing of clients of a mobile STD/HIV clinic. *AIDS Patient Care & STDs*, 19(4), 253-257.
- Lindberg, H., & Stensöta, H. (2018). Corruption as exploitation: Feminist exchange theories and the link between gender and corruption. In: H. Stensöta, & L. Wängnerud (Eds) *Gender and corruption. Political corruption and governance* (pp. 237-256). Cham, Switzerland: Palgrave Macmillan.
- Lindner, E. (2009). *Emotion and conflict: How human rights can dignify emotion and help us wage good conflict*. Westport, CT: Praeger.
- Lindner, E. (2010). *Gender, humiliation, and global security: Dignifying relationships from love, sex, and parenthood to world affairs*. Santa Barbara, CA: Praeger.
- Lindner, E. (2012). *A dignity economy: Creating an economy that serves human dignity and preserves our planet*. Lake Oswego, OR: Dignity Press.
- Litzinger, S., & Gordon, K. C. (2005). Exploring relationships among communication, sexual satisfaction, and marital satisfaction. *Journal of Sex & Marital Therapy*, 31(5), 409-424.
- Ludi, E., & Bird, K. (2007, September). *Brief no. 3: Risks & vulnerability*. Retrieved from <https://www.odi.org/sites/odi.org.uk/files/odi-assets/publications-opinion-files/5680.pdf>
- Luke, N. (2005). Confronting the 'sugar daddy' stereotype: Age and economic asymmetries and risky sexual behavior in urban Kenya. *International Family Planning Perspectives*, 31(1), 6-14.

- Luke, N., Xu, H., Mberu, B. U., & Goldberg, R. E. (2012). Migration experience and premarital sexual initiation in urban Kenya: An event history analysis. *Studies in Family Planning*, 43(2), 115-126.
- Macarthur, D. (2008). Pragmatism, metaphysical quietism, and the problem of normativity. *Philosophical Topics*, 36(1), 193-209.
- Machado, D. M., Galano, E., de Menezes Succi, R. C., Vieira, C. M., & Turato, E. R. (2016). Adolescents growing with HIV/AIDS: Experiences of the transition from pediatrics to adult care. *Brazilian Journal of Infectious Diseases*, 20(3), 229-234.
- MacPhail, C., & Campbell, C. (2001). 'I think condoms are good but, aai, I hate those things': Condom use among adolescents and young people in a Southern African township. *Social Science & Medicine*, 52(11), 1613-1627.
- Madiba, S., & Ngwenya, N. (2017). Cultural practices, gender inequality and inconsistent condom use increase vulnerability to HIV infection: Narratives from married and cohabiting women in rural communities in Mpumalanga province, South Africa. *Global Health Action*, 10(Suppl 2), 1341597. doi:10.1080/16549716.2017.1341597
- Madise, N. J., Ziraba, A. K., Inungu, J., Khamadi, S. A., Ezeh, A., Zulu, E. M., ..., Mwau, M. (2012). Are slum dwellers at heightened risk of HIV infection than other urban residents? Evidence from population-based HIV prevalence surveys in Kenya. *Health & Place*, 18(5), 1144-1152.
- Mahabir, R., Crooks, A., Croitoru, A., & Agouris, P. (2016). The study of slums as social and physical constructs: Challenges and emerging research opportunities. *Regional Studies, Regional Science*, 3(1), 399-419.
- Marmot, M., Friel, S., Bell, R., Houweling T. A., & Taylor, S. (2008). Closing the gap in a generation: Health equity through action on the social determinants of health. *The Lancet*, 372(9650), 1661-1669.
- Marston, M., Beguy, D., Kabiru, C., & Cleland, J. (2013). Predictors of sexual debut among young adolescents in Nairobi's informal settlements. *International Perspectives on Sexual & Reproductive Health*, 39(1), 22.
- Mason, M. (2010). Sample size and saturation in PhD studies using qualitative interviews. *Forum Qualitative Social Research. Volume 11(3)*, Art, 8 – September 2010.

- Mathar, T. (2008). Review essay: Making a mess with situational analysis? *Forum: Qualitative Social Research*, 9(2). Retrieved from <http://www.qualitative-research.net/index.php/fqs/article/view/432>
- Matovu, J. K. B., Wanyenze, R. K., Wabwire-Mangen, F., Nakubulwa, R., Sekamwa, R., Masika, A., ..., Serwadda, D. (2014). 'Men are always scared to test with their partners ... it is like taking them to the police': Motivations for and barriers to couples' HIV counselling and testing in Rakai, Uganda: A qualitative study. *Journal of the International AIDS Society*, 17(1), 19160. doi:10.7448/IAS.17.1.19160
- Mberu, B. (2012). *Adolescent sexual and reproductive health and rights: Research evidence from sub-Saharan Africa*. Paper presented at the Inter-Ministerial Conference on 'Evidence for Action: South-South Collaboration for ICPD beyond 2014'. 10 November 2012, Dhaka, Bangladesh. Retrieved from <https://aphrc.org/backup/search/Blessing+Mberu>
- Mberu, B., Mumah, J., Kabiru, C., & Brinton, J. (2014). Bringing sexual and reproductive health in the urban contexts to the forefront of the development agenda: The case for prioritizing the urban poor. *Maternal & Child Health Journal*, 18(7), 1572-1577.
- McFall, L., Du Gay, P., & Carter, S. (Eds.) (2008). *Conduct: Sociology and social worlds*. Manchester, UK: Manchester University Press.
- McLachlan, C. J., & Garcia, R. J. (2015). Philosophy in practice? Doctoral struggles with ontology and subjectivity in qualitative interviewing. *Management Learning*, 46(2), 195-210.
- Meyer-Weitz, A. (2005). Understanding fatalism in HIV/AIDS protection: The individual in dialogue with contextual factors. *African Journal of AIDS Research*, 4(2), 75-82.
- Miller, J., Glassner, B., & Silverman, D. (2016). The 'Inside' and the 'Outside'; finding realities in interviews. In D. Silverman (Ed.) *Qualitative research*. (pp. 51-66). London, England: Sage.
- Miller-Thayer, J. (2010). Health migration: Crossing borders for affordable health care. *Field Actions Science Reports* (Special Issue 2). Retrieved from <http://factsreports.revues.org/503>
- Mills, J., & Birks, M. (2014). *Qualitative methodology: A practical guide*. London, England: Sage.



- Min-Harris, C. (2010). Youth migration and poverty in Sub-Saharan Africa: Empowering the rural youth. *Topical Review Digest: Human Rights in Sub-Saharan Africa*. Retrieved from <https://www.du.edu/korbel/hrhw/researchdigest/africa/YouthMigration.pdf>
- Ministry of Health (2012). *Kenya AIDS Indicator Survey*. Nairobi, Kenya: Author.
- Ministry of Health (2014). *Kenya AIDS Strategic Framework 2014/2015-2018/2019*. Nairobi, Kenya: Author.
- Ministry of Health (2015). *Adolescent and Sexual Health fact sheet in Nairobi County*. Nairobi, Kenya: Author.
- Moery, C., Preusse, K., & Meek, S. (2014). The role of intent in deception. *George Manuel and Dr. Cole Cheek Spartanburg Methodist College*, 1-195. Retrieved from [https://www.researchgate.net/publication/261925741\\_The\\_Role\\_of\\_Intent\\_in\\_Deception](https://www.researchgate.net/publication/261925741_The_Role_of_Intent_in_Deception)
- Mohanty, C. T. (2003). *Feminism without borders: Decolonizing theory, practicing solidarity*. New Delhi, India: Zubaan.
- Montano, D. E., & Kasprzyk, D. (2015). Theory of reasoned action, theory of planned behavior, and the integrated behavioral model. In K. Glanz, B. K. Rimer, & K. Viswanath (Eds.), *Health behavior: Theory, research and practice* (5th ed., pp. 95-124). San Francisco, CA: Jossey-Bass.
- Montgomery, C. M., Lees, S., Stadler, J., Morar, N. S., Ssali, A., Mwanza, B., ..., Pool, R. (2008). The role of partnership dynamics in determining the acceptability of condoms and microbicides. *AIDS Care*, 20(6), 733-740.  
doi:10.1080/09540120701693974
- Morrow, A., & Samir, N. (2009). *Combating HIV/AIDS related stigma in Egypt: Situation analysis and advocacy recommendations*. Cairo, Egypt: Egyptian Anti-Stigma Forum.
- Morse, J. M. (2010). Sampling in grounded theory. In A. Bryant and K. Charmaz (Eds), *The Sage handbook of grounded theory* (pp 229-244). London, England: Sage.
- Moss, M. (2017, April 7). *The advantages and disadvantages of mixed methodology research*. Retrieved from <https://penandthepad.com/advantages-disadvantages-mixed-methodology-research-4263.html>

- Moyo, N., & Müller, J. C. (2011). The influence of cultural practices on the HIV and AIDS pandemic in Zambia. *HTS Theological Studies*, 67(3), 1-5.  
doi:10.4102/hts.v67i3.770
- Mwale, M., & Muula, A. (2017). Systematic review: A review of adolescent behavior change interventions [BCI] and their effectiveness in HIV and AIDS prevention in sub-Saharan Africa. *BMC Public Health*, 17(1), 718. doi:10.1186/s12889-017-4729-2
- National AIDS Control Council, (2015). *National AIDS Control Council research agenda, 2015–2018*. Nairobi, Kenya: Author.
- Naur, M. (2001). *Indigenous knowledge and HIV/AIDS: Ghana and Zambia*. Retrieved from <https://openknowledge.worldbank.org/bitstream/handle/10986/10808/multi0page.pdf?sequence=1>
- Navarro, V. (2007). Neoliberalism as a class ideology; or, the political causes of the growth of inequalities. *International Journal of Health Services*, 37(1), 47-62.
- Neuman, W. L. (2002). *Social research methods: Qualitative and quantitative approaches* (5th ed.). Boston, MA: Allyn and Bacon.
- Neuman, W. L. (2012). Designing the face-to-face survey. In G. L (Ed.), *Handbook of survey methodology for the social sciences* (pp. 227-248). New York, NY: Springer.
- Ngulube, P., & Ngulube, B. (2017). Application and contribution of hermeneutic and eidetic phenomenology to indigenous knowledge research. In *Handbook of research on theoretical perspectives on Indigenous knowledge systems in developing countries* (pp. 127-155): IGI Global.  
doi: 10.4018/978-1-5225-0833-5.ch006
- Nöstlinger, C., & Loos, J. (2018). Migration patterns and HIV prevention in Uganda. *The Lancet HIV*, 5(4), e158-e160.
- Okal, J., Luchters, S., Geibel, S., Chersich, M. F., Lango, D., & Temmerman, M. (2009). Social context, sexual risk perceptions and stigma: HIV vulnerability among male sex workers in Mombasa, Kenya. *Culture, Health & Sexuality*, 11(8), 811-826.
- Okwunde, C. I., Uthman, O. A. Okoromah, C. (2012). Antiretroviral pre exposure prophylaxis (PrEP) for preventing HIV in high-risk individuals. *Cochrane*

- Database of Systematic Reviews 2012*, 7, ART. No. CD007189. Doi: 10.1002/14651858.CD007189.pub3.
- Omran, A. R. (2005). The epidemiologic transition: A theory of the epidemiology of population change. *Milbank Quarterly*, 83(4), 731-757.
- Onoya, D., Zuma, K., Zungu, N., Shisana, O., & Mehlomakhulu, V. (2014). Determinants of multiple sexual partnerships in South Africa. *Journal of Public Health*, 37(1), 97-106. doi:10.1093/pubmed/fdu010
- O'Sullivan, L. F., Harrison, A., Morrell, R., Monroe-Wise, A., & Kubeka, M. (2006). Gender dynamics in the primary sexual relationships of young rural South African women and men. *Culture, Health & Sexuality*, 8(02), 99-113.
- Palermo, T., Bleck, J., & Peterman, A. (2013). Tip of the iceberg: Reporting and gender-based violence in developing countries. *American Journal of Epidemiology*, 179(5), 602-612.
- Parker, R., Barbosa, R. M., & Aggleton, P. (Eds.). (2000). *Framing the sexual subject: The politics of gender, sexuality, and power*. Berkeley, CA: University of California Press.
- Parsons, J. T., Halkitis, P. N., Bimbi, D., & Borkowski, T. (2000). Perceptions of the benefits and costs associated with condom use and unprotected sex among late adolescent college students. *Journal of Adolescence*, 23(4), 377-391.
- Pauketat, J. (2013). *Honor and dignity culture differences in the concept of worth: Consequences for response to group insults*. Masters Dissertation. University of California, Santa Barbara. Retrieved from <https://alexandria.ucsb.edu/lib/ark:/48907/f37d2s7h>
- Payne, G., & Payne, J. (2004). *Key concepts in social research*. London, England: Sage.
- Payne, Y. A. (2011). Site of resilience: A reconceptualization of resiliency and resilience in street life-oriented Black men. *Journal of Black Psychology*, 37(4), 426-451.
- Pellowski, J. A., Kalichman, S. C., Matthews, K. A., & Adler, N. (2013). A pandemic of the poor: Social disadvantage and the US HIV epidemic. *American Psychologist*, 68(4), 197-209. doi:10.1037/a0032694
- Perkel, A. K., Strebel, A., & Joubert, G. (1991). The psychology of AIDS transmission—issues for intervention. *South African Journal of Psychology*, 21(3), 148-152.
- Pink, S. (2013). *Doing visual ethnography* (3rd ed.). London, England: Sage.

- Plummer, D. (2011). Masculinity+ HIV= risk: Exploring the relationship between masculinities, education and HIV in the Caribbean. In J. Klot & V.-K. Nguyen (Eds.), *The fourth wave: Violence, gender, culture & HIV in the 21st Century* (pp. 139-156). Paris, France: UNESCO.
- Plummer, D., & McLean, A. (2010). The price of prejudice: The corrosive effect of HIV-related stigma on individuals and society. In M. Morrissey, M. Bernard, & D. Bundy (Eds.), *Challenging HIV and AIDS: A new role for Caribbean education* (pp. 232-239). Miami, FL: UNESCO Office Kingston/Ian Randle Publishers.
- Porter, S. E., & Robinson, J. C. (2011). *Hermeneutics: An introduction to interpretive theory*. Grand Rapids, MI: William. B. Eerdmans Publishing.
- Powers, T. (2017). Pathways, intersections, and hotspots. *Medicine Anthropology Theory*, 4(5), 73-98.
- Ragnarsson, A., Onya, H. E., Thorson, A., Ekström, A. M., & Aarø, L. E. (2008). Young males' gendered sexuality in the era of HIV and AIDS in Limpopo Province, South Africa. *Qualitative Health Research*, 18(6), 739-746.
- Ramalho, R., Adams, P., Huggard, P., & Hoare, K. (2015). Literature review and constructivist grounded theory methodology. *Forum: Qualitative Social Research*, 16(3). Retrieved from <http://www.qualitative-research.net/index.php/fqs/article/view/2313>
- Rao, D., Kekwaletswe, T., Hosek, S., Martinez, J., & Rodriguez, F. (2007). Stigma and social barriers to medication adherence with urban youth living with HIV. *AIDS Care*, 19(1), 28-33.
- Rice, F. P., & Dolgin, K. G. (2005). *The adolescent: Development, relationships and culture* (11th ed.). Boston, MA: Pearson.
- Richey, L. A. (2003). HIV/AIDS in the shadows of reproductive health interventions. *Reproductive Health Matters*, 11(22), 30-35.
- Ritzer, G. (2008). *Sociological theory, from modern to postmodern social theory (and beyond)*. New York, NY: McGraw-Hill Higher Education.
- Robson, C. (2002). *Real world research: A resource for social scientists and practitioner-researchers* (2nd ed.). Malden, MA: Blackwell.
- Roffee, J. A., & Waling, A. (2017). Resolving ethical challenges when researching with minority and vulnerable populations: LGBTIQ victims of violence, harassment and bullying. *Research Ethics*, 13(1), 4-22.

- Rolfe, G. (2006). Validity, trustworthiness and rigour: quality and the idea of qualitative research. *Journal of Advanced Nursing*, 53(3), 304-310.
- Rosenthal, D., Moore, S., & Flynn, I. (1991). Adolescent self-efficacy, self-esteem and sexual risk-taking. *Journal of Community & Applied Social Psychology*, 1(2), 77-88.
- Rowley, J. (2012). Conducting research interviews. *Management Research Review*, 35(3/4), 260-271.
- Russell, A. (2014). A comment on gerunds: Realizing the researcher's process. *Grounded Theory Review*, 13(2). Retrieved from <http://groundedtheoryreview.com/wp-content/uploads/2014/12/A-COMMENT-ON-GERUNDS-2014.pdf>
- Ryan, G. W., & Bernard, H. R. (2003). Techniques to identify themes. *Field Methods*, 15(1), 85-109.
- Sales, A. (2012). Introduction. In A. Sales (Ed) *Sociology today: Social transformations in a globalizing world* (pp 1-41). Thousand Oaks, CA: Sage.
- Samson, A. (2014). *The behavioral economics guide 2014*. Retrieved from <http://www.behavioraleconomics.com>
- Sbaraini, A., Carter, S. M., Evans, R. W., & Blinkhorn, A. (2011). How to do a grounded theory study: A worked example of a study of dental practices. *BMC Medical Research Methodology*, 11(1), 128.
- Schiffman, J., Darmstadt, G. L., Agarwal, S., & Baqui, A. H. (2010). Community-based intervention packages for improving perinatal health in developing countries: A review of the evidence. *Seminars in Perinatology*, 34(6), 462-476.
- Schimmack, U., Schupp, J., & Wagner, G. G. (2008). The influence of environment and personality on the affective and cognitive component of subjective well-being. *Social Indicators Research*, 89(1), 41-60.
- Scorgie, F., Vearey, J., Oliff, M., Stadler, J., Venalbes, E., Chersich, M., Delany-Moretlwe, S. (2017). 'Leaving no one behind'. Reflections on the design of community-based HIV prevention for migrants in Johannesburg's inner-city hostels and informal settlements. *BMC Public Health*, 17(Suppl 3): 482. <https://doi.org/10.1186/s12889-017-4351-3>
- Shaw, S. A., & El-Bassel, N. (2014). The influence of religion on sexual HIV risk. *AIDS & Behavior*, 18(8), 1569-1594. doi:10.1007/s10461-014-0714-2

- Shearer, C. L., Hosterman, S. J., Gillen, M. M., & Lefkowitz, E. S. (2005). Are traditional gender role attitudes associated with risky sexual behavior and condom-related beliefs? *Sex Roles, 52*(5-6), 311-324.
- Sheldon, K. M., & Lucas, R. E. (Eds.). (2014). *Stability of happiness: Theories and evidence on whether happiness can change*. London, England: Elsevier.
- Sheldon, K. M., & Lyubomirsky, S. (2012). The challenge of staying happier: Testing the hedonic adaptation prevention model. *Personality & Social Psychology Bulletin, 38*(5), 670-680.
- Shubber, Z., Mishra, S., Vesga, J. F., & Boily, M.-C. (2014). The HIV modes of transmission model: A systematic review of its findings and adherence to guidelines. *Journal of the International AIDS Society, 17*(18928). doi:10.7448/IAS.17.1.18928
- Singh, Z., & Banerjee, A. (2004). HIV/AIDS: Social and ethical issues. *Medical Journal, Armed Forces India, 60*(2), 107-108. doi:10.1016/S0377-1237(04)80096-0
- Slap, G. B., Lot, L., Huang, B., Daniyam, C. A., Zink, T. M., & Succop, P. A. (2003). Sexual behaviour of adolescents in Nigeria: Cross sectional survey of secondary school students. *British Medical Journal, 326*(7379), 15.
- Smith, D. J. (2003). Imagining HIV/AIDS: Morality and perceptions of personal risk in Nigeria. *Medical Anthropology, 22*(4), 343-372.
- Solar, O., & Irwin, A. (2010). *A conceptual framework for action on the social determinants of health*. Social Determinants of Health Discussion Paper 2 (Policy and Practice). Geneva, Switzerland: World Health Organization.
- Solomon, S. S., Mehta, S. H., Latimore, A., Srikrishnan, A. K., & Celentano, D. D. (2010). The impact of HIV and high-risk behaviours on the wives of married men who have sex with men and injection drug users: Implications for HIV prevention. *Journal of the International AIDS Society, 13*(Suppl 2), S7. doi:10.1186/1758-2652-13-s2-s7
- Spaulding, A. B., Brickley, D. B., Kennedy, C., Almers, L., Packel, L., Mirjahangir, J., . . . Mbizvo, M. (2009). Linking family planning with HIV/AIDS interventions: A systematic review of the evidence. *AIDS, 23*(Suppl 1), S79-S88.
- Speizer, I. S., Magnani, R. J., & Colvin, C. E. (2003). The effectiveness of adolescent reproductive health interventions in developing countries: A review of the evidence. *Journal of Adolescent Health, 33*(5), 324-348.

- Ssali, S. N., Atuyambe, L., Tumwine, C., Sequija, M. A., 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 & STDs*, 24(10), 675-681. doi:10.1089/apc.2010.0062
- Stangl, A. L., Lloyd, J. K., Brady, L. M., Holland, C. E., & Baral, S. (2013). A systematic review of interventions to reduce HIV-related stigma and discrimination from 2002 to 2013: How far have we come? *Journal of the International AIDS Society*, 16(Suppl 2), 18734. doi:10.7448/IAS.16.3.18734
- Steffenson, A. E., Pettifor, A. E., Seage III, G. R., Rees, H. V., & Cleary, P. D. (2011). Concurrent sexual partnerships and human immunodeficiency virus risk among South African youth. *Sexually Transmitted Diseases*, 38(6), 459.
- Sterk, C. E., Klein, H., & Elifson, K. W. (2005). Self-esteem and 'at risk' women: Determinants and relevance to sexual and HIV-related risk behaviors. *Women & Health*, 40(4), 75-92.
- Strauss, A., & Corbin, J. (1994). Grounded theory methodology: An overview. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 273-285). Thousand Oaks, CA: Sage.
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Procedures and techniques for developing grounded theory*: Thousand Oaks, CA: Sage.
- Strauss, A. L. (1987). *Qualitative analysis for social scientists*. New York, NY: Cambridge University Press.
- Strauss, A. L., & Corbin, J. (1990). *Basics of qualitative research*. Newbury Park, CA: Sage.
- Sultana, A. (2012). Patriarchy and women's subordination: A theoretical analysis. *Arts Faculty Journal*, 4, 1-18. doi:10.3329/afj.v4i0.12929
- Suphanchaimat, R., Sommanustweechai, A., Khitdee, C., Thaichinda, C., Kantamaturapoj, K., Leelahavarong, P., ..., Putthasri, W. (2014). HIV/AIDS health care challenges for cross-country migrants in low-and middle-income countries: A scoping review. *HIV/AIDS Research & Palliative Care*, 6, 19-38. doi:10.2147/HIV.S56277
- Suri, H. (2011). Purposeful sampling in qualitative research synthesis. *Qualitative Research Journal*, 11(2), 63-75.

- Taggart, T., Grewe, M. E., Conserve, D. F., Gliwa, C., & Isler, M. R. (2015). Social media and HIV: A systematic review of uses of social media in HIV communication. *Journal of Medical Internet Research*, *17*(11), e248.
- Timmermans, S., & Tavory, I. (2012). Theory construction in qualitative research: From grounded theory to abductive analysis. *Sociological Theory*, *30*(3), 167-186.
- Toews, I., Glenton, C., Lewin, S., Berg, R. C., Noyes, J., Booth, A., . . . Meerpohl, J. J. (2016). Extent, awareness and perception of dissemination bias in qualitative research: An explorative survey. *PLoS One*, *11*(8), e0159290.  
doi:10.1371/journal.pone.0159290
- Tomé, G., de Matos, M. G., Simões, C., Camacho, I., & AlvesDiniz, J. (2012). How can peer group influence the behavior of adolescents: Explanatory model. *Global Journal of Health Science*, *4*(2), 26-35.
- Tschann, J. M., Adler, N. E., Millstein, S. G., Gurvey, J. E., & Ellen, J. M. (2002). Relative power between sexual partners and condom use among adolescents. *Journal of Adolescent Health*, *31*(1), 17-25.
- Turok, I. (2013). Securing the resurgence of African cities. *Local Economy*, *28*(2), 142-157.
- UNAIDS. (2014a). *The cities report*. Retrieved from <http://www.unaids.org/en/resources/documents/2014/thecitiesreport>
- UNAIDS. (2014b). *Global AIDS progress report*. Geneva, Switzerland: Author.
- UNAIDS. (2014c). *Progress report on the global plan. Towards the elimination of new HIV infections among children by 2015 and keeping their mothers alive* (Report No. JC2681/1/E). Geneva, Switzerland: Author.
- UNAIDS. (2015). *On the fast track to end AIDS by 2030: Focus on location and population*. Geneva: UNAIDS, 2030.
- Vaillancourt, T., & Hymel, S. (2006). Aggression and social status: The moderating roles of sex and peer-valued characteristics. *Aggressive Behavior*, *32*(4), 396-408.
- Ven der Elst, E. M., Mbogua, J., Operario, D., Mutua, G., Kuo, C., Mugo, P. . . . Sanders, E. J. (2013). High acceptability of HIV pre-exposure prophylaxis but challenges in adherence and use: Qualitative insights from a phase 1 trial of intermittent and daily PrEP in at-risk-populations in Kenya. *AIDS & Behavior*, *17*(6), 2162-2172.

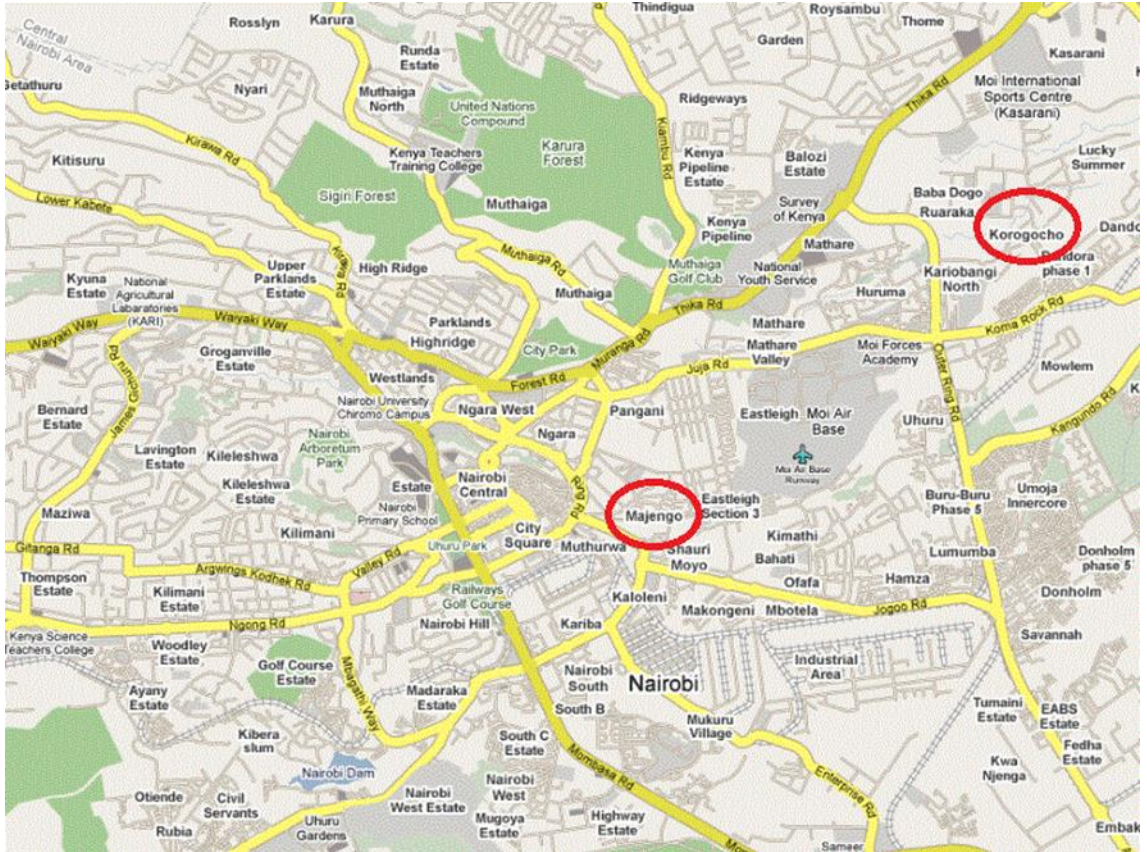


- Van der Elst, E. M., Gichuru, E., Muraguri, N., Musyoki, H., Micheni, M., Kombo, B., ..., Operario, D. (2015). Strengthening healthcare providers' skills to improve HIV services for MSM in Kenya. *AIDS*, 29(3), S237-240.
- Van Donk, M. (2006). 'Positive' urban futures in sub-Saharan Africa: HIV/AIDS and the need for ABC (a broader conceptualization). *Environment & Urbanization*, 18(1), 155-175.
- Varga, C. A. (2003). How gender roles influence sexual and reproductive health among South African adolescents. *Studies in Family Planning*, 34(3), 160-172.
- Vávrová, D. (2014). *'Skin has eyes and ears': audio-visual ethnography in a Sepik society*. PhD Thesis, James Cook University.
- Vearey, J. (2010). Hidden spaces and urban health: Exploring the tactics of rural migrants navigating the city of gold. *Urban Forum*, 21(1), 37-53.
- Veinot, T. C. (2009). Interactive acquisition and sharing: Understanding the dynamics of HIV/AIDS information networks. *Journal of the American Society for Information Science & Technology*, 60(11), 2313-2332.
- Vellem, V. S. (2013). The reformed tradition as public theology. *HTS Theological Studies*, 69(1), 1-5.
- Vlahov, D., Freudenberg, N., Proietti, F., Ompad, D., Quinn, A., Nandi, V., & Galea, S. (2007). Urban as a determinant of health. *Journal of Urban Health*, 84(1), 16-26.
- Volpp, L. (2000). Blaming culture for bad behavior. *Yale Journal of Law & the Humanities*, 12, 89-116.
- Walker, D., & Myrick, F. (2006). Grounded theory: An exploration of process and procedure. *Qualitative Health Research*, 16(4), 547-559.
- Wanyenze, R. K., Tumwesigye, N. M., Kindyomunda, R., Beyeza-Kashesya, J., Atuyambe, L., Kansiime, A., . . . Mirembe, F. (2011). Uptake of family planning methods and unplanned pregnancies among HIV-infected individuals: A cross-sectional survey among clients at HIV clinics in Uganda. *Journal of the International AIDS Society*, 14(1), 35.
- Welch, A. (2011). The challenge of comparative research: A critical introduction. In L. Markauskaite, P. Freebody, & J. Irwin (Eds), *Methodological prospects in the social sciences* (Vol. 9, pp. 187-201). Dordrecht, The Netherlands: Springer.

- WHO, & United Nations Human Settlements Programme (UN-HABITAT). (2010). *Hidden cities: Unmasking and overcoming health inequities in urban settings*. Geneva, Switzerland: WHO.
- Wild, L. G., Flisher, A. J., Bhana, A., & Lombard, C. (2004). Associations among adolescent risk behaviours and self-esteem in six domains. *Journal of Child Psychology & Psychiatry*, 45(8), 1454-1467.
- Willig, C. (2014). Marital discourse and condom use. In P. Aggleton, P. Davies, & G. Hart (Eds.), *AIDS: Foundations for the future* (pp. 118-130). London, England: Taylor & Francis.
- Wilson, G. (2001). Conceptual frameworks and emancipatory research in social gerontology. *Ageing & Society*, 21(4), 471-487.  
doi:10.1017/S0144686X01008315
- World Health Organization—see WHO.
- Zulu, E. M., Beguy, D., Ezeh, A. C., Bocquier, P., Madise, N. J., Cleland, J., & Falkingham, J. (2011). Overview of migration, poverty and health dynamics in Nairobi City's slum settlements. *Journal of Urban Health*, 88(2), 185-199.
- Zulu, E. M., Dadoo, F. N.-A., & Chika-Ezeh, A. (2002). Sexual risk-taking in the slums of Nairobi, Kenya, 1993–98. *Population Studies*, 56(3), 311-323.

# Appendices

## Appendix A: Map of Research Sites



## Appendix B: Data Generation Tools

### The Discussion Guide

#### 1. Interviewer introduction

*(Use if Gary Jones is not conducting interview)*

*My name is (insert name) and I am a research assistant for Gary Jones of James Cook University. Thank you for agreeing to talk to me.*

*Purpose: Introducing the interviewer to the participant; conveying important info.*

*Obtain permission to audio record.*

*Time allocation: 10 minutes*

Assurances: I would like to assure you of four things:

- 1) Everything you tell me is completely anonymous. When we write our report we will never identify you or anything you said. We will report only on an overall level.
- 2) You may discontinue participation at any time.
- 3) If at any time, you feel that you need emotional or other assistance as a result of participation in this study, please make contact with <insert name> and we will refer you to the relevant place to get help.
- 4) There are no right or wrong answers.

Audio recording: Would you mind if I make an audio recording of our discussion so that I have a record to go back to when we write our report? It will remain anonymous.

Lastly, before we begin, do you have any questions?

#### 2. Participant introduction

*Purpose: Establish rapport and broad context*

*Time allocation: 10 minutes*

Please tell me a little about yourself?

- What is the most difficult thing about living in <Korogocho/Majengo >?
- What is the best thing about living in <Korogocho/Majengo>?

#### 3. Mind-space and daily life

*Purpose: Understand priorities, daily activities, employment/study or lack thereof, places, objects and activities that define their lives*

*Time allocation: 15 minutes*

- Please tell me about your daily life.

- Let's start with a normal week-day, what is your routine?
- Do you ever feel bored?
- What are your responsibilities?

#### **4. Historical, emotional and practical connection to neighbourhood**

##### **Neighbourhood membership**

*Purpose: Understand emotional connection to neighbourhood*

*Time allocation: 5 minutes*

- Where do you come from?
- What made you decide to live here?
- Does Korogocho/Majengo feel like home? Why/why not?

##### **Living arrangements**

*Purpose: Briefly understand living arrangements, reason for migration. Please note that this may be a traumatic topic and that these questions should be asked with compassion and empathy*

*Time allocation: 10 minutes*

- Who do you live with?
- How do you feel about living here?
- Could you describe your home to me?
- What would you change about your home and living arrangements if you could? Why?
- What would you say are the differences between the best and worst homes available in Korogocho/Majengo? Describe in detail.
- How do each of these groups of people feel about their home?
- Where would you hate to live? How would you feel if you had to live there? Would you feel ashamed and hide it from people?

##### **Moving around**

*Purpose: Understand movements within and outside micro environment*

*Time allocation: 5 minutes*

- Do you like to leave your immediate neighbourhood and explore other areas in Nairobi? What for? /Why not?
- Would the community keep you living here? Would life be impossible without their support?

## 5. Money

*Purpose: Understand source of money and spending*

*Time allocation: 10 minutes*

### Source of money

- How and where do you get money?

### Role of money

- What does money give you? Spontaneous reaction first
  - *Important: Participant will start with tangible things that can be bought. But then guide them to also talking about the intangible things money gives you.*
  - If necessary, probe: Money can buy a lot of things (things you can touch), but what are things that money gives you that you can't touch. Status? Recognition? Integration?

### Spending

- What do you spend most money on?
- What are your essentials (things you have to buy/spend money on)?
- What are luxuries that you spend money on?

## 6. Social connections

*Purpose: Understand social ties and support structures, the nature and significance of peer relationships and community hierarchies*

*Time allocation: 10 minutes*

### All people

- Who are all the people who have the biggest influence on your life? Please explain.
  - ⊖ *Probe if necessary: peers, family, community members such as health care professional*
- What are your support structures?
  - If you have a problem ... how would you go about solving it?

### Peer group

- Which people do you spend most time with?
- What can you tell me about your friends?
  - *Probe if necessary: Who are they, where do they live, how do you know each other?*

- What do you and your friends do together? Activities
- What are things that you and your friends typically talk about?

### **Social hierarchy**

- In most communities, people tell us that there are hierarchies/social ladders of people. People who are higher and lower up in social standing. How does this work in your community?
- Which people are higher up on the social ladder?
  - Describe where they live, what they do, how they look and dress
- And people lower on the social ladder?
- What can those at the bottom do to improve their status?

### **Dignity and humiliation**

- Some people have told us that it is important to have ‘**dignity**’. Do you know that word? What do you understand by it? Which word would you and your friends use to talk about this idea?
  - Can you think of an example in your life that explains dignity?
  - Can you think of an example in your life that explains humiliation?

## **7. Morality**

*Purpose: Understand the values and norms of the peer groups*

*Time allocation: 10 minutes*

- What are some of the things you and your friends think is good/important in life?
- What are those things that are felt to be bad and unacceptable?
- What are the things which would be hard to share or someone would be embarrassed if others found out?
- What would be more shameful in the eyes of your peers:
  - Having nothing and HIV–
  - Having everything and HIV+?

## **8. Risk, vulnerability and resilience**

*Purpose: Understand the nature and significance of peer relationships*

*Time allocation: 10 minutes*

### **Risk**

- What are **risks** in your life? Do you have different word for ‘risk’?’ What is a risk?

- *Give example only if necessary: A farmer may plant vegetables but there is a risk that there will be no rain and he may lose the crop. But it is worthwhile for him to take that risk.*
- Can you think of risks in your life?
- Do you and your friends have a different word for risk?
- What are the risks that young people in your life take out of necessity?
  - If participant struggles to answer, give an example or two like:
    - What is riskier, walking alone at night or having unprotected sex with a stranger?
    - What is riskier, sharing a sleeping space or living alone?
- What are general things that you and your friends worry about most in your day to day life? (*Brief*)
  - Only if not mentioned spontaneously: Is HIV/AIDS a risk at all? In what way?

### **Vulnerability**

- What do you understand by the word **vulnerability**?
  - *Give example only if necessary: A farmer may not have put anything in place to protect his crop from floods. If he doesn't have a flood proof fence, he is vulnerable in heavy rains.*
  - Can you think of any ways that someone in your community may be vulnerable?
- Are young people less or more vulnerable than older people? (and to what...) Why do you say that?
- What would make you more vulnerable?
  - E.g. losing your home vs losing a friend?

### **Resilience**

- What would you say is the **opposite of being vulnerable**? Some people use the word resilient.
  - *Give example only if necessary: The farmer may have sons who can help him rebuild his farm if there are floods or he may have another piece of land in another area so that if a flood hits him, he will be able to survive and bounce back and recover.*



- Can you think of examples in your community? What would make someone resilient/prepared/able to bounce back?
- Do you have a different word for this?
- How would you describe a strong and resilient person in your community?
- How would you describe a weak person?
- What are things that make you feel proud?
- What are things that make you feel humiliated?

## **9. Sex in general**

*Purpose: Understand sexual history and peer group*

*Time allocation: 10 minutes*

- If I asked your group of friends about Sex, what would they tell me?
- What is the best thing about sex?
- What, if anything is the worst thing about sex?
- What is the biggest difference that sex makes to your group of friends?
- Think of a girl/boy that is most like you, what would he/she write about sex in their diary?
- Is sex risky?
- Does sex always have to be enjoyable?
- What is more important money or sex?

## **10. Intimate relationships**

*Purpose: Understand the nature and significance of intimate relationships*

*Time allocation: 10 minutes*

### **Intimate relationships in general**

- Thinking of your friends, what would they consider a ‘good partner’?
  - Probe if necessary: Older, younger, someone from outside
- Is it sometimes necessary to have more than one partner?
- If someone’s partner refused to have sex, what could they do?
  - What action is justifiable?
- If someone didn’t want to have sex with their partner, what could they do?
  - What action is justifiable?
- How do young people in your community feel about:
  - People who have many sexual partners?
  - Who are known to have had sex?

- Being pregnant?

## **11. HIV**

*Purpose: Unpack perceptions around HIV in depth*

*Time allocation: 10 minutes*

- If I asked your group of friends about HIV, what could they tell me?
  - *Free association, spontaneous 'knowledge dump'*
- How about AIDS?
  - *Free association, spontaneous 'knowledge dump'*
- Do people talk about HIV? Why/why not?
- If I were to go to <insert place mentioned above where participant spends a lot of time>, and sat and listened to what people were talking about, what would I hear them say about HIV?
- If someone had HIV what would they do?
- Where would they go for help?

## **Follow-up questions**

**(if they have not already been covered during the interview;  
check for consistency)**

1. What personal characteristics make a role model?
2. Living in Korogocho / Majengo, do you feel angry/sad/forgotten? Why?
3. When you are angry or sad what do you do? Does sex help?
4. Why are people violent in Korogocho / Majengo? Is it because they are frustrated and deeply unhappy with life?
5. Do you feel that people listen to you when you speak? What does it take? Do people believe in you and think you'll get ahead in life?
6. Do you feel that your life will ever change living here?
7. Do you feel that you are trapped?
8. How hard is it to integrate into the local life in Korogocho / Majengo? Is it a good thing to integrate here or better to stay isolated?
9. Can you live a dignified life here?
10. Do you have self-esteem? Can you respect and dignify yourself without self-esteem?
11. What are some of the things you need to do to dignify your life?
12. What can a man do to help prevent women getting HIV?
13. What do friends think of you if have a child, do you grow in their estimation? Or diminish? Why, please explain?
14. How hard is it for men to start self help and support groups?
15. When was the last time someone or something shamed or humiliated you, what happened?
16. When was the last time someone or something dignified and respected you?
17. What are the five biggest risks involved in living here?
18. Do you feel enabled and empowered?
19. Why would you not use a condom in having sex?
20. Are thieves respected here? Do girls want to have partners who are thieves? Why?  
Is it because now they will feel safe?

## Photovoice Guide

Please tell us a bit about yourself (circle the correct answer)

Are you...	Male	Female					
Where do you live?	Korogocho	Majengo					
How old are you?	18 yrs	19 yrs	20 yrs	21 yrs	22 yrs	23 yrs	24 yrs

**I, hereby give permission for my photographs to be published anonymously as part of the research results**

**Signature:** \_\_\_\_\_

**Date:** \_\_\_\_\_ **Place:** \_\_\_\_\_

\_\_\_\_\_

### Photovoice

Thank you so much for taking part in the interview! For the next week, please take pictures of:

1	1 picture of your house from the outside
2	1 picture of the room where you sleep
3	1 picture of your bed
4	1 picture of your most precious belonging
5	3 pictures of things in your life that make you <b>feel a bit shy</b>
6	3 pictures of things in your life that make you <b>feel proud and dignified</b>
7	3 pictures of things that remind you of sex
8	Please fill up the rest of the camera with things that you would like to share with us and please explain why



**How to take good-quality photographs:**

- Always use the flash
- Switch on the lights and open the curtains wide
- Take pictures with a wide angle so that we can see what is going on around the thing you are taking a picture of
- Do not take pictures of faces so that it is not possible to identify individual people in a photograph

We want to know how **you see life**. There are no right or wrong pictures; everyone is good. We want to see what really moves you deep down! For example,

- What makes you so happy? / What makes you so sad?
- What disgusts you? / What do you hate to see?
- What really makes you angry? / What do you really want to change living here
- What looks beautiful?

**1 picture of your house from the outside**

What is going on around the photograph?	
How does this picture make you feel?	

**1 picture of the room where you sleep**

What is going on around the photograph?	
How does this picture make you feel?	

**1 picture of your bed**

What is going on around the photograph?	
How does this picture make you feel?	

### 1 picture of your most precious belonging

What did you photograph?	
What is going on around the photograph?	
Why is this precious to you?	
How does this picture make you feel?	

### 3 pictures of things in your life that makes you feel a bit shy

1

What did you photograph?	
What is going on around the photograph?	
Why does this make you feel shy?	
Which other feelings do you have about this picture?	

2

What did you photograph?	
What is going on around the photograph?	
Why does this make you feel shy?	
Which other feelings do you have about this picture?	

3

What did you photograph?	
What is going on around the photograph?	
Why does this make you feel shy?	
Which other feelings do you have about this picture?	

### 3 pictures of things in your life that makes you feel proud and dignified

1

What did you photograph?	
What is going on around the photograph?	
Why does this make you feel proud and dignified?	
Which other feelings do you have about this picture?	

2

What did you photograph?	
What is going on around the photograph?	
Why does this make you feel proud and dignified?	
Which other feelings do you have about this picture?	

3

What did you photograph?	
What is going on around the photograph?	
Why does this make you feel proud and dignified?	
Which other feelings do you have about this picture?	

### 3 pictures of things that remind you of sex

1

What did you photograph?	
What is going on around the photograph?	
Why does this remind you of sex?	
How does this picture make you feel?	

2

What did you photograph?	
What is going on around the photograph?	
Why does this remind you of sex?	
How does this picture make you feel?	

3

What did you photograph?	
What is going on around the photograph?	
Why does this remind you of sex?	
How does this picture make you feel?	



**Please fill up the rest of the camera with things that you would like to share with us and please explain why**

What did you photograph and why?	
How does this make you feel?	

What did you photograph and why?	
How does this make you feel?	

What did you photograph and why?	
How does this make you feel?	

What did you photograph and why?	
How does this make you feel?	

What did you photograph and why?	
How does this make you feel?	

**Please continue on the back of this page if you need more space...**

## Appendix C: Situational Analysis Maps

### i. Extract from the Messy Map



ii. **Extract from the Ordered Map**

<b>Individual human elements/actors</b>
<i>Community Health Workers Clinicians Chief's Office Landlords Parliamentarians</i>
<b>Collective human elements/actants</b>
<i>Korogocho VCT Primary Health Clinics Police Posts SWOP NACC/UNAIDS Employers Clubs/Bars Chama groups Community organisations Formal religious bodies Private schools</i>
<b>Discursive construction of individual and/or collective human actors</b>
<i>Social world construction of slum-dwelling young people, as 'low life' (robbers and prostitutes) Illusion of a youth voice Illusion of justice and rule of law Illusion of controlling and reducing the HIV epidemic Severe lack of vital public social services</i>
<b>Political/economic elements</b>
<i>Resources—Nairobi County Budget Decentralized system—New Constitution For profit/not for profit organisations General policy for Kenya (MTPII) Specific policy agenda (slum improvement/clearance) NACC /NASCOP/Nairobi County Health Authorities Lack of transparency/clarity</i>
<b>Temporal elements</b>
<i>Capitalism Neoliberalism Projected Disaster Residential areas Infrastructure</i>
<b>Non-human elements/actants</b>
<i>Disaster/war zone Availability of public documents HIV Messages Health centres</i>
<b>Implicated/salient actors/actants</b>
<i>Young children/adolescents Slum Dwellings Factors for HIV risk Violence</i>
<b>Discursive constructions of non-human actants</b>
<i>Urgency/shifting power for female headed household Private sector (health and education) Destruction and dilapidated public buildings Slum as a war zone Informal economy Illusion over politician promises HIV stigma HIV services (access) and fees</i>
<b>Sociocultural/symbolic elements</b>
<i>Social status, gender dynamics, Resident location Religion Community cohesion and conflict Capitalist patriarchy</i>
<b>Spatial elements</b>
<i>Constantly changing environment (schools, street lighting, slum resident areas) Availability of quality-assured health centres Transport to and from slums</i>
<b>Related discourses (historical, narrative and/or visual)</b>
<i>Representation of young people/young slum dwellers in media Kenya as a middle-income country and fulfilment of Social Development Goals Illusion of choice Accounts of elevated violence in the slum and levels of gender-based violence National HIV prevalence versus slum incidence</i>

## Appendix D: The Storyline Framework

Heading	Themes
Storyline	Perceiving HIV risk by young slum dwellers and given meaning within interlinking and evolving social moral worlds
Core concepts	Perceptions of risk and vulnerability; risk amplifiers & modifiers; knowledge of HIV; knowledge of modes of transmission; finding and building capacity and sustaining health and wellbeing; agency and social organisation; structural and environmental determinants; integration and assimilation
Core category	HIV and the Integrity of Risk
Concept paradigm	<p>Causal Conditions Associated risk factors for managing HIV; closely-knit social environment; adaptive behaviour suited to changing situations; social recognition and acclaim; social and sexual networks; the hierarchy of need</p> <p>Phenomenon Coping strategies within moral social worlds and the processes for managing risk of infection and living with HIV</p> <p>Action and Consequence</p> <p>Empowerment from an informed perception of risk and vulnerability; participating in the collective generation of meanings relating to reward, safety and wellbeing; avoiding shaming events and loss of social connections; establishing alliances of trust; interpretation and use of prevention technologies; dealing with stigma and discrimination; disclosure and treatment regimens; finding dignity in the here and now</p>